

# **Tactics of Diabetes Control**

Turkish immigrant experiences with chronic illness in Berlin, Germany.

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*Für meine Eltern*

*Mit liebem Dank für Eure uneingeschränkte Unterstützung, Euer stetes Vertrauen,  
Zuspruch und Begeisterung.*

## Declaration

I hereby declare that this thesis has been composed entirely by me and is my own work. No part of this thesis has been submitted for publication or any other degree or professional qualification.

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## **Abstract**

This thesis explores Turkish migrants' practices of diabetes care in Germany. Health statistics frequently identify minority groups as vulnerable to chronic illness and Turkish-origin Germans are said to be more likely to suffer from type 2 diabetes than Germans or Turks in Turkey. Anthropological studies on marginal population groups with diabetes explore experiences of social suffering and inequality that influence such high illness prevalence, or investigate how conflictual lay beliefs and medical encounters affect illness care. Those studies that analyse active diabetes patient and healthcare practices concentrate on the majority population. Drawing on ethnographic fieldwork in Berlin from September 2006 to September 2007, this thesis examines how Turkish Berliners actively engage in diabetes care, and thus joins two themes seldom connected: illness practices and marginality. Initial interviews with healthcare professionals alluded to a Turkish migrant patient group living in deprivation and immobilised by high illiteracy rates, lacking language skills and health knowledge. Despite such experience of marginality, ethnographic exploration revealed that informal diabetes care, for example through a Turkish-language self-help group, is nonetheless individually and collectively negotiated where formal care is inadequate. On the one hand, the thesis investigates practices of diabetes control in learning, monitoring and manoeuvring diabetes. Rather than representing the common image of the inert, disadvantaged migrant patient, Turkish Berliners of the self-help group engage in deliberate "tactics of diabetes control" to make their chronic illness experience habitable. On the other hand, the thesis explores how "diabetes among Turkish-origin Berliners" can be a form of sociality, political activism and economic enterprise that involves many social actors not only patients and their healthcare professionals, in order to fill a provision gap.

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## SECTION 1

### Introduction

Let me start this thesis with a scene from my ethnographic research with Turkish Berliners living with diabetes (from field notes 05.05.2007). On a hot day in May 2007, I gathered with around seventy people in one of Berlin's district town halls for an information event that offered diabetes advice in Turkish. Squeezed on the narrow benches of the lecture hall's dress circle I sat with a group of women who I regularly met up with at their Turkish language self-help meetings. We were listening to the self-help group's leader who had just taken over the podium after a medical talk by a local Turkish-origin family doctor. Rather more engagingly, he was prepping us for the common annual summer stay in Turkey that many Turkish Berliners enjoy. He explained about the use of cool bags to store insulin during long car drives and outings in the summer heat, advised to take insulin as hand luggage to avoid it freezing in the plane's hold cabin, and not to walk barefoot on the beach to avoid treacherous injuries to the foot. The second part of his talk was entirely devoted to the perils of their holiday diets – especially that of people's abundant fruit gardens. What followed was a long list of fruit and we joined in shouting out the guessed sugar content: “An orange?” – “100g of fruit sugar”, “two kiwis” – “120g”, “mango” – “90g”, “15 grapes” – “100g”, “two mandarins”, “honey melons”, “nectarines”, “green plums” – “hmm, we love green plums...”. He didn't approve of our growing silliness. “*Arkadaşım! My friends! Take notes.*” This snippet from my fieldwork should serve as a little outlook to what this thesis will be about. Many Turkish Berliners may live challenging lives that include social problems and chronic illness. However, they are not immobilised or defeated by such challenges. Diabetes is actively addressed and managed. Moreover, Turkish Berliners' experience with diabetes is not lived behind closed doors of homes or of doctor's consultant rooms. Diabetes is a social and communal experience – and it is this that provided me with rich ethnographic data.

This thesis explores the chronic illness diabetes as experienced by Turkish migrants in Germany's capital city Berlin. Health statistics frequently identify population groups at the margins such as people from migrant backgrounds or ethnic

minorities as vulnerable to chronic illness (Marmot 2006). Turkish Germans, for example, are said to be almost twice as likely to suffer from type 2 diabetes as Germans, or Turks in Turkey (Laube et al. 2001). I used these statistics as a starting point to investigate experiences of marginality through the lens of illness management and health maintenance.

I chose Berlin as my field site for its large Turkish-origin population, Germany's biggest minority group. Its several Turkish-dominated districts are, on the one hand, marked by social deprivation and marginalisation and are frequently at the centre of attention of the media that generates public images of social isolation and crime. On the other hand, these districts boast a vibrant and confident multi-ethnic community life. The same Janus-face image describes diabetes in this context. While the Turkish-origin population in Berlin seems to experience the burden of high diabetes rates<sup>1</sup>, it also has a growing number of Turkish-origin doctors offering native language care and a thriving Turkish diabetes self-help group. Looking at the experiences of Turkish-origin Berliners who are involved in this informal diabetes care, thus makes this a very local, specific, and perhaps therefore peculiar, narrative. Indeed I encountered – albeit the anticipated and disquieting challenges of migrant social lives – quite unexpected and maybe unusual experiences with diabetes. Unusual, as many Turkish-origin Germans outside and even within Berlin would not identify with the stories of active diabetes practice told in this thesis. And yet, the stories represent lived experiences of my research participants; and they invite us to challenge public images of disadvantaged, inert migrant lives as well as to reconsider anthropological conceptualisations that aim to make sense of such experiences.

Two bodies of literature spring to mind when framing this research. First, there is Michel Foucault's powerful concept of bio-power (1998 [1976]). Diabetes<sup>2</sup> requires severe lifestyle changes, careful monitoring of bodily states, and meticulous discipline in nutrition, in order to keep this chronic illness under control. In fact, such

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<sup>1</sup> This is an observation made by all of my research participants; there are no statistics on Berlin or a national register that could confirm prevalence rates.

<sup>2</sup> Unless otherwise stated, "diabetes" refers to type 2 diabetes in this thesis. Type 2 diabetes is the most common form of diabetes and accounts for 80 to over 95 per cent of cases depending on the population; type 1 diabetes is an autoimmune disorder that typically develops at an early age and requires insulin therapy for survival, though also strict lifestyle management (WHO 1999). For a longer discussion see Chapter 1.1.

everyday body maintenance and monitoring is as important as any medication. Although diabetes self-management is a vital part of the therapy from a clinical perspective, I will argue that this is a story beyond bio-power, beyond domination (over knowledge or bodies) or resistance for that matter. The Turkish-origin Berliners with diabetes I met engaged in deliberate *practices of diabetes control* and are not mere subjects of a dominant medical system that promotes a healthy living paradigm. Foucault's "technologies of the self" (1990 [1984]) are a more adequate concept, but again I seek to look beyond Foucault's understanding of self-care, not to consider it as an ethical exercise but suggest an exploration of self-care as a practical motivation to alleviate bodily and emotional distress. A Foucauldian perspective might also imagine a state that is concerned about its migrant population whose status of health – and thus healthcare costs – seems to be particularly vulnerable to chronic illness and obesity. However, interestingly, state institutions are almost absent in this narrative. While universal access to healthcare provision is guaranteed on paper, in practice, migrant patients are faced with healthcare services that do not acknowledge their special needs; services are often overwhelmed and strained by high illness rates and social deprivation, provided in a language many patients do not speak or understand very well, with dietary recommendations that ignore or offend their own food practices. The Turkish-origin Berliners in this thesis who engage in practices of diabetes control largely taught themselves to adopt such discipline.

The other body of literature that frames this thesis is on biosociality, coined by Paul Rabinow (1996a) who imagined social groups forming around biological identities marked by ill-health or illness susceptibility. This might be a less obvious choice as biosociality appears to require biotechnologies, broadband communication, high-profile advocacy and a quest for gene markers and subsequent high-tech therapy (see e.g. Rabinow 1999; Gibbon 2008). Neither can be found in this thesis and, although literature suggests that marginality and social disadvantage prevents sociality (Bharadwaj 2008; Sunder Rajan 2008), here are narratives of biosociality and bio-activism outside the realm and capital of biotechnologies. In what I summarise as *politics of diabetes control* I argue that I find social, political and economic engagement due to and with diabetes beyond previous conceptualisations of biosociality. The growing prevalence and awareness of diabetes in the Turkish

population of Berlin, together with their increasing political organisation and economic entrepreneurship, gives rise to biosociality unanticipated in previous accounts. While the self-help group may be at first sight an obvious representation of biosociality, marginal groups are previously only considered bio-available (Cohen 2005). Moreover, the self-help group's bio-activism is less interested in advocacy work than in community outreach work and peer-education; and bio-capital (Sunder Rajan 2008) here is less a story of the power of pharmaceutical companies but about local business ventures and interests that form around diabetes care.

In short, this thesis explores practical engagements with diabetes, *doing diabetes*, much like Annemarie Mol (2008: 89) looked at “doing bodies” in her diabetes research. However, my exploration expands from patient practices to political and economic activities. Also, while Mol (2008: 9ff) was interested in healthcare practices and extracted tales of doing diabetes from professionals' and patients' narratives, patient consultations and text analysis, I concentrated as much as possible on observing such practices in everyday lives. An ethnographic approach was used, including a 12-month period of participant observation as well as narrative interviews with members of a Turkish self-help group, family members, health professionals, and others involved, exploring relative access to diabetes management knowledge, negotiation and strategies of diabetes control, and social, political and economic action and participation in diabetes care. In doing so, *diabetes among Turkish-origin Berliners* becomes both a personal, individual exercise of everyday practice as well as a form of sociality, political activism and economic enterprise that involves not only patients and their healthcare professionals.

The following thesis has eight chapters which are divided into three large sections. Section 1 should serve as an introduction.

Chapter 1 aims to give background information on diabetes and Turkish-German migrants but should also highlight why I think that these are relevant anthropological avenues of investigation. Diabetes appears as a mundane illness and thus sits uncomfortably between its perceived everyday-ness and triviality and its actual severity and rising global prevalence. The clinical stance on diabetes is similarly ambivalent. Diabetes has been known for thousands of years and is still not

fully understood; there is no “magic bullet” and its diagnostic categories are somewhat arbitrary and contested. Moreover, the main therapy for the vast majority of diabetes cases lies in the hands of the patient in lifestyle modification and body maintenance, and here lies the most fruitful line of inquiry for anthropology. Similarly, the Turkish population in Germany has a specific history, it is now a large population group, highly stratified, and increasingly (politically) organised, yet still much marginalised, living with high rates of unemployment and social deprivation. Such an increasing social, political and economic organisation while living in challenging social circumstances may explain how they respond a bit differently (or very specifically) to diabetes than the less politically organised and challenged main population.

Chapter 2 outlines the methodology of this study and its initial research question of exploring marginality. It introduces the setting, Berlin, and the major research participants that not only include patients and doctors, but respective interests groups, their representatives, and more.

Chapter 3 locates the thesis in its theoretical framework and presents a review of “bio-anthropologies”. By that I mean contributions from various branches of social anthropology (and neighbouring disciplines) that bring the biological into the focus of social investigation. This thesis addresses Foucault’s bio-power (1998 [1976]) as well as his later work on self-care (1990 [1984]). Numerous scholars have taken these theoretical frameworks, for example in order to investigate public health. I will also introduce Rabinow’s notion of biosociality (1996a), its legacy and limitations in ethnographic explorations.

In Section 2, the thesis explores “practices of diabetes control: beyond bio-power”. It is largely drawing from experiences of a Turkish-language self-help group whose members have become *expert patients*, rather than representing the common image of the inert, disadvantaged migrant patient. Themes are chosen in terms of their prevalence in everyday conversations, narratives and group meetings: learning about and knowing diabetes as a prerequisite of managing one’s diabetes, the presence of numbers to talk about diabetes, personal experience and perceived health, and the everyday tactics of diabetes control with food as the most prominent example.

In Chapter 4, I explore the importance of acquiring knowledge, discovering the practicality of knowledge and negotiating access to knowledge. Patients seek knowledge on their illness when initially diagnosed, and education is the first therapeutic strategy from a clinical perspective. Knowledge/education also seems to be the main provision gap of the Turkish diabetic population in Berlin. I look at patient education and the self-help group's peer education and explore that there are all kinds of knowledge, and that these are inevitably linked to power relations, are guarded or deliberately sought. There is basic knowledge, deemed fit for "challenged patients", and very complex knowledge that "make" expert patients. Knowledge can be very specific and specialised, taking varied lifestyles, eating habits and social lives into account. Knowledge can be very abstract, the jargon and expertise of an elite, but can be appropriated by patients and very practical. Knowledge can already exist although not be recognised, for example on food and cooking, and knowledge can be embodied, for example knowing the symptoms of an approaching "hypo" (low sugar that can lead to coma), or feeling too high sugar levels that start affecting eye sight. Emphasis in this chapter is on the practicality of knowledge; knowledge as practice.

Chapter 5 is then about the most abstract knowledge and practice in diabetes control: numbers and glucose meters. It investigates the specific knowledge of numbers, clinical metrics of blood glucose levels, cholesterol, hypertension. These numbers act as forms of communication and are both abstract representations of diabetes and practical parameters for experiencing and engaging with diabetes. While it could be regarded in terms of technologies of the clinical gaze (Foucault 1986 [1963]), turning lived experiences into abstract meter readings, I argue that this is a deliberate and practical practice *by patients* in order to make diabetes visible, static and thus manageable and habitable.

Finally, Chapter 6 is about such active practical engagement with diabetes as both a daily obligation and inevitability but also a means of negotiating diabetes management and making the experience habitable. With the example of diet I aim to show how patients manage diabetes control in the everyday. If strict recommendations of how to control diabetes (by severely amending lifestyles according to biomedical frameworks of healthy living) can be understood in terms of

Foucault's bio-power (1998 [1976]), I suggest to understand my informants' active involvement in such daily practices as *bio-tactics* (in accordance to de Certeau's tactics of everyday life, 1984). I go on to explain that, indeed, the management of complexities goes beyond their experience of diabetes but expands to their generally challenged life circumstances. Their highly routinised practices of diabetes control could even be conceived as a general tactic of life management when other problems such as depression or deprivation lack management tools.

Section 3 shifts its attention to another dimension to Turkish Berliners' experiences with diabetes. This could be described as the collective response to the presence, burden, or even threat of diabetes: "politics of diabetes control: beyond biosociality".

Chapter 7 examines how diabetes spearheads communal activity and participation. Diabetes is diagnosed and treated as a communal problem that requires a self-management approach as formal state provision is inadequate. The diabetes self-help group is not only a social mode of diabetes control but offers social activities that are independent of health concerns. The group offers social participation and engagements for its members beyond their – often marginal or solely private – family and work roles. Such sociality of diabetes control can be related to frameworks of biological citizenship, bio-activism and biosociality. Here I revisit biosocial literature (Rabinow 1996a) that only assumes social momentum in new bio-technologies that challenge "old socialities", while I say that a social and political situation of deprivation and increasing political organisation as experienced by Turkish Berliners combined with the relatively new biological burden of diabetes can trigger similar reconfigurations.

Chapter 8, finally, looks at the kind of biosocialities that emerge around Turkish diabetes care in Berlin and how diabetes indeed provides Turkish Berliners with a platform of economic and political engagement. There is a vibrant field of involved individuals and groups. What marks these participants are the fluent and complex roles they occupy within this field of informal diabetes care. While biosocial literature imagines the patient-cum-activist, this chapter explores how diabetes adds many roles, for example a patient can be student, teacher, expert, layperson, activist, and businessman. These varied and often competing roles, then,

play out in a local micro-political economy. Diabetes care is embedded in a local economy of healthcare, but also in social structures of deprivation and entrepreneurship. This local market competition also links to contestations of authority and knowledge and hierarchical structures. In addition to such social and political economies of diabetes care, there are also moral economies at play that question and negotiate motivations and motives of engagement. Performances of ethical behaviour emphasise solidarity and philanthropy and discredit monetary motivations.

## Chapter 1: Context

The following chapter aims to provide the context for this thesis. It will explain what is relevant to know about diabetes when reading this thesis, and give an introduction to Turkish-German migrants, their place in German society and experiences of marginalisation and increasing political activism. Above all this chapter should highlight why Turkish-German diabetes is a relevant and fruitful anthropological avenue of investigation.

### 1.1 The social life of diabetes

Starting with diabetes, I will, first, address how diabetes seems to be perceived as a very mundane, perhaps uncontested, illness. I will argue that, on the contrary, diabetes addresses several ambiguities, being widespread yet public awareness is low, perceived as a sign of affluence but inflicting the poor (Unwin and Zimmet 2009), a chronic and largely invisible illness yet severely life-threatening and requiring daily management (WHO 1999). Second, diabetes is even within the medical realm a contested category. It has been known for millennia in medical history (Schadewaldt 1989) but causation varies and there are several forms (WHO 1999), some population groups are more vulnerable to diabetes than others (Unwin and Zimmet 2009), and there is still no cure. In fact an important part of diabetes care is – the rather nonclinical – lifestyle management (IDF 2005). Thus, third, diabetes is a fascinating research object for anthropologists as its therapy is performed by the patient. Everyday practice of diabetes care is not merely an anthropological focus but a clinical requirement (IDF 2005). This is emblematic for a general shift in (global) medicine from shift from cure to secondary and tertiary prevention in times when chronic illness increasingly replaces infectious disease as the main health burden (WHO 2005).

#### *Diabetes as the mundane*

Diabetes is a common disease: many of us know friends or relatives affected by it, and it is frequently mentioned in the news on the obesity epidemic that is “sweeping” our countries and threatening the population with its nasty “side-effects” of coronary

heart disease and diabetes. Having said this, it might be too ordinary to attract much interest or attention. Many people do not actually know much about diabetes, underestimate its severity (it can lead to stroke, kidney failure, blindness, limb amputation and early death; WHO 1999), and hold the view that it is affecting mainly affluent populations (Unwin and Zimmet 2009) (unsurprisingly, if above mentioned media reports shape public opinion). My own interest in diabetes as an anthropologist lies not only in the fact that it is oddly outside public view but, more astonishingly, that diabetes has largely escaped the anthropological gaze for so long. Compared to highly ethically charged fields such as HIV/AIDS or human genetics of various kinds, diabetes appears awfully mundane. While ethnographic research questions increasingly tend to include an exploration of the everyday, it seems that finding the exotic is still high on anthropologists' agenda. Then again, there is plenty of "out of the ordinary" in the story of diabetes and it is the ambiguities that surround diabetes that make it a promising object of anthropological investigation.

The following story shows how diabetes is considered a world epidemic in the public health realm, yet it is a real challenge to raise public awareness of this issue. Few people know that World Diabetes Day is celebrated on 14 November, the birthday of Frederick Banting, who discovered insulin together with his colleague Charles Best in 1921. 2007 was the first time that the day was observed by the United Nations after a UN resolution on diabetes had been passed in December 2006 (Unite for Diabetes 2007). Type 2 diabetes is becoming increasingly common in the world. Recent estimates by the International Diabetes Federation (IDF) suggest that 246 million people, that is 5.9 per cent of the adult world population (age 20-79 years), have diabetes (International Diabetes Federation 2007). Taking demographic trends, age and population size but also urbanisation into account, IDF (2007) estimates that by 2025, the number of people living with diabetes will have risen to 380 million.<sup>3</sup> Quite remarkably, diabetes is one of only a few health related issues that has made it on the agenda of the United Nations' General Assembly and received enough international backing to be adopted by a resolution. These

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<sup>3</sup> Both WHO and IDF use more or less the same methodology and criteria to make such projections on the basis of age specific prevalence and of UN population figures and projections. Interestingly these projections do not include trends in risk factors such as obesity.

resolutions are usually predominantly politically concerned, and the first ever “health-only” resolution was passed in 2000 on AIDS; 2004 followed a resolution on road safety (UN 2007). UN Great Assembly resolutions are only recommendations and not binding, but they are internationally recognised and mark a global concern. The aim of putting diabetes on the UN agenda was to raise awareness in all member states of the global pandemic of diabetes that increasingly affects low and middle income countries, urge member states to respond in their capacity building of adequate healthcare provision, and finally to designate World Diabetes Day as a United Nations Day (Unite for Diabetes 2007). Interestingly, the campaigners of this resolution – chiefly the International Diabetes Federation, the umbrella organisation of national diabetes unions – had embraced themselves for a long, stony way. To the astonishment of many people working in this field, the resolution was passed within the year of officially launching the campaign. Key of the sudden success might have been the involvement of Bangladesh and its diplomatic effort of having the resolution backed by the G77 (Unite for Diabetes 2006). This majority voting bloc in the UN General Assembly is the coalition of 133 developing and transitional countries led by the Republic of South Africa. Their attachment to the resolution ultimately convinced the governments of high income countries to support this resolution which, for the first time, recognised that chronic, non-infectious disease poses a threat to world health.

Unfortunately, the media has not embraced Diabetes Day in quite the same way as their coverage of HIV/AIDS related global campaigns. To mark the first UN observed World Diabetes Day, the IDF invited nations across the globe to light landmark monuments in the campaign’s (and UN) colour blue. On 14 November 2007, New York’s Empire State Building, Sydney’s Opera House, Rio De Janeiro’s Christ the Redeemer of Corcovado, Istanbul’s Bosphorus Bridge, Paris’ Eiffel Tower and the London Eye were among the almost 250 monuments lit in over 195 countries (World Diabetes Day 2007). These celebrations had one major flaw: it seems that nobody was watching. It had failed to make it as a news item that day; even local

media – arguably not busy with too much regional news that day – failed to comment on our own blue lit monument, the Gateshead Millennium Bridge.<sup>4</sup>

There are further example of lacking awareness and attention. The UN noted that diabetes afflicts the poor and marginal most severely, but it is often perceived as an illness of affluence. The involvement of the poor G77 in the UN resolution might thus seem surprising to many, but it is estimated that between 70 and 80 per cent of all people affected from diabetes are living in low and middle income countries (Wild et al. 2004).<sup>5</sup> It is these countries that have to grapple most with the immense economic costs of diabetes care on top of the burden of infectious disease. In 2006, the annual World Diabetes Congress, hosted by the IDF, was set in Cape Town, South Africa, to mark that year's motto of "Care for Everybody" which aimed to raise awareness for marginalised people with diabetes. Despite its relatively remote location, the conference was attended by more than 12,000 experts in medicine, pharmacology and public health, and – as diabetes experts told me proudly – rivalled the size of the 2006 International AIDS Conference, held several months earlier in Toronto with over 20,000 delegates. The congress' agenda included a stream on diabetes in Africa that discussed the relevance of poverty, traditional medicine and public health provisions, and links between diabetes and TB and AIDS. Other streams included biochemical studies on Asian and African herbal hypoglycaemic remedies, as well as epidemiological and health education presentations on marginalised population groups such as migrants or homeless people. Ironically, these presentations in the spirit of the congress' motto were mere footnotes in an overpowering programme of biomedical and biochemical research talks and the adjacent drug industry exhibition, that failed to properly acknowledge that it is in fact marginal people – those in low and middle income countries and marginal population groups in high income countries – that are most affected by diabetes. While it seems

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<sup>4</sup> While this initial hesitant reaction to the resolution could be easily observed, it remains to assess in the coming years if low and middle-income countries make more of their healthcare resources available for chronic illness prevention and care. I left Germany before the passing of the resolution and could not observe any reaction within the field. The Disease Management Programme for diabetes that allocates specific resources of the national health insurances to diabetes care had usually been mentioned to me as Germany's policy answer to the increasing burden of diabetes. For more details see Chapter 7.2, pp.197.

<sup>5</sup> Figures of diabetes in the developing world are often estimated as they try to include something up to 80 per cent undiagnosed diabetes in some countries (Unwin and Zimmet 2009).

more obvious why the drug industry shows little interest in consumer groups with little spending power, biomedicine's indifference raises more worrying ethical concerns.

Moreover, people underestimate the severity of diabetes. This might be as it is a chronic and largely invisible illness, or because it is so common that we all know relatives or friends that quietly live with their illness. However, diabetes causes severe secondary illness and leads to early death. The WHO (1999) lists such long-term complications as “the specific complications of retinopathy with potential blindness, nephropathy that may lead to renal failure, and/or neuropathy with risk of foot ulcers, amputation, Charcot joints, and features of autonomic dysfunction, including sexual dysfunction. People with diabetes are at increased risk of cardiovascular, peripheral vascular and cerebrovascular disease.” In sum, diabetes can lead to blindness, amputation, stroke, kidney failure and impotence. While these further health damages can be avoided or at least postponed with good diabetes management, those without good diabetes care can suffer severe complications. In the case of diabetes in low-income countries this means that, as diabetes develops at relatively older age, it is often the breadwinner of a family that is afflicted, and losing eye sight or limbs puts the whole family in jeopardy. A similar fate can afflict marginalised people in wealthy societies whose healthcare systems do not provide adequately for their particular needs.

Diabetes notably affects the lives of people in low-income countries most painfully but some population groups are generally more afflicted than others (Unwin and Zimmet 2009). Urban populations are at much higher risk of diabetes than rural population groups. Epidemiological research also shows that those people living in the lowest socio-economic groups in high-income countries show the highest diabetes prevalence (Connolly et al. 2000; Whitford et al. 2003), while studies in some developing countries have pointed out the opposite effect with those rising the socio-economic ladder being increasingly exposed to the risk of developing diabetes (Herman et al. 1995; Abu Sayeed et al. 1997; Xu et al. 2006).<sup>6</sup> Moreover, there are quite distinct differences between some ethnic groups. The North American

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<sup>6</sup> However, as pointed out in the previous paragraph, even if prevalence is higher in high income groups of such developing countries, it is the poorer that suffer greater consequences.

Pima Indians, for example, are famously mentioned in many textbooks for their unusually high prevalence of type 2 diabetes, and different Pacific Islander populations, Melanesian, Micronesian and Polynesian, apparently vary remarkably in their diabetes rates (Qiao et al. 2004). There is also a growing literature on ethnic minority groups and migrants such as South Asians and African Caribbean origin people in the UK, or African and Hispanic Americans in the USA (Unwin and Zimmet 2009). In public health and epidemiology, especially, the plethora of hypotheses on causal relationships of migration, socio-economic status and health is often not matched by actual research projects. There is only one study in Germany that suggests a similar pattern among Turkish migrants in Germany (Laube et al. 2001). Beside reports of experience from health professionals in this field (who largely agree), there is no further data that could confirm or deny the unusual high rates in this population group.

Such research begs the question of a possible genetic susceptibility of certain ethnic groups. So-called “thrifty gene” theories explore the possibility of an ethnic proneness to metabolic chronic illnesses, as some genetic make-ups are suspected to be less adapted to Western affluent nutrition and lifestyles (McDermott 1998). The idea is that some population groups might have still retained a kind of “hunter-and-gatherer” gene pool which is highly tailored to store energy in the body and which can be fatally exposed to affluent diets after migration or after rapid transformation of indigenous economies. While there is indeed a strong genetic component in the causation of type 2 diabetes and insulin resistance, research continues to try to unravel the multiple gene defects that seem to be involved (Almind et al. 2001; Permutt et al. 2005). In relation to vulnerable population groups, however, much research suggests a combination of biological and environmental risk factors that could explain high prevalence (Unwin and Zimmet 2009).

### *Contested medical territories*

Diabetes is not a straight-forward medical category and, as mundane it might appear, it is still considered a “mysterious illness” (Schadewaldt 1989: 43). This quote by the Greek physician Aretaeus of Cappadocia (ca. 81-138 AD) is still undisputed and despite medicine’s long interest in diabetes, its causation and classification still raises

much controversy. For example, diabetes' varied prevalence in different population groups raise the challenge to unravel the complexities of genetic and environmental factors in diabetes risk.

Diabetes can be described as an endocrinological illness, regarding the hormone insulin, or a metabolic illness as it affects our metabolism. A healthy pancreas secretes the hormone insulin. Insulin is vital to transport glucose (that is sugar we consume with carbohydrates) to our cells. Without this key – either because it is insufficiently or not at all produced, and/or there is resistance to insulin's action in the cells – our cells (mainly liver, muscle and fat cells) lack this vital energy source to work properly. The glucose building up in the blood stream harms organs, the vascular and nervous system. This explains both the immediate symptoms of diabetes, excessive urinating and thirst, as the body tries to wash out too much glucose in the blood, as well as effects on vision, general constitution etc., and the long-term effects of organ damage. The long name is diabetes *mellitus* (Latin for honey). Many languages know diabetes as sugar sickness (German: *Zuckerkrankheit* or *Zucker*, Turkish: *şeker hastalığı* or *şeker*, Arabic: *sokkor*).

While the scientific community can agree on above definition of diabetes as an illness of elevated blood sugar, there is much discord over definition and classification of diabetes. Diabetes can have many different causes and require different treatment. Diabetes is therefore classified in several types. The World Health Organisation (WHO) changed its diabetes classification several times, and still the only real agreement within the international medical scientific community seems to be that diabetes is not one disease but encompasses several forms. Difficult to pin diabetes down to one easy definition, WHO (1999) finally summarised: “The term diabetes mellitus describes a metabolic disorder of multiple aetiology [causation] characterized by chronic hyperglycaemia [high blood glucose levels] with disturbances of carbohydrate, fat and protein metabolism resulting from defects in insulin secretion, insulin action, or both.” As the causation of diabetes varies, WHO (1999) classifies different types. Type 1 diabetes mellitus refers to the situation in which diabetes is due to the destruction of the cells (specifically the beta cells of the Islets of Langerhans) that produce insulin. This type of diabetes usually develops in childhood or teenage years but can also develop in adults. Previous

terms, later deemed imprecise, were juvenile diabetes and insulin dependent diabetes (WHO 1999).

This thesis is concerned with type 2 diabetes mellitus. Type 2 diabetes mellitus refers to the situation in which the pancreas still produces insulin but is unable to produce enough to keep blood glucose at normal levels. Most people with type 2 diabetes are insulin resistant, which means that the cells where insulin acts, such as those of the muscle and liver, respond poorly to insulin (DeFronzo et al. 1997). Consequently, higher levels of insulin are required to keep blood glucose normal and diabetes develops when the pancreas is no longer able to produce enough insulin to overcome the insulin resistance. Insulin resistance is particularly associated with obesity and physical inactivity. Previous but somewhat confusing terms for type 2 diabetes include adult onset diabetes (but with increasing levels of childhood obesity type 2 diabetes is increasingly seen in children) and non-insulin dependent diabetes (however, some people with type 2 diabetes require insulin to properly control their blood glucose levels). There are further types such as gestational diabetes which occurs during pregnancy, and current research in Africa and elsewhere tries to unravel the mystery of a type of diabetes that appears in later age but resembles much more type 1 diabetes in its causation.

The above classification is less than ten years old, and much classificatory confusion proceeded. In 1965, WHO published a first classification of juvenile diabetes and adult onset diabetes in accordance to the age of the first recognised onset of diabetes (Zimmet et al. 2004). 1980 followed the distinction of type 1 insulin-dependent diabetes mellitus and type 2 non-insulin dependent diabetes mellitus, and 1985 type 1 and 2 were omitted to retain the clinical description insulin-dependent (IDDM) and non-insulin dependent (NIDDM) diabetes. It also included other types such as malnutrition-related diabetes mellitus (MRDM), gestational diabetes mellitus (GDM) and impaired glucose tolerance (IGT). Today, WHO's finally revised classification (WHO 1999) is internationally largely accepted, yet still considered somewhat incomplete and not always clear cut (Unwin and Zimmet 2009). It tried to capture the different causation of diabetes in accordance to current research knowledge but the rapid innovations in research render such an exercise challenging. Rock (2005: 117) suggests that recent research, particular in

genetics, only adds further complexity to such classifications, for example emerging “types of type 2 diabetes” such as MODY (maturity onset diabetes of the young). This seems to correspond with the current distinction into type 1 and type 2 diabetes. Also, the American Diabetes Association (ADA) produced a series of recommendations throughout these decades of changing WHO reports that largely concurs with WHO’s typology and is also used outside the USA. Less agreement, however, can be reported on diagnostic criteria. It is generally accepted that the cut point for diagnosing diabetes should be when levels of blood sugar levels start posing a risk to the body; what this cut point is remains controversial (Unwin and Zimmet 2009).

A differentiated classification appeared as early as 1889, when Etienne Lancereaux (1829-1910) divided diabetes into *diabète maigre* (“lean diabetes”), which resisted any therapeutic attempts and was deemed incurable, while *diabète gras* (“fat diabetes”) showed a promising response to dietary changes (Schadewaldt 1989: 53ff). The (written) history of diabetes goes back to antiquity. This following history may mainly concern type 1 diabetes as its quite dramatic presentation and short life expectancy received much attention in historic medical texts. That is not to say that some ancient texts do not also contain complaints that would today be associated with type 2 diabetes, afflicting the wealthy – and quite likely obese – elites and rulers. The first physician documented to have used the expression “diabetes” was the 3<sup>rd</sup> century B.C. Alexandrian Demetrius of Apamea (Schadewaldt 1989: 46). The word “diabetes” referred to the ancient Greek word *diabeinein*, literally translated “to go to excess” but was commonly used for a wine siphon (Engelhard 1989: 3). In Greco-Roman physicians oversaw the sweetness of the urine – as many other (Western) physicians did for a long time. The adjunct *mellitus* in diabetes mellitus was added much later by Thomas Willis (1621-1675) who first reported the sweetness of diabetic urine. He did not, however, attribute the honey-like taste to sugar in the urine but to salt and sulphur in the blood that decomposed in excessively inflowing liquefied body substance (Schadewaldt 1989: 52). This (today) somewhat peculiar theory combined ancient notions of impurities of the blood with his contemporaries’ views on the importance of chemicals in the understanding and treatment of disease (ibid. 52). Historians today know of much

earlier records of “honey urine” (Sanskrit: *madu mehé*) in ancient Indian medical texts (probably written between 300 B.C. and 600 A.D.) in which taste (Sanskrit: *rasa*) – technically meaning “fluid” – played an important role<sup>7</sup> (Müller 1989: 164). These ancient Indian textbooks of the *Susruta*, *Charaka* and *Vagbhata* mentioned diabetic symptoms quite comprehensively and leave as much historic controversies as to why this knowledge had not been passed on to Greek medicine, and whether it was known that diabetic urine actually contained sugar (Schadewald 1989: 48). Moreover, historic records have emerged that point towards the knowledge of the sweetness of diabetic urine in Arab medical texts, specifically of the Islamic physician Avicenna (980-103) (ibid. 50). It is also possible that Paracelsus (1493-1541) recognised the urine’s sweetness (he spoke of *dulcedo*) earlier than Willis (ibid. 52). It was not until 1776 though, when Matthew Dobson (1745-1784) first isolated the white cane-sugar-like residue in the urine, and not until 1838 that glucose was first chemically identified in diabetic urine (independently) by Apollinaire Bouchardat (1806-1886) and Eugène Melchior Peligot (1811-1890) (Engelhardt 1989: 4ff).

Paracelsus also changed the focus of diabetes research towards the metabolic system in general (Schadewaldt 1989: 52). In 1869 the young pathology research student Paul Langerhans (1847-1888) submitted a short doctorate thesis on the microscopic anatomy of the little explored organ pancreas, identifying nine different pancreatic cells (ibid. 60). The beta cells of, what by 1893 Edouard Laguesse had coined, the Islets of Langerhans were to become the focus of pancreatic diabetes research. Although the function of these cells remained unknown for many years, some researchers became increasingly enthusiastic about diabetes as a pancreatic illness, as diabetes patients showed changes in their pancreatic islet cells (ibid. 63). Though it was not until 1889, that Mering (1845-1908) and Minkowski (1858-1931) discovered by chance that the dogs whose pancreas they had removed were developing severe diabetes and that it therefore must be the pancreas itself that was the source of diabetes (ibid. 61ff). What followed was years of scientific investigation of pancreatic function, subsequent findings of its secretion and ultimately attempts to isolate pancreatic extract for the therapy of diabetes. Research

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<sup>7</sup> The six *rasas*: sweet (*madhura*), sour, salty, sharp, bitter, astringent.

proved difficult, leading towards many wrong conclusions and much frustration in the scientific community that almost brought the endeavour to a halt (Bliss 1996: 25ff).

The dedication of medical scientists to finding a cure for diabetes might be comparable to today's efforts in the field of cancer and HIV/AIDS. For much of its history, (type 1) diabetes was an acute, quickly deadly disease. Willis mentioned diabetics' weight-loss and growing weakness in the 17<sup>th</sup> century (Schadewaldt 1989: 52) and Indian Sanskrit texts already contained accounts of diabetic coma (ibid. 48). Many of these ancient accounts of diabetes highlighted the rarity of the illness – the genetic component of diabetes, as we know today, would have been precluded by the sometimes quite rapid premature deaths. Throughout history, the main therapeutic advice for diabetes had mainly been diet. Celsus (25 B.C. - 50 A.D.) already recommended diet (and even physical exercise), and so did Galen, Aretaeus and many of their “humoral” contemporaries (ibid. 49). Some of these therapies proved entirely unhelpful if not dangerous, as the residue of sugar in urine was interpreted as a sugar deficiency, or as many physicians concentrated on their patients' wasting and hunger and prescribed a high-caloric diet. Nutritional advice during the last couple of centuries included the “meat diet”, “milk cure”, “cereal diet”, “fat diet” and “potato diet” (Schadewaldt 1989: 84ff).

The possibly most effective diet was Frederick Madison Allen's (1879-1964) early 20<sup>th</sup> century “starvation therapy” (Bliss 1996: 33ff). Contrary to many of his predecessors and colleagues, the American diabetologist Allen did not believe that it was the diabetics' undernourishment that needed attention. Exploring how a certain diet could not worsen laboratory dogs' diabetes, he developed a low caloric diet that reduced all food intake. Often to the horror of family and even hospital staff, already very skinny patients who had lost much initial weight through their diabetes were put on a radical diet. His therapy proved quite effective – if it were not for his patients' lack of discipline that often undermined his strict dietary constraints. Some of his famous patients (prominent in medical text books for their extreme skeletal figures) who kept to their diets showed marked improvement and prolonged life expectancy. Others, however, died of undernourishment. Allen's “ruthlessness” caused much controversy in a country “where being well-fed was still a sign of good health” (Bliss

1996: 35). Pictures emerging after WWII of KZ survivors reminded doctors of this era in diabetes therapy (ibid. 39).

But medical history should change with the discovery of insulin. In summer 1921 Frederick Banting (1891-1941) and his student assistant Charles Best (1899-1978) discovered insulin at Toronto University, and in 1922 patients were successfully treated with insulin which was subsequently commercially produced. In 1923 this milestone in medical history was recognised with the Noble Prize, although many controversies over authorship preceded and succeeded Banting's discovery (Bliss 1996). In his engaging account, the Canadian medical historian Bliss (1996) traced this outstanding narrative, exploring the complexities that shape and negotiate medical sciences, their contributors and findings. The young, inexperienced provincial doctor Banting more or less stumbled across insulin in a series of amateurish and haphazard laboratory tests. His supervisor Macleod tried to provide some training and subsequent staff assistance to turn the discovered pancreatic extract into therapeutic insulin. The extract was called "insulin" (Latin *insula* for island), although nobody could actually prove the islets of Langerhans as the source (nor was anyone in Toronto aware that this name had already been proposed by Schafer in 1916 who did not know of de Meyer's same idea in 1909) (ibid. 126ff). Ultimately, some historians argue that insulin had been "discovered" earlier – as both the Romanian Nicolae Paulesco (1896-1931) and the German Georg Zülzer (1870-1949) probably had insulin in their hands (Bliss 1996: 125ff; Drügemöller and Norpoth 1989: 431). However, while these experienced researchers were concerned by the side effects and inconsistencies in the effects of insulin, the novices Banting and Best ignored or overlooked such problems. Finally, it was their collaboration with the small American drug-company Eli Lilly whose intensive clinical work started producing insulin commercially for a large market and transformed the company into an industry giant (ibid. 154ff).

The consequences of this therapeutic breakthrough were unexpected. Many believed that insulin could cure diabetes or at least replace strict dietary recommendations. Little was it anticipated that insulin merely turned an acute disease into a chronic condition that ultimately took its toll on the body's organs (ibid. 244ff). Complications such as cardio-vascular diseases had previously gone

unnoticed as diabetes patients simply did not reach older age. It soon became clear that dietary advice should remain at the core of diabetes control. Insulin was further developed with the advance of genetic engineering which developed human insulin and solved the problem of insulin supply. Moreover, with increasing wealth and life expectancy in industrial countries, there was also a rise in type 2 diabetes, much like it is now experienced by low- and middle-income countries (Unwin and Zimmet 2009). For the therapy of type 2 diabetes, oral blood-sugar lowering agents were developed, but none ever made dietary control obsolete. Modern medicine achieved increasing understanding of the complexities of diabetes but even this latest era in diabetes research – now increasingly genetic research – still raises more questions than it can answer.

### *Doing diabetes: on self-care*

After this long history of medical attention, research and innovation, diet remains the most important feature of diabetes management (Wallace and Matthews 2002: 1706). Day-to-day patient self-management is essential in diabetes care which ideally requires knowledgeable, responsible and dedicated diabetes patients. People living with diabetes do not only negotiate their own care but their lives, in turn, are fundamentally shaped by their illness and their strategies to control it. This thesis will explore these practices of diabetes control, the “doing diabetes”.

The central aim of diabetes therapy is to keep blood glucose levels down to a level that minimises the risk of diabetes complications. Newly diagnosed type 2 diabetes patients are often initially prescribed oral anti-diabetic drugs which have hypoglycaemic agents, i.e. they chemically lower blood glucose levels. There are five different kinds of drugs that either enhance insulin activity, increase insulin release (stimulating the pancreatic beta cells), delay insulin absorption in the bowel, or reduce insulin resistance in order to enable better glucose absorption (Wirges 2002: 18, 35, 89,185ff). Doctors can mix and match these tablets – also with insulin – (though not all can be combined) to achieve good diabetes control. Patients eventually tend to progress to insulin, and today, there are different forms of insulin available. Human insulin has replaced the original animal source insulin with the emergence of DNA recombination (Bliss 1996: 247), and human insulin, in turn, is

increasingly replaced by so called insulin analogues (whose molecular structure is modified to enhance certain properties) (Wirges 2002: 109ff).

A careful diet and physical activity can help to manage the illness without any medication, at least at the early stages of the illness (Wallace and Matthews 2002). An excessive intake of sugary and low-fibre food can trigger and worsen the management of type 2 diabetes mellitus. Traditionally patients were cautioned to watch their carbohydrate intake, while current dietary advice, as a rule of thumb, recommends a healthy balanced diet, high in fibre, fruit and vegetables. Having said this, food becomes a highly complex issue for diabetics once they learn more about nutrition. Chapter 6 will explore the avenues of understanding why one should prefer brown to white bread and cottage to feta cheese. People living with diabetes must learn the complex and varied workings of food on their metabolism. As Allen knew in the early 20<sup>th</sup> century, fat and protein intake need to be watched as closely as carbohydrates, and today, salt intake is discouraged in those with and without diabetes. In short, diabetes patients need to know more about their diet than simply how to identify carbohydrates.

Another core element of diabetes management is physical activity. Exercise can lower blood glucose levels and enhance insulin activity (Kraus and Levine 2007: 424). Patients are therefore encouraged, for example according to IDF's Global Guideline for Type 2 Diabetes (IDF 2005) to be physically active at least 30 to 45 minutes on three to four days a week. Part of these recommendations is also to instruct the patient to adjust "medications (insulin) and/or adding carbohydrate for physical activity", as physical activity is very effective to lower blood sugar and can therefore lead to too low blood glucose levels (IDF 2005). As with diet, physical exercise is far from straight-forward and needs to be individually assessed for each patient. There are different recommendations for different kind of exercise and medication, patients who are already suffering from complications should refrain from certain exercise, and researchers still struggle to assign specific types, frequency and intensity of exercise their effect on glycaemic control (Sigal, Kenny et al. 2004; Kraus and Levine 2007: 423).

All these components of diabetes therapy, diet, physical activity and medication, will be explored in this thesis as their ambiguities and uncertainties

require a highly individualised therapeutic approach that not only places the patient at its centre but also puts them in charge of administering it. Key to diabetes control is diabetes self-management (Day 2004). People living with diabetes must be conversant with controlling their blood glucose levels as, most of the time, patients are left to their own devices to handle it. As the thesis will explore, diabetes control is not confined to clinical spaces; rather, everyday life is shaped and negotiated around the concern of keeping one's blood glucose levels at normal levels. And this is not an easy task. One size does not fit all, and patients have to become experts of their own diabetic bodies. Moreover, different sites of the body are at stake. Controlling constant blood glucose levels aims to avoid, or at least, delay diabetes complications. Patients must be aware of and knowledgeable about the consequences of high blood glucose levels on their organs. Diabetes self-management includes watching those body parts at risk through diabetes: feet, kidneys, heart, and eyes.

Health professionals' role is not only to provide check-ups to prevent complications and clinical care of such complications but also to support patient self-management at home. There is a growing body of health science literature that aims to understand what it means to self-manage diabetes as a patient and what the facilitators and barriers are. Acknowledging the considerable psycho-social aspects of diabetes care, these studies use social research methods and analysis in order to interrogate patients' experiences with diabetes self-management and improve outcomes of self-management. While some of this research focuses on quantitative social research methodology such as surveys (e.g. Johnson-Spruill et al. 2009; Melkus et al. 2009; Scollan-Koliopoulos et al. 2007), there is also an increasing number of health science researchers, often with a background or borrowing from medical sociology, that conducts qualitative studies. Methods used are sometimes described as ethnographic but overwhelmingly comprise interviews and focus groups.

As improving diabetes control outcomes is central to these clinically driven studies, often an emphasis is placed on compliance or adherence, the management of everyday diabetes self-care according to care plans and recommendations, in short, "doing what the doctor told". Research questions focus on evaluating how well patients comply and what reasons lie behind possible non-compliance. Kelleher

(1988) conducted interviews with thirty patients with diabetes in the UK. He divided them into three distinct groups according to their responses to their illness. While “worriers” were anxious about their diabetes as well as the task to self-manage, “normalisers” took some degree of control over their diabetes, made some adjustments to their routines but played down symptoms and disruptions to their lives. A third group was identified as “copers” who showed a high degree of control over their illness, made individual and active management choices and alterations to their lives. Maclean (1991) also looked at people’s responses to diabetes in regards to adherence and non-adherence to dietary recommendations, conducting interviews in Canada with 34 people. Like Kelleher (1988) she found that while some worried about their diabetes, felt out of control or burdened by their illness, others were much more confident. However, she allowed for a more fluent account that did not place people in fixed groups but on a continuum from strict adherence, strategic indulgences or “cheating” to non-adherence. She also identified various factors that influenced dietary management and self-care: individual factors (food preferences, lifestyle preferences, character traits, ease of adjustment), diabetes-related factors (severity, experience, threat of complications) and contextual factors (family/peer support, professional support, social stigma, equipment, cultural norms, occupation). Another example is a US study conducted by O’Connor and colleagues (1997). In focus groups and interviews with 34 people participating at an education programme they also identified positive responders who tended to “cheated” strategically but did not feel guilty about such transgressions, were knowledgeable about diet and not fearful of medication/insulin. Interestingly, they considered diabetes a serious illness but accepted lifestyle changes in their everyday lives. Conversely, negative responders did not view diabetes as serious and were more casual about diet but they were also fearful of insulin and tended to dwell on lifestyle changes.

Increasingly studies acknowledged varied and highly emotional responses to diabetes in the last two decades, research has shifted somewhat away from concentrating on patient adherence towards exploring patients’ assessment of their needs. Maclean (1991), for example, emphasised the importance of personal interpretations of health and suggested that health professionals must accept personal decision making and autonomy in diabetes control self-care. This paradigm shift to

an “empowerment philosophy” (Funnell and Anderson 2003: 457) placed emphasis on patient-centred studies, interventions and education programmes. Murphy and Kinmonth (1995) conducted interviews with diabetes patients in the UK to compare their interpretations of diabetes and perceived seriousness with the degree of lifestyle changes and how these are rationalised. Murphy and Kinmonth (1995: 184) suggested that health professionals should respect such rationalisation, even on “non-adherence”, and a greater understanding of patients’ perceptions could lead to better “therapeutic alliances”. Such studies that take patient perspectives into account also increasingly emphasise well-being as a separate issue than health (also see Cohen et al. 1994). Furler and colleagues (2008), for example, propose not to measure success solely in terms of clinical success and compliance but to take patients’ evaluation of quality of life and well-being into consideration (also see Karas Montez and Karner 2005). In their Australian study, they conducted four focus groups with English-speaking, Turkish and Arabic-speaking people with diabetes in order to explore the emotional context of and impact on diabetes self-care. A much earlier Swedish study by Wikblad (1991) also concluded that diabetes care should be less about monitoring and more about achieving a balance of diabetes treatment and personal life choices and well-being. In this study in which 55 patients were interviewed patients distinguished between health and well-being and demanded more from health professionals than only check-ups and medication but that they recognised individual needs.

Within this literature that explores patient perspectives, there is a range of research that specifically focuses on lay understandings of diabetes causation and its impact on self-care practices. Parry and colleagues (2006) interviewed forty newly diagnosed diabetes patients in the UK about their perceptions on illness causation. Those who described diabetes causation mainly in terms of their own behaviour engaged actively in diabetes management (“down to me”). Those patients, however, who referred to external causes such as hereditary factors relinquished more responsibility to the health professionals (“down to them”). While most participants did not represent such polar opposites, Parry et al. (2006) highlighted that understanding such discursive accounts of causation can put these patients in a disadvantaged position in regard to their illness management. Illness lay beliefs,

especially in connection with health inequality, seem of particular interest in the case of ethnic minority diabetes patients. Lawton and colleagues (2007) reassessed in secondary analysis interviews with 32 white and 32 Pakistani and Indian participants about their understandings of diabetes aetiology and while white respondents tended to emphasise internal behavioural causations, the Pakistani and Indian respondents externalised the causes of diabetes to stressful events, life circumstances and risky environments. Hunt et al.'s (1998) study with 49 Mexican Americans explored in interviews how varied illness causation beliefs resulted in three forms of treatment activity: self-active, other-active (someone else takes responsibility for care) and non-active, much like Parry et al. (2006) concluded. Interestingly, the level of activeness not only depended on perceptions of lay causation (heredity and diet, but also personal events and behaviours as provoking factors) but self-care experiences were also used to (re-)interpret illness causation beliefs.

There is a range of studies that explored lay diabetes beliefs more generally, such as Chowdhury, Helman and Greenhalgh (2000) that conducted interviews with forty first-generation immigrants in order to explore dietary classifications in British Bangladeshi. Respondents tended to distinguish their food in “strong/weak” and “digestible/indigestible”, rather than an expected South Asian dichotomy of “hot/cold”, or a biomedical classification in carbohydrates, proteins and fats. Mull and Mull (2001) investigated diabetes beliefs among 38 US Vietnamese migrants with diabetes and their families. Participants largely believed that a diabetic body was considered “hot” that required treatment by “cooling” herbal remedies rather than equally “hot” insulin injections and called for culturally-sensitive healthcare. Indeed most of these studies conclude that health professionals should take such “cultural” particularities into account and provide more culturally adequate or sensitive care. Polzer and Miles (2007) concluded from their study with African Americans with diabetes that their spirituality was part of their “rich cultural heritage” that such provided support in self-management but could also eliminate responsibilities for self-management. Chesla and Chun (2005) suggested in their study on the importance of social relations in diabetes self-care among Chinese American families that healthcare should acknowledge social negotiations of illness management and, for example, consider family counselling. The notion of “culture”

in many of such studies is borrowed from disciplines such as medical anthropology (lay beliefs and folk illness, e.g. Helman 2001; explanatory models, Kleinman 1980) and trans-cultural psychology (concepts such as acculturation, e.g. Berry 1994). Medical anthropologists view such literature sceptically; mainly as such borrowed concepts and a simplistic understanding of culture are largely considered outdated. However, while these studies may not contribute to the understanding of “culture”, they seem to serve to broaden the perspective of health professionals in which ways patient perspectives need to be taken into consideration. From an anthropological perspective, these studies also provide an insight into the health service’s “culture” of individualised prevention and risk and in which way they “cope” with those who do not share their perspective.

Much of the above reviewed health research aims to understand the complexity of diabetes self-management in order to improve patient education interventions. Diabetes education provides the context where patient can learn how to self-mange their diabetes but also where their perspectives can be addressed, understood, perhaps respected and taken into account, where patients could be empowered. Patient education is an essential part of diabetes care (Day 2004). It is said that the first diabetes education programme was introduced in Portugal in the early 20<sup>th</sup> century by a Dr. Roma, while in Britain, Dr. R.D. Lawrence, the pioneer of British insulin care – and first British recipient of insulin – highlighted the importance of education in order to develop skills but also to adjust well to living with diabetes (ibid. 1599). Many studies show the efficacy of diabetes education in decreasing complication rates, while others point out that one-off courses or short interventions have little value (ibid. 1600). In Germany, every patient with diabetes is entitled to these services, as much as they are entitled to patient education sessions, and those doctors who cannot provide their patients with sessions themselves can refer them to diabetes practices or clinics. This generous availability and access to education sessions, however, exists only on paper for some patients. As it will be investigated in this thesis, during my fieldwork I experienced that structurally disadvantaged patients might not be aware of education sessions, (busy) doctors are reluctant to refer patients outside their practice, and above all, only few education sessions are offered in other languages or incorporate other food cultures. (The latter

seems to call for “cultural sensitivity” in patient education.) Self-management becomes an impossible task without the necessary knowledge on how to do it (see Chapter 4). International efforts for diabetes care often concentrate (besides distributing insulin) on making such education sessions – in theory very low cost interventions – available to everyone. At the 2006 World Diabetes Congress in Cape Town, a Mexican public health practitioner introduced a scheme to bring education session to remote rural areas; another presentation explained how “training-the-trainer” programmes were rolled out in the Caribbean.

In summary, in this chapter I have outlined why the study of diabetes is complex, timely, and can be a fruitful endeavour for anthropologists. Health research provides us with a plethora of examples that diabetes management is a challenging task for patients and experienced in the everyday. Two issues seem particularly relevant for this thesis. Several studies describe patients’ individual strategies of self-care and “cheating” that can be more than a transgression but a skilful tinkering with health advice in order to manage everyday lives (Kelleher 1988; Murphy and Kinmonth 1995; O’Conner et al. 1997; Thorne et al. 2003; and Campbell et al. 2003 in their “ethnographic meta-analysis”). Furthermore, some health literature explores how minority patient groups may perceive and experience diabetes unanticipated by health professionals. Health research approaches such research with a set of research objectives that aims to improve healthcare and ultimately adherence of patients to their healthcare strategies, uses interviews and focus groups as their main research methodology and tends to analyse data deductively. Social anthropologists may not agree with the often deductive research design of such studies that aim for generalisation and applicability and may limit responses and avenues of explorations of such emotional and bodily experiences.<sup>8</sup> Social anthropologists seem to be well placed to provide a more detailed and “thick description” (Geertz 1973) of patient experiences with diabetes self-management but diabetes ethnographies are scarce (cf. Ferzacca 2000). In regards to the above mentioned two issues raised in health science literature, this thesis will provide an ethnographic account of individual strategic

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<sup>8</sup> For a longer discussion on ethnographic research methods see Chapter 2.3.

practices of self-care, perhaps similar to what Thorne et al. (2003: 1345) called “calculated cheating”, and describe this as *tactics of diabetes care*. This is also an ethnographic exploration of how Turkish migrants with diabetes have to actively negotiate self-management advice in order to make it relevant in their social lives (as such health services studies and intervention programmes targeted at migrant diabetes groups are missing in Germany). As this anthropological, ethnographic research project set out to broadly investigate Turkish immigrants’ individual and communal experiences with diabetes, it goes beyond the above summarised body of literature on diabetes self-care experiences and, looking at communal responses to diabetes, demonstrates how practices, experiences and politics are intrinsically linked. However, although the project thus did not set out to foremost contribute to the above body of literature, the thesis’ ethnographic accounts, not only of individual practices of diabetes self-management but also the explorations of social, economic and political diabetes experiences relevant to the research participants, may be of interest to health service researchers and providers.

## 1.2 Turkish migrants in Germany

I mentioned earlier that the assumption that Turkish-origin Germans suffer from significantly higher diabetes rates than the rest of the population hinges on one study (Laube et al. 2001). The study is quite controversial, mainly as its result was reported to reveal that Turkish-origin Germans are almost twice as likely to suffer from diabetes as Germans or Turks in Turkey (Gießener Anzeiger 2006); but the study outcomes are far more complex and not every finding reflects the above claim. Due to recruitment in mosques, Turkish clubs and the Turkish consulate in Frankfurt, elderly male participants are over-represented in this study, while the Turkish-origin population in Germany is generally very young and with males and females equally distributed (Goldberg et al. 2004: 17). Such representation biases – here in terms of age and sex – are not uncommon but need to be controlled for during analysis. The study did this in three different ways, adjusting the data set for the general age distribution in Turkey, the Turkish migrant population in Germany, and finally for

the general German age distribution. Only this latter version, adjusting the sample of Turkish elderly men to Germany's average age distribution, reveals these high diabetes rates for Turkish migrants compared to the German or Turkish population. This is a valid method of handling such data but the research can nonetheless be criticised for its initial recruitment biases and that it is not a population based study that may reveal sounder data. The research team – mainly Turkish-origin academics – highlighted that they aimed to alert to the high diabetes rates among the Turkish-origin elderly. These findings represent the worries of many of their (also mainly Turkish-origin) colleagues that report such prevalence in their daily practice. The result that would control the data set for the very young Turkish migrant population group, in contrast, may misrepresent the diabetes problem, and, in the opinion of many health professionals I met, high rates of obesity among these young should ring alarm bells for future illness rates anyway.

The obvious redemption for this contested study would be further research that took such concerns into account. However, there is hardly any epidemiological data on health among minority Germans, unlike other countries, for example the UK, that produce frequent studies on their minority population groups (e.g. Agyemang and Bhopal 2002; Hayes et al. 2002; Pollard et al. 2008). This dearth in German epidemiological data seems quite remarkable considering that people of Turkish origin constitute the biggest minority group in Germany. I suggest that this research vacuum represents a more general national indifference towards the particularities and needs of a minority group that is, despite opposition, well established and formative in German society. The following chapter will give an introduction to Turkish migrant lives in German today, their everyday lives and public image. It then gives a brief overview of the history of Turkish migration to Germany, and finally aims to address issues of social provision that should form the context to this thesis.

#### *Turks in Germany today: everyday lives and public image*

Let me start with an incident that happened before embarking on the field work for this thesis. On 30 March 2006, Germans read in their newspapers (any newspaper really; I refer to *Süddeutsche Zeitung* 2006a, 2006b, 2006c, 2006d) about a group of teachers in Berlin's district *Neukölln* who could no longer cope with the

disobedience, chaos and violence at their school and decided to publish a letter about their unbearable situation, a “cry for help” as newspapers quickly called it. *Neukölln* is one of the most multi-ethnic and socially deprived districts in Berlin. Frequent media reports about this area dwell on stories of crime and violence such as “honour killings” and “clan feuds”. At the centre of this news story was the *Rütli*-school which belongs to Germany’s education system’s lowest type of high school, *Hauptschule*, with pupils leaving after nine years of school education and (if at all) the lowest high school degree obtainable in Germany. This stratified education system has increasingly been criticised and *Hauptschulen* are often portrayed in the media as breeding grounds of violence and social welfare recipients rather than sites of education. The teachers’ letter of the *Rütli*-school, of which a majority of pupils are from migrant backgrounds, sparked a media frenzy that revived these public debates. Politicians hastily commented on both immigration and education legislation, and the bleak state of Germany’s society burdened with failed integration and youth with no future perspectives. Over the course of several days, media assembled at the gates of *Rütli*-school, filming agitated (and amused) male youths who enjoyed brief fame showing their knives and shouting cynically “Terror!” and “Let’s kill some teachers!” The media coverage also captured images of intimidated veiled girls that tried to hide from the cameras diligently pointed at their school grounds. More newspaper articles appeared that reported how journalists allegedly paid those teenagers for “a good show” while others moved on to general debates on ghettoisation and *Fremdenland* (“foreign land”) in the neighbourhood (Süddeutsche Zeitung 2006c). The pupils of the school found their own way of dealing with this new publicity. Youth in *Neukölln* can now be found wearing t-shirts with the simple logo *Rütli*. With the help and inspiration of three fashion students, *Rütli* pupils are reclaiming their label in a positive way, and there are plans for an extended fashion project during art lessons (Der Spiegel 2006).

This media incident – as it is not the actual events at that school but the consecutive media attention that it sparked which is of interest – resonate with an ethnography on Sikh asylum seekers in Germany (Nijhawan, in Ecks and Sax 2005). Nijhawan argues in his account “that the migrants’ marginality in everyday life does not mean that they are at the margins of public discourse” (Ecks and Sax 2005: 207).

The Turkish migrant population seems to occupy an even more ambiguous space. On the one hand, frequent media reports as well as political debate on violent male youth – which seem to capture so many European countries right now – are quite routinely discussed as an “*Ausländer*-problem”. A problem of the “other” in our midst. A German daily newspaper recently commended the British debate and reported curiously that even the internationally notorious British tabloids assign their “knife- and gun-culture” London Black youth unquestioned British status (Süddeutsche Zeitung 2008)<sup>9</sup>. Indeed in the German case, it is notable how the term “foreigner” (*Ausländer*) is employed, even in reference to German-born citizens of migrant background (Mandel 2002). And of course, some people turn out to be more “other” than others. On the other hand, in recent years Turkish-origin Germans increasingly occupy the public stage. Turkish Germans are represented in politics, not merely as problematic or needy citizens but as the concerned politician, on TV, not in media reports or as the token Turk but in an own Turkish sitcom, and in public health, not just as the suffering patient but the concerned health professional. Yet public discourse remains one of conflict and failure, and literature suggests that ambiguous emotions towards the new country, widespread institutional discrimination and social inequality have largely hindered settling in German society (Flam 2007).

Academic contributions that are concerned with exploring such migrant lives are plentiful and stem from different disciplines such as sociology, political and Middle Eastern studies, and (later) anthropology, but most of this literature fails to paint a complex picture of diverse migrant living in Germany. The anthropologist Jenny White (1995) reviewed the so-called “guest worker literature” and concluded that initial accounts in academic literature largely evoked the idea of one “Turkish culture” and focused on conflicts between migrant and host communities that were to be explained as “culture-clashes”. Such research hypothesised that it was either “the Germans” who were reluctant to accept “the Turkish” to their community and subsequently segregated them, or it was “the Turkish” failing to integrate or assimilate with “the Germans”. Recent media reports on rising xenophobic tendencies within Germany after reunification or violent behaviour at schools in

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<sup>9</sup> This fails though in the case of young British born Muslim terrorists that suddenly puts their citizenship back into the spotlight.

Turkish “ghettos” of German cities still assume such clear-cut cultures – German versus Turkish (cf. White 1995).

Contributions from anthropologists such as Mandel (1989) and her research on the so-called headscarf debate in both Turkey and Germany provide an alternative to such a generalised view of German “Turkishness” yet is “conflict” still at the heart of her explorations. She acknowledged German Turks’ identities as defined or self-ascribed by different Muslim faiths or ethnic groups, and how religious symbols such as headscarves were used in order to construct these differentiated identities. She pointed out that certain religious practices (wearing headscarves in public institutions such as banks, schools and universities) or organisational modes of preaching and education were allowed in Germany but not in Turkey and thus embraced in migrant lives.

Indeed, despite much discrimination, conflict and social inequality, the Turkish origin population has made its stamp on German society as its biggest minority group. Contrary to the image of the poor rural guest worker and literature that evokes notions of one “Turkish migrant culture”, today’s Turkish migrant population is (and has always been) heterogeneous, including all social classes, education levels, different religion and ethnic roots. While a large percentage of original migrants have migrated from rural Anatolia, I also met several first generation migrants who recounted how they had left their vibrant Istanbul urban lives to explore the less developed post-war German cities, or even to settle in rural Germany. Today, Islam is the third biggest religion in Germany after Catholicism and Protestantism (probably a third of Turkish origin Germans are actually practising Muslims; Goldberg et al. 2004: 84). As in Turkey, most Turks in Germany are Sunni Muslim, but there is also a substantial Alevi population in Germany. It is estimated that about 400,000 German Turks follow this Anatolian Shi’ism (Goldberg et al. 2004: 83). Ethnically, the main distinction can be made between Turks and Kurds, with an estimated fifth of the Turkish origin migrants of Kurdish ethnic background (ibid. 128). Both the intensive recruitment from rural East Turkey and political migration explains this certain overrepresentation of Turkey’s minority groups. Despite political repression and still present tension within Turkey between this ethnic minority and the state, Turks and Kurds live relatively peacefully alongside

each other in Germany and focus on their shared migrant roots (ibid. 132). A new generation, however, is increasingly exploring their ethnic heritage, for example learning the Kurdish language their “guest worker” grandparents had not been allowed to speak in Turkey.

Statistics on education and employment show that the Turkish population is represented in all educational and employment levels, and that Turkish businesses make a significant contribution to the German economy and vocational training. However, people of migrant backgrounds are still significantly overrepresented in low-skilled employment, unemployment, and household income under the EU poverty line (Statistisches Bundesamt 2007).

Finally, the Turkish population in Germany is today highly stratified in age compared to the fairly age homogenous guest worker cohort. There are families of four generations that settled in Germany (with children having to take special Turkish lessons to understand their grandparents), but there is also a constant influx through marriage immigration of “new” young first generation migrants (Goldberg et al. 2004: 62). Today only a about a quarter of Turkish origin residents in Germany have immigrated as “guest workers”, over 50 per cent came as part of the family reunification schemes, while 17 per cent of Turkish-origin adults were born in Germany. 800,000 of the 2 million Turkish nationals<sup>10</sup> in Germany are under 21 years of age, another 440,000 are between 21 and 30 years old (ibid. 17). In comparison to the German majority population, the Turkish minority is a very young population. Many studies concentrate on this young generation, their place in society, their “between two cultures”-ness and consequent identity making (e.g. see Soysal 2002; Yildiz 2002).

However, different generations have different concerns and the initial “guest worker” generation seems almost forgotten. Physical and mental health, a certain

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<sup>10</sup> These statistics may be somewhat confusing. Due to decades of strict *ius sanguinis* (right of blood or parentage) based naturalisation laws, it is not unusual in Germany that a 30-year-old second generation Turkish German, born in Germany, still only holds a Turkish passport, while a 60-year-old first generation migrant from Turkey is a German national. Since 1998, children with migrant parentage finally receive automatic German citizenship, however they must still choose between the German and their parents’ citizenship by their 21<sup>st</sup> birthday to prevent “dual citizenship” (Fücks 2002). As ethnicity is not recorded in national census (see Chapter 2.2) they often only record nationality. The new national census aims to record place of birth of parents to add “migrant background” as a category.

persistent homesickness may seem old fashioned “guest worker themes” but are still relevant in their lives. After all, of nearly 2 million Turks living in Germany, an estimated 1,200,000 were born in Turkey (Statistisches Bundesamt 2007). A few ethnographies still explore a certain “transnationality” and the “first generation’s” strong emotional and factual ties to home (e.g. Wolbert 1995, 2001). All first generation Turkish migrants of retirement age that participated in this research spend several months a year, sometimes almost six months each year, in Turkey, where many own property. Mandel (1990) investigates shifting centres and gives interesting insight into what I would call discourses on marginality. She narrates how Germany with its more than two million Turkish residents is jokingly referred to as Turkey’s sixty-eighth province in Turkish public debates and how Germany has become some sort of new centre with Turkey being peripheral (or marginal). She explores “visits home”, the encounters between migrants and those that stayed in Turkey, and analyses the notion of *gurbetçi* (those living away from home) and *gurbet* (this exile or “diaspora”). Mandel concludes that Turkish residents in both Frankfurt and Istanbul might share the same identification with their Turkish rural natal village rather than to any of these cities. Nonetheless, *gurbetçi* returning from Germany to their home country encounter changed perceptions of their identity and find their identities as “Turkish” challenged by those that remained home. Mandel furthermore explains that Turkish residents in Germany share notions of “migrant” rather than “immigrant” identity, still embracing frequent visits home and the notion of a possible return. Still missing is the link between these explorations of identity and how they shape their everyday lives, dealing with deteriorating health, shifting roles as grandparents and unanticipated circumstances of aging (for example in a German nursing home).

#### *The history of Turkish guest workers in Germany*

Labour migration from Turkey to German started in the early 1960s but German Turkish history proceeds the era of labour migration, most notably with the political allegiance of the German and Ottoman Empire in WWI (Corrigan 1967). As a result of longstanding military connections, Germany has had small Turkish Muslim communities since the 18<sup>th</sup> century, mostly in Berlin whose Muslim cemetery

founded in 1863 is the oldest in Germany (Goldberg et al. 2004: 71-72). After WWI the two young republics shared a similar early development. Atatürk gave the newly found nation Turkey a distinct Western direction with state-enforced secularism, for example by abolishing the Sharia as the legal codex and banning headscarves from public buildings, changing the official script from Arabic to Latin lettering, and handing women the right to vote in 1930. Istanbul developed a Bohemian Parisian charm with its residents embracing a certain French-inspired lifestyle (not the least as the Orient Express had been connecting Paris with Istanbul since 1889). Similarly the young Weimar republic blossomed with democratic liberalism in what remains known as (Berlin's) Golden 20s.

Large scale immigration of Turks to Germany started when, in the aftermath of World War II, Germany suffered from a severe shortage of (male) workers in the 1950s that was worsened by the closure of the East German border and consequent unavailability of East European migrant labourers. In order to compensate for this lack of labour force in the booming German economy, so-called *Gastarbeiter* – temporary “guest workers” – were recruited from southern European countries such as Italy, Greece, former Yugoslavia and finally Turkey. On 31 October 1961, Germany signed a so-called recruitment agreement (*Anwerbeabkommen*) with Turkey that started the over forty year long migration history between these two countries (Goldberg et al. 2004: 4). Incidentally, the agreement coincided with a change in the Turkish constitution to allow their citizens to leave the country.

Migration, however, started from rural to urban Turkey, where prospective guest workers finally awaited their move to Germany. There were various motives for such a life-changing decision. A majority of Turks came from rural south east Turkey with its quasi feudal system in which great land owners' power extended far beyond economic influence (Goldberg et al. 2004: 7). Migration to the thousand kilometre further West Turkish cities Istanbul, Ankara, Antalya and Izmir did not bring the opportunities they had hoped for due to a lack of demand for unskilled labourers and high unemployment. The work schemes to gain employment in the German industry, providing transport and accommodation for whoever is willing to sign up, answered their demand. Tales of those migrants who settled successfully into steady employment in Germany promoted further migration of relatives and

former neighbours. There were also political immigrants from Turkey, so today Germany hosts a substantial Kurdish community (also including Iraqi, Iranian and Syrian Kurds) (ibid. 128). The guest workers were mostly men, but there were also young women who sought their luck abroad. Many of my female informants did not migrate in order to accompany their husbands but came to Germany on their own at the tender ages of 18, 19 or their early 20s. They welcomed a bit of adventure in their lives, new opportunities, although I also encountered tales of escaping loveless arranged marriages and hard labour at home.

Regardless of their motivation, most of these migrant stories involved (at least initially) leaving family behind. Welcomed at the airports of Munich, Cologne or Berlin with flowers (red roses, as one research participant recalled), the guest workers were allocated in dormitories, and initiated into dire factory life. In the beginning, the migrant labour market was anticipated to work with a great “turn-over”. Migrants should come to work in low-skilled jobs for a couple of years and then be replaced by new recruits. However, neither could migrant workers earn enough money in a few years to return to a better life in Turkey, nor did their employers consider it practical to constantly train new staff. Eventually work contracts were extended and, especially when family followed to Germany, employers would help finding cheap rented flats. Living conditions did not improve greatly for most families as money was meticulously saved and sent home to family or invested in the home country.

The German population largely appreciated the Turkish immigrants’ presence for their contribution towards the German industry, most notably since “this was a non-demanding, non-unionised, cheap and hard-working labour force, which was available where and when needed and which was ready to undertake the least desirable tasks that the host nation was reluctant to do“ (Kağucibaşı 1997: 44-45). This initial acceptance by Germans, however, turned into resentment after the OPEC crisis in 1973 heavily struck the German economy and unemployment hit the population. During this time of recession, recruitment of guest workers ceased (*Anwerbestopp*) and schemes developed to entice return to their respective home countries (*Rückkehrförderung*). Migrant labourers from Turkey, Italy, Yugoslavia, Spain, Portugal, Morocco etc. were offered

enticement aids of 10,500 Deutsche Mark<sup>11</sup> (plus DM 1500 per child) and the offer to cash in any retirement funds (Goldberg et al. 2004: 19). In 1983/84, about 250,000 people, mostly Turkish, returned while only 42,000 entered Germany through family reunion schemes. It seems that both those who decided to return and those staying in Germany were left holding the bag. The high financial enticements created much envy towards the “home comers” in Turkey. Reintegration schemes within Turkey largely failed due to its starkly expanding population size, high unemployment and rising inflation rate. Similarly, those migrant workers who decided to stay in Germany had to face social envy by the German population triggered by these high financial enticements and oddly directed towards those left in the country. Above all though, many Germans resented those thought-to-be “temporary” migrant workers who decided to stay in the country despite its bad economic situation.

In the early 1980s, Germany faced an initially unanticipated situation: the temporary guest workers became permanent residents, brought their families from Turkey and raised new children. As many migrants initially came to Germany without their family, schemes to reunite them with their families (*Familiennachzug*) needed to be in place in accordance to various international agreements such as the European Social Charter and the European Convention on Human Rights that stipulate the human right to live with one’s family (Goldberg et al. 2004: 15). Moreover, an educational system had to figure out how to take care of many children and especially teenagers who did not speak German and did not have German school education. New schemes aimed to integrate these teenagers in vocational training, however these were largely irrespective of their level of Turkish education (that might have favoured a university education) (ibid. 16).

While the young generation of migrants and those siblings born in Germany slowly started to grapple with an emerging Turkish German identity, the older Turkish migrants realised that their anticipated return to their home country became an increasingly distant prospect that should, nonetheless, not be given up. Migration literature tended to explain this “myth of return” with the unsettling feeling of not being welcome in the new country and the attempt to come to terms with it by imagining the

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<sup>11</sup> DM 10,000 was a substantial amount of money in the early 1980s and would be worth about EUR 10,000 today.

eventual homecoming (Anwar 1979). These sentiments are quite understandable as Germany is evidently (as my informants insured me) a much greyer, colder and quite possibly less affectionate and neighbourly country than Turkey. Even more so, the Turkish migrant population was increasingly facing overt discrimination, exclusion and violence (Goldberg et al. 2002; Kağucibaşı 1997).

A second decisive period for Turkish migrants started after Germany's reunification in 1990 with new xenophobic tendencies and violence towards migrants and asylum seekers (Horrocks and Kolinsky 1996; also see: Toelken 1985). Interestingly enough, White's (1996: 25) ethnography explores a very different xenophobia in post-reunification Berlin, where Turkish residents gained new status of recognition and were suddenly awarded trust and belonging to the "West-community" against the "more foreign" East Germans. Since 11 September 2001, a new element of general Islamophobia has been added to resentments against the Turkish population that is characterised by a much more widespread, above all, media attention to perceived threats to human rights and civic order in the form of youth crime, forced arranged marriages and honour killings. Interestingly though, a frequent ethnocentrism survey to test the population's sentiments towards "foreigners'" rights and freedom attested a steady improvement of tolerance even post 11 September despite this scaremongering (Dietrich 2007: 239).

#### *Social provision and self-help*

Despite this long history of Turkish settlement, Germany seems still at odds with accommodating this population group. It took until 1998 and a change in government to amend the German citizenship law to facilitate naturalisation of the migrant populations and their children born in Germany (Fücks 2002).<sup>12</sup> The latest census of Germany's population also included, for the first time, a category to "migrant background" in order to also subsume those migrants with German citizenship to the minority groups (Statistisches Bundesamt 2007). These latest statistics state that in 2005, 18.6 per cent of the German population are of migrant background.

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<sup>12</sup> German citizenship is still mainly allocated according to *ius sanguinis* (right of blood or parentage) rather than *ius soli* (right of the soil).

Significant for this thesis is, that, nonetheless, German society fails to acknowledge this diversity, as well as the deprivation and inequality large groups of the population are subjected to. Germany is a wealthy country and spends a lot of money funding its strong social welfare system (Sawicki and Bastian 2008). But it is also a conservative system that seems surprised by societal changes, and fails to adequately respond and address these. Revisiting the troubles of the *Rütli*-school, it is emblematic for the experience of a marginalised population group that faces complex challenges. Students join the school with little language skills, they live in deprivation and with bleak future prospects. The educational system is structurally overwhelmed by such demand, as education in Germany is a federal system and the relatively poor federal state Berlin lacks the financial means to employ more social workers or teacher aids. However, public and political debates tend to evoke images of “failed integration”, how such population groups create a problem for society, rather than discussing how parts of the population are let down by society.

Despite – or perhaps because of – such failed politics, social and political action is taken elsewhere. During my fieldwork I was living two blocks away from *Rütli*-school, and I took Turkish lessons at a Turkish club for education (*Türkischer Bildungsverein*). These language classes provide the club with extra funding, but its main objective is to offer homework help for local youth whose parents could not afford private lessons. This is the first example of local self-help I encountered. Other clubs, for example, offer Muslim religious education in association with local mosques, or Turkish language courses for children who did not grow up bilingual. As the German constitution guarantees the right to religious education to their citizen – and as a consequence of the much revised citizenship and naturalisation laws – schools are finally also developing and implementing Muslim religious education, and Berlin’s schools increasingly also offer Turkish language classes. It was mainly the activism and lobbying of Turkish-origin political groups and the support of the increasing numbers of Turkish-origin politicians that led to these developments. The majority of this education is still organised privately or voluntarily, and there are also projects for private boarding schools that aim to provide Turkish-origin children with non-biased, non-discriminatory school education (although children of all backgrounds are welcome; Die Zeit 2007).

This thesis is mainly concerned with healthcare, which shows similar increasing political organisation and activism in clubs, NGOs and charities. The case of healthcare shares the same dilemma with education. Social deprivation not only creates ill-health but poverty and high illness rates also strain the services that should care for ill-health. And structural reforms that aim to alleviate the problem fail to acknowledge the complexity of the problem in everyday practice. For example, a society of medics with migrant backgrounds invited me to their talk on new insulin prescription regulations. The German Institute for Quality and Efficiency in Health Care (IQWiG), an equivalent of UK's NICE, had recommended that human insulin was just as effective and less costly than the more refined insulin analogues. This way the healthcare system could better cope financially with its increasing numbers of diabetic patients. As a result of the recommendation, state health insurances would only pay for the prescription of human insulin, and patients on analogues should be switched back to human insulin as soon as possible. The doctors in the medics' society were outraged as their resource strained practices in largely socially deprived areas with high percentages of diabetes patients could not possibly cope with this task. What was more, they believed that human insulin needs stricter monitoring to achieve as good diabetes control, which the doctors considered a difficult task for their migrant patients (from field notes 17.10.2006).

Berlin was a vibrant place for such activism and political activities. At the German-Turkish Congress of Medicine and Public Health a whole range of social workers, medics, politicians, NGOs, interest groups and private companies discussed how the healthcare system failed to provide for a population group in special need (from field notes 27.10.2006). Participants expressed their disapproval of national politics that framed problems in terms of duties of this population group in the interest of integration (learning German), rather than acknowledging that the state needs to make more adequate provision (translation services). They were appalled by the expectation that a sick and elderly person should learn German to converse with her doctor, or chose to be translated by her grandchild as the only other option. Participants demanded funding for translation services, more Turkish-origin doctors in primary care and training of Turkish-origin practice nurses; they debated an

already established migrant patient consultancy, and private businesses of Turkish nursing homes to provide adequate elderly care.

Last but not least, the congress was attended by representatives of Berlin's Turkish diabetes self-help group. As German diabetes care has yet largely failed to acknowledge diversity or structural health inequalities, it was (mostly Turkish-origin) health professionals that initiated a self-help group that should fill this provision gap. This initiative of self-help aims to provide individual support to diabetics in their native language, access to education and resources. They also engage in community outreach work to raise awareness of diabetes and offer help to a patient group whose healthcare system makes no provision of native language care or education or cultural-specific dietary advice. As this thesis will explore, in this group Turkish-origin Berliners teach themselves to adopt a strict discipline of body maintenance into their lives that manages their illness better than any medication can.

## Chapter 2: Research methodology

From September 2006 to August 2007 I conducted ethnographic fieldwork in Germany's capital city Berlin. I had planned to trace common public health perceptions on the alleged vulnerability of migrant populations to chronic illness and explore the scarce accounts on unusually high type 2 diabetes rates among Turkish migrants in Germany (Laube et al. 2001). Initially, I expected to speak to (mostly German) health professionals about their perception, as to whether they experienced a local "public health challenge" in terms of above-average illness rates or inadequate health provision. Through these professionals, I had hoped for access to "the other side of the story" and explore actual patient experiences. In order to investigate illness management as an individual and community practice, I aimed to use the concept of "marginality" as a relational approach to both illness (susceptibility and care) and migrant status. It should be ethnographically investigated who and what is placed at the margins (by whom), and how centre and margins are constructed, connected and contested. Despite my analytical goal to overcome a dichotomy of "centre" and "margin", "majority" and "minority", and even the "healthy" and "ill", the study design nonetheless envisioned two sets of research participants – the Turkish patient with diabetes and the (mostly) German health professional, or more generally the Turkish migrant and the German healthcare system. However, during fieldwork these dichotomies largely disintegrated. Instead I found a whole network of Turkish-language diabetes-related services, interest groups and individuals, which was difficult to sort into neat categories of lay-professional, formal-informal, Turkish-German, (non)citizen-state, and so on. Not only did I encounter this structural answer to diabetes within the Turkish migrant community but I also had to revise another preconception drawn from public health literature. My diabetic informants did struggle with their illness but, despite their disadvantaged demographics, had a firm grip on their illness management.

In this chapter, I will describe the methodology used in this research project. I will explain more about my initial research question, and then introduce my research

setting and sample. Finally, this chapter describes important aspects of the study design and data analysis.

## 2.1 Researching marginality: the initial research question

My original research proposal had outlined to investigate “Chronic Illness at the Margin” and positioned itself within an “anthropology of the margins” (Das and Poole 2004). “Marginality” in its connection to ill-health was borrowed from Ecks and Sax’s (2005) paper on the “ills of marginality. “Marginality” served those scholars as new ways of conceptualising health inequalities. They referred to both illness as the reason for being marginalised within a society as well as the marginal status within a society leading to illness.

The notion of “marginality” is nothing particularly new within social theory, for example see the sociologist Edward Shils’ (1975) distinction of centre and periphery in his investigation of authority in society. Eickelman and Piscatori (1990) borrowed Shils’ approach when looking at “centrality” in the study of Muslim societies. Although acknowledging its utility, they considered Shils’ framework of centre and periphery problematic. They argued that “centrality” should be understood in more complex ways insofar as there is more than one centre or that one can find more than one hierarchy within the centre (referring in this case to the pluralism of Islam). I found their approach very useful and could see that in the study of “marginality” (or “centrality” respectively), one should account for these pluralities (also see Ecks and Sax 2005). The “centre” in my research, for example, was not envisioned as a single entity; the German state is not necessarily the same as German healthcare politics or provision, and there are hierarchies (centres and margins) within that.

At first sight, “marginality” refers to the spatial position of many marginal subjects. It includes those groups or individuals living in “developing” countries rather than their adjacent wealthier neighbours, in rural areas rather than the cities, or in inner cities’ ghettos rather than their trimmed suburbs. The latter clearly shows that the centre and its margins do not always own clearly assigned status. Most

importantly though, “marginality” does not turn out to be a solely spatial concept but serves as a way of describing marginal positions in hierarchical systems, stratified societies with unequally divided opportunities or access to services or participation. However, concepts such as inequality could also accommodate such meaning. Instead, “marginality” was chosen to be understood as “a radically relational concept” which recognises the connectivity of centre and margins (Ecks and Sax 2005: 199).

Moreover, “marginality” should be understood as social process, social practice and transitive action (Ecks and Sax 2005: 208). Nijhawan argued in his account on Sikh asylum seekers in Germany “that the migrants’ marginality in everyday life does not mean that they are at the margins of public discourse” (Ecks and Sax 2005: 207). He thus suggested moving beyond simplistic conceptualisation of marginality and exploring its complexities and relations, and how “marginality” is not just a status but a performance or technology. In his contribution, different facets of marginality were explored, including how marginality can also be a position of power. Marginality here becomes the subject of documentation. Both the German state and the asylum seekers document “evidence” of the trauma of violence and political prosecution. Marginalisation is a means of governmentality and state control as much as performance and activism.

Accordingly, my research project aimed to employ “marginality” as a starting point to explore Turkish migrant experiences with diabetes in Germany. In doing so its design included possible agency, power or more concrete ways of actively handling healthcare, illness management or encounters with the state that affect the body as much as notions of residency or citizenship. Above all, these Turkish migrants should not be regarded as a bounded group without relation to other Berliners.

Current emphasis on “health inequalities” in Euro-American migrant health studies seemed to offer limited and over-simplified understandings of the processes at play. There, both migrant status and chronic illness are described in their debilitating mode and static and discriminatory position (e.g. Marmot 2006). In my proposal I suggested that investigating migrant experiences with chronic illness in their relation to the “centre” – may that be the state or its representation as healthcare

(practice) – allowed for social practice and agency. This could ultimately not only shed light on the understanding of migrant illness experiences but also on the understanding of German healthcare (the state) and biomedical knowledge production and practice. Das and Poole (2004: 4), after all, argue that “the anthropology of the margins offers a unique perspective to the understanding of the state, not because it captures exotic practices, but because it suggests that such margins are a necessary entailment of the state, much as the exception is a necessary component of the rule”.

I originally stated in my research proposal that it should not be “the other” or the “pathological” at the centre of investigation but the social processes that define the margins, how boundaries are set and contested. I anticipated that research of people’s experiences of marginality should therefore not solely include these people at the margins as main research participants; that it was not distinct communities but rather their embeddedness in wider societal networks that should serve as the research setting. Having said that the research design should accommodate a fluent and multi-layered conceptualisation of centres and margins, the actual fieldwork soon uncovered misconceptions. For example, I still (if reluctantly) expected a dichotomy of (Turkish) patient versus (German) doctor, a (Turkish) migrant minority community interacting within wider (German) society. Most of my research participants, however, turned out to be – with very few exceptions – Turkish-origin, mostly first generation immigrants, of various backgrounds, doctors, nurses, patients, patient consultants, drug company representatives, active group members and group leaders and assistants, those considering themselves activists, involved in NGOs, but also researchers – family doctors researching and giving talks, and clinical researchers guiding German public health rhetoric in this field and NGO agendas. I also shared the “observer’s seat” at a self-help group for a while with a Turkish-origin nurse writing her Master’s dissertation. This quickly faltered any attempts to identify “minority group” vs. majority society, disadvantaged vs. elite, or probably most obviously lay knowledge vs. expertise. Marginality, indeed, turned out to be a truly relational concept: a self-help group member could assume a “central”, privileged position as an expert; the German healthcare system can be rendered

marginal to the experience of my research participants that move in more informal care settings.

## 2.2 Research setting and participants

### *Setting: Berlin*

For my fieldwork I settled in Germany's capital city Berlin, which is often described as the ultimate "postmodern" city and offers a unique research setting for a study of marginality. The city has been defined and shaped by its boundaries which were at times salient and deadly, the Berlin wall, later silent and invisible as the borders of East and West are still drawn in the imagination of its residents (Borneman 1992). Berlin's boundaries though were never absolute, often permeable or at least challenged by its residents. They shared a historic memory of social ties across borders; questions of belonging, being marginalised and yet at the centre of world politics are intrinsically tied to a Berliner's identity (Borneman 1992). Berlin seemed thus the ideal setting for exploring marginality, questioning the static and unrelational character of marginalised people.

Berlin is also a diverse European metropolis, with 13.4 per cent of Berlin's almost 3.4 million residents without German citizenship (Statistisches Bundesamt 2007). It has been chosen as the setting for this research as it has, with around six per cent, one of the highest percentages of Turkish-origin residents of all German towns and cities (Statistisches Landesamt Berlin 2006). Many Turkish residents live in city districts such as *Neukölln* and *Kreuzberg* where the immigrants constitute up to one third of the population. *Kreuzberg* is known among Germans as "Little Istanbul" – much to the offence of Istanbulis who regard their modern, metropolitan lifestyles to be in stark contrast to the migrant lives in Berlin. The Istanbul author Aykol (2002), for example, suggests calling it "Little Anatolia" in order to more accurately describe the migrants' often rural backgrounds from Turkish Anatolian hinterland. In Turkey, Germany is nonetheless humorously called Turkey's sixty-eighth province (Mandel 1990).

I specifically chose the district *Neukölln* as my major research setting, as it received much media attention lately that depicted *Neukölln* as Berlin's "new Bronx", a "ghetto" of ethnic segregation where schools have an overwhelmingly "non-German" student population, unemployment is high, and stories of violence and crime are frequently reported in national newspapers. A local family doctor told me that *Neukölln*'s benefit office hands out the largest social benefit and unemployment payments in Germany. It used to be infamous for regularly running out of money by December and leaving benefit recipients not able to pay their bills at the end of the year. *Neukölln* has become the centre of debates on multiculturalism and integration, an idiom of the "foreigner" in German society, and an example how the "marginalised" can enter "central" public debates.

I also chose this research setting for its large population of Turks (Sunni, Shi'a Alevi, Kurds), who share their neighbourhood with an eclectic community of Arabs (Palestinians, Lebanese, Syrians, Iraqis), Persians (Iranians, Afghans), East Europeans (Russians, Polish), Africans (mostly from North- and West-African states), and Germans (those born in Berlin, growing up in the East or West, and those who moved to Berlin more recently)<sup>13</sup>. Walking down the streets of my neighbourhood gave little evidence of media tales of ghetto culture, crime and poverty.<sup>14</sup> On the contrary, day-to-day street life resonated *Neukölln*'s multiethnic character of vibrant social interaction and relaxed co-habitation. I would share a *U-Bahn* carriage with groups of teenage girls from various ethnic backgrounds in the latest fashions of skinny jeans or mini-shorts who discussed celebrity gossip with their friends in long sleeved coats with colourful headscarves. Elderly couples in traditional Eastern-Turkish clothing were strolling down the street back from their shop at one of the many big Turkish supermarkets, the woman pulling a shopping trolley behind her, and at my local discount-bakery *Backfactory* tables would be

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<sup>13</sup> This list is only exemplary but attempts to highlight the community's diversity. Defining ethnic or migrant groups in Berlin seems an unpromising endeavour. National census, e.g., register nationalities but subsume second or third generation immigrants as "migrant background" without specifying their origin. The term Turkish in this thesis should include religious and 'ethnic' distinctions such as Sunni, Shi'a Alevi and Kurdish Turks. For a longer discussion see *On terminology: Turkish Berliners* further on in this chapter.

<sup>14</sup> This is perhaps because I avoided unsafe situations, e.g. walking at night in certain neighbourhoods. Crime rates are high in this area, there is a gang culture; however, my everyday life was not affected by this.

shared by the international students of the adjacent language school and elderly Muslim men who prefer the cheap coffee to the pricier Turkish men's tea-house around the corner. Shops, supermarkets, hairdressers, mobile phone shops, etc., were locally owned by *Neukölln*'s ambitious businessmen, and the names of the many doctors, lawyers, insurance agencies, etc. sign-posting their services in multiple languages gave me a first hint that the multiethnic neighbourhood expands into all social classes. It turned out, however, that my Turkish-origin informants lived spread all across Berlin, as they were all first generation immigrants who had been subject to initial migrant policies of "anti-ghetto" urban planning (Mandel 2002: 369).

*Participants: family doctors*

What I could achieve locally in my district *Neukölln* was to visit family doctor surgeries that either attended to a large patient group with migrant backgrounds or whose doctors were Turkish, Arab, Persian, etc. themselves. Interviews proved hard to get, as I had to by-pass the surgeries' receptionists who enjoyed their power of turning down requests to speak to the doctors with their on-the-spot assessment of whether their bosses would be interested in my research at all. Those doctors who I managed to get through in the first place, and who then would give a time slot of 20 or 30 minutes for an interview, were often reluctant to talk about "migrant health". Some seemed nervous about the quite politically incorrect exercise of singling out their Turkish patients, others finally highlighted the difficulties of working in a socially deprived area and with "high-maintenance" patients with poorer health and little language knowledge. I formally interviewed 5 German doctors and 7 Turkish-origin doctors.

Two Turkish-origin doctors offered more of their time for my interviews and a subsequent invitation to an evening hosted by a professional society of foreign doctors provided further opportunity to discuss diabetes among the Turkish community of Berlin. Further into fieldwork I met another group of medics, all Turkish-origin, which was very active in raising diabetes awareness within the Turkish community, and whose members were interested in in-depth interviews. This medics' society is an association of about fifty doctors, dentists, nurses and pharmacists. It was founded 23 years ago when Turkish-speaking healthcare

provision was not quite as common in Berlin. In the early 1990s the Senate funded the association quite generously, mostly in order to provide an HIV/AIDS drop-in clinic for testing and consultancy for those affected and their families. The Turkish migrant community had been identified as vulnerable to HIV, but the association also had enough money to employ full time Turkish-speaking staff to attend to various other health problems. Instead of HIV/AIDS, diabetes quickly crystallised as the most pressing issue and when funding got cut despite rising demand, the medics' society hosted a first information event. The huge audience that turned up surprised everyone, and the idea of a proper patient-led diabetes self-help group was born. However, still involved in regular health programmes at the local Turkish-speaking TV station and offering Turkish-speaking patient education sessions, the doctors considered themselves an important part of Turkish diabetes care in Berlin.

In my interviews all doctors seemed to agree that Turkish patients struggled with a certain set of problems. Medically speaking, this patient group mostly grappled with obesity, and then at older age diabetes and cardio-vascular conditions were common, often multi-morbid, i.e. suffering from several illnesses also including skeletal illnesses and very widespread depression. Most doctors saw the causes in social conditions and life style choices, highlighting social deprivation, unemployment or hard manual labour but also the rise of cheap fast food and a general lack of "health awareness". All doctors emphasised that they were only speaking from "mere experience" and could not provide "objective" statistical "hard facts". In order to back their observations, German doctors liked to quote a study the city Berlin has undertaken recently, which found that obesity rates of Turkish origin children starting school are twice as high as of German 1<sup>st</sup> year school children (Delekat 2005), whereas Turkish-origin doctors would also frequently mention the Laube et al. (2001) study on high diabetes rates among Turks in Germany. In summary, doctors' experience with diabetes among Turkish migrants suggested that a complex combination of socio-economic status, education and illiteracy, migrant status and lacking German language skills contributed not only to the cause of illness but also hindered treatment and management. Additionally, doctors stressed that their surgeries were situated in the very same socially deprived area and were therefore

chronically underfunded and understaffed considering such high maintenance patients.

*Participants: diabetes consultants*

The first months of fieldwork left me with a rather bleak picture of migrant diabetes care in Berlin. Encouragingly, some of the Turkish-origin doctors told me they offered Turkish-speaking diabetes education sessions for their patients and I could sit in on them – but after months of chasing them up I realised that the surgeries did not seem to find time to offer these sessions any time soon. Dealing with my own disappointment I could only imagine the patients' frustration being confronted with a diagnosis of diabetes without receiving much explanation or information for months. I was finally invited to attend the Turkish-language diabetes patient education sessions of a locally well-known family doctor who specialised in diabetes care and who I had first met during a medical congress where he gave a presentation on diabetes self-management and illiteracy.

Patient education sessions are typically held by practice nurses or nutritionists who have undergone special training as diabetes consultants. Later I also attended a regular (German-speaking) patient education programme in a more middle-class borough of Berlin. Participating in such sessions not only gave me an insight into clinical expectations of patient knowledge and patients' reactions but (subsequent interviews) also provided me with an alternative "health profession" perspective to doctors' experiences and opinions. Somewhat acting as intermediates within diabetes care, these diabetes consultants gave frank assessments on both their patients' ability to manage their illness and doctors' actual efforts to provide adequate care. Access to the attending patients' opinions, however, was difficult as the short period of a set of education sessions was not enough time to establish rapport and conversations remained sketchy.

*Participants: diabetes self-help group*

Attending several local medical congresses I finally came across a Turkish-speaking diabetes self-help group, founded in 2003, that was recommended to me if I were interested in getting to know some patients. Most doctors I spoke to before did not

mention that such a group existed, and later explained that they did not know about it. While the group seems invisible for many of Berlin's healthcare professionals, it was very noticeable to Turkish Berliners, as they frequently advertised on Turkish-language radio and TV and on leaflets in benefit offices. Meeting their group leader on several occasions I was invited to join their group meetings. Over the following months the self-help group became the main focus of my research, providing me with access to Turkish migrant experiences in Berlin, friendships, and an entirely different perspective on migrant diabetes management. The members of the self-help group ticked all the boxes I had been hearing about Turkish first generation migrants with diabetes: often recipients of social welfare, early retired or unemployed, many women had not attended school or only primary school, and many spoke only little German (or only with people they knew well). Nonetheless, my informants demonstrated excellent knowledge of diabetes and therefore good levels of diabetes control – something health professionals seemed to have deemed impossible.

The group's leader Mr Yılmaz<sup>15</sup> is a forty-eight year old first generation immigrant who was born in a town in West Turkey and was diagnosed with type 2 diabetes in Germany many years ago. He has been living in Berlin for over twenty years and is a well known and highly respected member of the Turkish community of Berlin. He told me that through his job as an undertaker and later door-to-door salesman he got to know thousands of Turkish families in Berlin (and through them the diversity of his homeland Turkey) and that had made him the perfect candidate to jump-start such a project. Yılmaz led his group with an authoritative yet compassionate hand. He had undergone training with the German Diabetes Union which was organised with the help of some doctors. Involved were members of the medics' society as well as the German doctor who practices in the dialysis ward of the private hospital that hosted the self-help group meetings. On his own initiative, Yılmaz also travelled to Turkey to be trained there and visit Turkish self-help groups for “an alternative perspective”, as he explained to me.

The group meetings were held in a small lecture room in the dialysis centre at a hospital every Saturday afternoon at 2pm. The eight ascending rows of chairs were usually well occupied by an eclectic group of people. Some well-dressed women in

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<sup>15</sup> All names in this thesis are anonymised.

their forties to sixties, with smart hairstyles, elaborate jewellery and make-up would always sit next to each other exchanging latest news. Some men formed similar groups, often discussing latest Turkish and/or German politics – or simply sharing how they got on with their diabetes management. Young women accompanied their mothers, and brought their children along too who kept themselves busy with homework. Elderly couples attended the sessions, some very traditionally clothed, the men in formal jackets, with head caps, beards and prayer beads in their hands, the women in long, wide coats and colourful headscarves, some couples looked more urban or “modern”.

Usually, a group of ten to twenty people met, depending on the weather and the time of the year. In good weather, some members seemed to prefer their allotment gardens to the stuffy lecture hall, in the early summer and autumn months many members were already or still on their annual leave in Turkey. These about twenty people were the core member group that not only seemed devoted regulars at normal group meetings but also helped with organisations tasks and fund raising. Not everyone gathered, not even of the regulars, had type 2 diabetes, there were also family members, friends, neighbours, and simply those who were interested.

I was the only one without a Turkish background and while my Turkish surname sparked discussions on the close history of Turkey and Germany, my broken Turkish gained me many compliments on the commendable attempt to learn this difficult language. I did not receive much translation help, however, but was “left to it”, to make my own sense of their meetings. Only every now and then we had little discussions of clarification when several of us struggled with Yılmaz’s tables, for example of elevated risk percentages (“If you are xx kg overweight, your risk of stroke rises xx %.”). Despite occasional difficulties to follow Yılmaz’s elaborate presentations, Yılmaz had an extraordinary talent to explain rather complex issues on nutritional values, anatomy, organ function, and bio-chemical mechanisms in very simple terms. As Yılmaz also hosted community information events with his group and appeared on local Turkish TV to give presentations, the group meetings attracted a much larger crowd of people at times. At these occasions these first-timers filled the entire lecture hall and while all were made to fill in a membership

form and thus added to the substantial list of around 8000 official members, only some would return at subsequent meetings and become new regulars.

On a final note, Yılmaz and the medics' society had explained to me that the self-help group mainly addressed patients with type 2 diabetes as type 2 diabetes had been identified as a burden within this populations group.<sup>16</sup> Yılmaz's training was on type 2 diabetes and recommendations were targeted at people with type 2 diabetes. However, the membership form did not specifically inquire about the type of diabetes people had; Yılmaz merely asked at times how many people were insulin users, especially how many had recently progressed to insulin. Therefore there may have been also members with type 1 diabetes and I can imagine that Yılmaz was helpful to find more specific information for such members. Community gatherings were specifically advertised as type 2 diabetes information events.

#### *Participants: diabetes patients*

The self-help group was the focal point of my ethnographic research in Berlin and offered me access to everyday practices of diabetes control. Although these practices were extensively discussed in the group, it ultimately proved more enlightening to explore them in actual practice – following people into their homes. Through my regular attendance of group gatherings, I slowly got to know the members of the self-help group but it took several months until I felt confident enough to suggest meeting outside the group setting. I began to visit some group members in their homes and some of them became my key informants. I not only learned about their two major life narratives: the story of their migration and the story of diabetes, but I could also observe their daily practices of managing diabetes.

I followed 7 people with diabetes into their everyday lives. All, with the exception of one, were women, in their 40s to 60s; disease duration ranged from twenty years to the year I met them; all were first generation migrants from both urban and rural Turkey, east and west; some spoke little German, the youngest in their 40s were fluent and accent-free in German; all had children living with them or nearby, some grandchildren in Berlin; all spend some time each summer in Turkey, some owned property there.

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<sup>16</sup> For a more detailed discussion, see Chapter 7.1.

Narrative interviews dominated these first encounters. I was invited to their home – or homes, for example their allotment garden – where I would meet family and friends. There we would chat, have tea, various snacks, lunches or dinners, browse through photo albums or consult maps. During such visits, “lived diabetes practice” could be observed without difficulty as food dominated any visit and checking of blood glucose levels, injecting of insulin or limiting food portions intruded any conversation. Nonetheless, participant observation proved difficult in such an urban setting. My initial intention to follow people through their daily lives did not turn out to be practicable and feasible. While being welcome in their private homes or within the context of self-help group meetings, further exploration of their lives, even diabetes-related, was out of the question. For example, I did not accompany any research participants to their doctor’s consultations and would only discuss them prior and after their visits to the doctor. Anxieties over test results – anticipated or confirmed – were the subject of several phone conversations and chats over tea. I would be shown their diabetes diaries that list test results but at no time did I feel comfortable enough to ask if I could join the actual consultations. Furthermore, my informants spent several months during my fieldwork period in Turkey. I did not accompany any of them to their home country but met them after returning to Berlin to look back on their trip and experiences while there.

*Participants: others involved (media, working groups, NGOs, private sector)*

Within the area of Turkish migrant diabetes care in Berlin I had developed a whole range of contacts at that time. Almost every month, Yılmaz and his self-help group hosted big information events for the Turkish community in Berlin. Set in turn in the town-halls of two Berlin districts, Turkish migrants were invited to listen to talks on diabetes (often with seasonal topics such as “with diabetes on summer holiday and diet” or “fasting and diabetes” but also on cholesterol or hypertension, or the healthcare reform and social benefits). A consultant for Turkish-speaking patients, and some Turkish doctors supported the group in presenting to an audience of around 70 people. The patient consultant Hilal, a Turkish-origin nurse and academic researcher, soon became a key informant – and friend – who often acted as a mediator when my explanations of my role as an anthropologist created confusion.

Those doctors of the Turkish medics' society who appeared regularly for talks at these events also turned out to be more available for in-depth interviews in their own surgeries.

Also part of these events' regulars were a Turkish optician who offered free eye check-ups, a Turkish drug company representative who offered free blood glucose tests (and provided the group with free glucose meters), and the women of the group who sold sandwiches, tea and coffee. The drug rep also stepped in to conduct small group sessions at those rare times when Yılmaz could not attend, and he also provided the group with free blood-glucose meters and information brochures.

Yılmaz would also regularly appear on local Turkish-speaking TV and radio, with whose producers he was well acquainted. This was part of Yılmaz's effort to advertise for these events and recruit new members for his self-help group. Also he saw this as another way of community outreach to disseminate information and raise awareness. Similar "shows" were done by members of the Turkish medics' society. As I was interested in the content of such "messages to the public", I could accompany Yılmaz to appearances, and the presenter of these TV programmes provided me with tapes of past shows.

Finally, there was a whole range of individuals who were active in the field of Turkish diabetes care in Berlin who were available for interviews. I met the project leader of a local NGO, a working group of the German Diabetes Union, clinical researchers, and got in contact with two of the many Turkish nursing services that has sprung up in recent years to provide elderly Turkish migrants with "culturally appropriate" care in a foreign country. Aside from interviews with service management, I could spend time in a day care centre and chat with personnel and some elderly on their experience with diabetes.

#### *On terminology: Turkish Berliners*

The German context makes little reference to the category of "ethnic minority" and I try to avoid this terminology. Germany is not alone, with France, for example, only registering nationality rather than identifying its population in terms of race, ethnicity or religion (Delphy 2005: 231). Delphy (2005: 230) argues that this approach is

rooted in racism rather than *avoiding* racism as it is claimed, as, in her opinion, it is only North African origin French that are habitually ascribed the extra label “second generation immigrants” and thus rendered “alien”.

Ascribing a certain “ethnicity” to people who immigrated to Germany from Turkey seems to harbour similar contention and contestations. Rather than subsuming this whole migrant population as one ethnic minority, the most apparent distinction should be the division of Turks and Kurds (in USA, commonly and unproblematically Turkish-Americans and Kurdish-Americans; Mandel 2002: 362). Having said this, Turkey is a multiethnic nation state with far more than these two ethnic groups. In fact, there are over 20 linguistic minorities in Turkey and considering religious sectarian differences one could count more than 40 distinct groups (Goldberg et al. 2004: 125). Turkey’s vehement (and often violent) nation-state efforts to favour nationality over ethnic belonging makes such an endeavour of identifying ethnicity an even more sensitive issue.

“Ethnicity” in its academic use has undergone several reconfigurations, conceptualising notions of separation from other groups (e.g. see Barth 1969), understanding ethnicity as political interest groups (e.g. Cohen 1974), as “sets of relations” produced by “specifiable historical forces” (e.g. Comaroff 1992: 66), or as a social “mapping enterprises” (Banks 1996). Mandel (2002: 363) casts doubt on whether “ethnicity” is always a fruitful analytical approach and if there are not alternatives to understand such social relations. Gerd Baumann’s (1996) “community study” of multi-ethnic Southall in London is a good example for such a critical use of such terms as “ethnic minority” or “migrant” or “Muslim community”. He describes social interaction and relation between groups, whose boundaries are fluent, and distinctiveness or membership contextual.

I agree with Mandel (2002: 365) that “ethnicity” is not necessarily a helpful concept, neither as an analytical category, and even less so as a colloquial truism. In this thesis, I often refer to my research participants as migrants. The migrants I met were mostly women, but also men, various ages, different class, and ethnically and religiously different background. They share being born in Turkey – some are still Turkish nationals, many own German passports. Most would not consider themselves German, despite their German citizenship. What unites them are their

“migratory” lives – a certain transnationality (Brettell 2000: 102), insofar as they embrace living in both countries. They have settled in one and spent most of their lives there, but equally stayed connected to their home country where they maintain social ties, are politically active, for example participating in elections, or economically active, investing in Turkey, for example by owning property. This seems to happen in very eclectic ways, not a clinging to a lost past but a very present shaping of life. One of my research participants told me that they owned a holiday apartment – not in her birth village but in a much more exciting Aegean coastal resort. I also use the terminology “Turkish-origin” in this thesis, especially for those research participants whose background I did not get to know and who are younger generations with often very different expressions of identity.

There is no unifying terminology that all of my research participants used. Academics and health professionals referred to people of migrant backgrounds or Turkish-origin, many of my research participants simply called themselves Turks. The only term they all seemed to share was to call themselves Berliners – perhaps in opposition to me, the temporary resident, who had to be shown around, given repeated directions, and tips on public transport.

### 2.3 Reflections on study design, ethnographic data and ethics

The research participants included individuals and groups, patients and health professionals, those experiencing diabetes first hand and those who are actively engaged in diabetes care. I encountered them in many different settings, sometimes private homes, often public clinical places such as hospitals or primary care practices and civic places such as town or conference halls. Hence, various research methods were selected in the study design. Here, I am reflecting on these methods, the kind of ethnographic data they produced, and their utility in establishing my arguments.

Anticipating the time constraints in clinical settings, I planned to conduct semi-structured interviews with health professionals. To complement such accounts, educational brochures they gave out to patients, medical congresses they attended and public talks they gave, were considered. First encounters with patients and their

experiences of living with diabetes were expected to happen in similar interview-based fashion, less stringent perhaps in narrative explorative interviews, but nonetheless in an initially formal setting. Reflecting on this early ethnographic data and what kind of questions they answered produced some unexpected results. The fairly standardised interviews with health professionals have yielded only limited utility in terms of their insight into their patients' lives, attitudes, expectations, and motivations. Many accounts seemed simply limited, often ignorant or cautious. However, speaking to more and more doctors, getting to know their professional societies and hearing their public talks provided me with a window into their involvements and the political and moral economy of local clinical diabetes care. The patients' ideas about diabetes and their illness narratives, on the other hand, struck me as surprisingly clinical. As my main access was a self-help group, I realised I spoke to a medicalised minority of expert patients. Only when turning to practices, the "doing diabetes" that they recalled and rehearsed so diligently in their group meetings, in participant observation, much more interesting questions could be answered – even those as to why narratives were so clinical. Exploring such active and conscious practices of diabetes management finally also provided answers to my ethical conundrum. As research ethics were unregulated in the German fieldwork setting and seemed to demand utmost scrutiny by me, I discovered that questions of informed consent and conscious participation not necessarily have to be answered on behalf of research participants.

#### *Interviews, illness narratives and explanatory models*

Interviews with health professionals presented two main challenges. Firstly, approaching medical professionals in their clinical settings meant that I was faced with severe time constraints. Often I was only granted the timeframe of one or two average patient consultations, which meant that an open-ended interview style had to be abandoned for a more structured approach that should, nonetheless, allow for a certain explorative investigation. Secondly, healthcare professionals – and that includes NGO workers or nursing service managers – all shared an academic education and background that resulted in certain study design expectations. Mostly unfamiliar with ethnographic research methods, many envisioned a formal interview

structure with set questions that could be reviewed prior to the interview appointment. I decided to meet these expectations by composing a list of guiding questions for semi-structured interviews which could be abandoned on the spot in case more interesting themes emerged or the timeframe got extended. These guiding questions were shaped by the answers that were given in initial interviews at the beginning of fieldwork. Moreover, it was also common for my interviewees to seek statistics for validation of their observations and experiences, excusing these as merely anecdotal and thus quoting the previously mentioned studies on child obesity (Delekat 2005) and diabetes prevalence (Laube et al. 2001). I embarked on my own exploration of local statistical data. Finally, I was exposed to numerous information materials on diabetes in clinical settings. I was mostly interested in Turkish-language material. This ranged from merely translated German brochures (often with the cover photo of an agile blond couple on a Nordic Walking outing) to more or less ambitious attempts to create information that focused on Turkish diet and, for example, showed photos of Turkish people and meals.

Those research participants who were living with diabetes and most of whom I had met through the diabetes self-help group were providing me with a very different research environment. Long visits to their homes allowed for open-ended narrative interviews, which were often merely a series of conversations on reoccurring topics: their experiences as Turkish migrants and as diabetes patients. In first meetings they told their migration stories quite chronologically in biographical interviews, which was often assisted by family photo albums and maps of Turkey to show the location of home villages or towns. Such albums contained recorded life times of Turkish childhoods, early years of settling in a new environment, annual car journeys through Europe for visits “home”, and various family events in both countries – Turkish weddings of siblings, children’s first days at school, grandchildren’s first birthday parties.

In order to explore my informants’ experience with diabetes, I had initially planned to employ classic medical anthropology tools. As there was no pre-existing anthropological exploration on individual “Turkish migrant” concepts of diabetes, I anticipated following Kleinman’s (1980) framework of “explanatory models” (EM). Kleinman (1980: 104-9) introduced the concept of EMs in order to grasp different

ideas and practices concerning a particular event of ill-health. He suggested that one should ask the following questions: What is the presumed cause of ill-health? How are time and mode of onset of symptoms described? What is the pathophysiology of the illness? Which course will it take? Which treatment is being taken? When finding the answers one can elaborate where perceptions between official biomedical models and local understandings differ. Kleinman's EM framework can elaborate how people explain the onset of their illness and how they identify this onset. Furthermore it can shed light on the kind of treatment which is pursued and if this therapy is actually preferred.

I soon realised, however, that I got only "textbook answers" from my informants. Their long involvement with the self-help group and the training they had received there, had largely made them adopt the biomedical understanding of diabetes as their "explanatory model". This also questioned another "traditional" concept within medical anthropology: the distinction between "illness" and "disease" (Eisenberg 1977). For decades, medical anthropologists considered "disease" as "something that physicians diagnose and treat" whereas "illness" referred to "the experience of disease, including the feelings relating to changes in bodily states and the consequences of having to bear that ailment" (Radley 1994: 3). The simple binary division would be that there is the (allegedly universal) textbook definition of diabetes mellitus – "disease" – which is diagnosed by biomedical physicians, but that there is also the individually experienced "illness" diabetes (cf. Ecks 2008). However, this distinction in illness and disease has been rendered somewhat redundant in current approaches within medical anthropology, and this research project indicates that this simple dichotomy does not hold up any longer in many research settings. Patients would reproduce the textbook definition of diabetes mellitus – "disease", while health professionals acknowledge that the understanding of the individually experienced "illness" diabetes is at the heart of successfully guiding patients' self-management. Later Kleinman (1988) revised his approach of explanatory models and developed the less static and narrow framework of "illness narratives" in order to explore individual coping with illness. I agree that a narrative exploration of illness experience entails more utility in the framing of illness management as an active social process than a static "model approach". Nonetheless,

it seemed that in such a biomedically charged environment “illness narratives” also provides only very limited insight.

*Participant observation: witnessing diabetes*

Instead of solely relying on such narratives, I decided to refocus on the practices of “doing illness”, the practice of illness management rather than the perception of illness. Accordingly, participant observation became the heart of this project’s study design, sitting in on education sessions, self-help group meetings, TV studios, community information events and talks where knowledge on diabetes is shared, and accompanying people into their homes where this knowledge was put into practice.

Participant observation is the core method of ethnographic research, and distinguishes social anthropological inquiry from (most) other social sciences. Wolcott (1999: 46, emphasis in the original) states that “[e]xperiencing seems an especially appropriate label for drawing attention to what is gained through participant observation.” Such first-hand experience includes all our senses: we see (people, events, places, colours), hear (stories, music, laughter, sorrow), smell (sterile clinical spaces, aromatic mouth-watering food), taste (e.g. difference between tea with sweetener and sugar, fried and grilled meat, low-fat and full-fat yoghurt) and feel (heat, cold, anger, irritation, joy). The ethnographer can witness what people do in their everyday lives, how they go about in their mundane routines, and can participate in such practices.

The most prominent example in this research project is probably food, which is such an important element in diabetic and Turkish lives. I enjoyed great food at almost every visit to people’s homes. I was able to watch women cook, was sometimes made to help but always served as a guest. Often, I joined the rest of the family to eat different food than the diabetic host, and certainly always larger portions. I learned about norms of hospitality that are equally obliging to guests. Accepting several helpings was often inevitable, and such over-eating could be an uncomfortable experience – granted, not as uncomfortable as if I were diabetic and had to be concerned about my insulin dosage. Meals would be preceded by blood glucose self-testing and often insulin injections. Participant observation also meant to see how people interacted with family members and friends, in group meetings, in

supporting but sometimes tense social relations, and how they represented their groups to outsiders.

Finally, participant observation is a long-term methodological approach. Speaking to doctors about their patient education sessions produced an altogether different understanding than subsequently waiting for months for such a patient education session module to finally commence. Moreover, the experiences of research participants were not static. I witnessed, for example, a woman's perceived defeat of digressing from oral medication to insulin over the course of some months, and a man's success of significantly improving his diabetes control and glucose levels within months of joining the self-help group.

My ethnographic data was collected in hand-written notes in a fieldwork notebook, sometimes jotted down while sitting in at meetings, often recalled from memory on a jolting *U-Bahn* carriage on my way home. These jottings stand in awkward opposition to many taped and transcribed interviews with health professionals; narrative interviews with patients were only recorded in field notes as they happened while cooking, eating, watching TV and taping would have disturbed the conversation or activity. However, (more egalitarian,) both interview transcripts (in German) and field note jottings (in German and Turkish) were typed up as extensive field notes in English. All research participants were already anonymised in these word processing documents.

#### *Multi-sited ethnography and ethnographic network analysis?*

As mentioned in the previous subchapter, participant observation in an urban setting required a certain patience; "deep hanging out" with informants (Rosaldo in Clifford 1997: 188) took a much more structured approach than in more small-scale environments. As life did not happen and was not observable in front of my doorstep, it entailed making appointments, travelling across a wide area, and often gaining only limited access to various settings. On the other hand, this "removedness" from an immediate, observable group or "community" offered the overview over a much wider network of people and groups involved. As fieldwork progressed, I became increasingly aware of the relations that connected individuals and groups to a larger network of involvement in Turkish diabetes care. While many doctors did not seem

to know about the self-help group, most doctors who decided to participate further in this study were part of a medics' society, which was closely linked to the self-help group. The self-help group held strong ties to a drug representative, a patient consultant, people from the German Diabetes Union's migrant working group, local media and businessmen. NGOs and working groups worked together with doctors, and supported the self-help group. As mentioned before, while narratives of such interactions and engagements, at least at first, only alluded to such structures, participating in such events and observing relations uncovered what defined such structural arrangements. They were shaped by sociality, activism and collaboration as much as by personal quarrels, economic competition and hierarchical contestations.

As I entered more and more of these connections I started to explore the idea of a social network analysis (Scott 2000). It seemed a fascinating endeavour to attempt to map all these alliances, partnership, business contacts that make Turkish-speaking diabetes care in Berlin such an eventful experience, as well as mapping the private social and family relations that drew people with diabetes into participating in active illness management. At the same time I wanted to retain an ethnographic approach by not only visualising the connections but somehow qualifying them in terms of roles and domains, conflicts and loyalties. However, it soon became clear that trying to simplify such complexities in a visual, schematic and technical form was not possible, after all ethnography aims to provide "thick description" (Geertz 1973) rather than two-dimensional models. People held varied roles and relations and position themselves fluently within the socialities of diabetes care in Berlin. I chose to describe these socialities as Berlin's *field* of Turkish diabetes care as it did not hold the technical and structured connotation of networks or currently widely used concepts such as "assemblages" (cf. Ong and Collier 2005). That said, "field" is an similarly contested category subjected to a longstanding critique that started with the Writing Culture debate (Clifford and Marcus 1986). Alerting to the methodological challenges of contemporary fieldwork, anthropologists increasingly acknowledged that fields are hardly "small-scale", bounded or even confined to one site. Indeed this research project could have been a "multi-sited ethnography"<sup>17</sup> (Marcus 1995) as the

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<sup>17</sup> I did not follow research participants to these multiple sites, mainly for financial reasons.

migrant research participants led transnational lives, spending many months each year in Turkey, Berlin's activists cited Gießen's research findings, the self-help group spoke at a conference in Hamburg, invited by the German Diabetes Union, and of course in Berlin not everyone was each other's neighbour and there is no "Turkish community" bound to a locality. Choosing the terminology "field" should thus refer to both the organic metaphor (as opposed to technological assemblages or schematic networks) as much as to the much revised conceptualisation that challenges previous ideas of autonomous, bounded, homogenous or static units or environments (cf. Coleman and Collins 2006). Chapter 8 describes Berlin's complex and multilayered "field of Turkish diabetes care" and also provides a detailed discussion of the analytical choices.

### *More hurdles*

Finally, I had to consider my own position during this research. I had to ask myself in what way I was shaping interviews, conversations and representations. What did it mean that I was asking these questions, was interested in their group, opinions and experiences? I am a young woman, healthy, non-diabetic, slim, non-smoking. I am non-medically trained, yet academic, based at a prestigious university and perhaps publishing in international journals. I am German (but not a Berliner!), resident in Scotland and with a Turkish surname. While, during interviews with health professionals, some considered me as an ally, sharing a research interest or an educational status, others were sceptical about my anthropological background and research objective. Patients would find commonalities in our lacking medical background, my Turkish name, my struggle with a foreign language, my interest in diabetes, being a migrant myself in Scotland or because I happened to be the same age as many of their children. Others would assume medical expertise (I was writing a doctoral thesis), or view my German background, my non-diabetic status and acquaintance with many health professionals with suspicion. In any case I was an oddity to my research participants and power imbalances surely came into play, and not necessarily with me in a more authoritative position.

As narratives were inevitably shaped by my presence and interest, I had to explore settings, events and practices that were not quite as sensitive to my interests,

or at least that would have happened without me and I had nothing to do with their construction. Therefore, it also seemed important to move from a narrative exploration to an observation of practices of diabetes management, and to also seek out settings in social everyday life that were not shaped by the ethnographer and the specific interest in diabetes. Having said this, my presence at group meetings or family dinners was, of course, significant. Perhaps I should cautiously consider the practices I participated in or observed, and therefore influenced to some degree, as performance. Although, of course, the idea of long-term ethnographic fieldwork is that the ethnographer hopes to eventually cease to be an oddity. The most obvious consequence of my position as a female researcher was that six out of the seven people that I could follow into their everyday lives were women. The only man had initially been concerned that his wife may not approve of an interview at their home. As his wife became a regular in group meetings too and was close to my own age, we became friends and only then was I invited to their home. I only met the group leader at official events and we met for an official interview in a café.

On a final note, anthropological research always strives towards immersing oneself in the field and describing “a culture in its own terms” (Spradley 1979: 18). This means learning the “native language” rather than merely relying on translators, as “language is more than a means of communication about reality: it is a tool for constructing reality” (Spradley 1979: 17). I had learned basic Turkish prior to fieldwork but needed to acquire more proficiency once in the field. Most of my participation observation happened in self-help group meetings, community events or family homes and were in Turkish. This required not only a certain level of general comprehension but also the knowledge of Berlin Turkish “colloquialisms” that did not concur with my language training in Istanbul. Therefore, I undertook a language course at a local Turkish “education association” (*Bildungsverein*), which mainly offered homework help to the community’s youth. For me, this organisation did not only offer a more localised language training but also insights into my teacher’s Alevi community and his history of political asylum seeking as a socialist student. Most formal interviews during fieldwork, however, were held in German, some in a mixture of German and Turkish (at times with the little help of my dictionary or some informants’ family members).

### *Ethical considerations and consent*

Last but not least, this research required careful ethical consideration. I was conducting research with vulnerable people – patients with diabetes (who, as it turned out, often also suffered from depression) and migrants with low educational level and limited German language skills. This raised concerns about consent and my responsibilities as a researcher for my research participants. Usually such questions are addressed by an ethics committee that scrutinises the value and conduct of a research, but at my field site such institutionalised structures did not exist. Instead of centralised ethics committees, German hospitals run their own ethics boards that decide over research, and family doctors follow general ethical guidelines of patient data confidentiality set by the Medical Council. This means that they would approach their patients on the researcher's behalf and only establish the contact in case a patient expresses his interest in participating. I was uncomfortable with such quite grey areas of authoritative dependencies and decided to reach patients only through the self-help group where people could make contact with me in case of interest rather than the other way round. Ethics committees are missing at German universities and research foundations.

Although local ethics institutions were absent, my research was cleared by the School of Social and Political Studies (SSPS) Research and Research Ethics Committee of The University of Edinburgh, and I decided to follow the American Anthropological Association Code of Ethics. However, obtaining the informed consent as my responsibility towards my research participants was a difficult exercise. I questioned what kind of truly *informed* consent could be possible and in what way I had to protect their interest. In course of the fieldwork, though, I began to revise my ideas of consent and started to wonder if I assumed inertness and vulnerability too readily. As I explored the patients' day-to-day responses to illness experience I discovered their creativeness and agency. Neither victims of their illness nor blind mimics of biomedical healthcare paradigms, they manoeuvred diabetes management recommendations with their social lives and individual bodies. Rather than understanding diabetes control in terms of Foucault's (1998) "bio-power", subsequent analysis was guided by exploring "bio-tactics" based on De Certeau's

(1984) concept of “tactics in everyday life”.<sup>18</sup> The concept of consent could be brought into consideration here. One could argue that my research participants indeed consented to dominant illness management advice, as they could experience how their bodies “did better”, “felt better” if changing their lives in these ways. The execution of what they consented to then laid in their own hands, negotiating the practicality in their social lives.

Similarly, appreciating my research interest roughly as “trying to understand their experiences”, they had a very clear idea as to what they would like to share with me (sometimes telling me, that this is not information for my research), when they would like to invite me, and when I was not welcome to be present. Some had experience of telling their life stories to journalists, the self-help group leader and many doctors were quite media-savvy, and they discussed the extent of their involvement in my research. For example, initially agreeing to show me their group statistics, the self-help group withdrew this offer later but shared their many photos that documented their events with me. All research participants expressed their gratitude and curiosity that someone would be interested in telling a more in-depth story about their experiences. Having said this, I would nonetheless challenge the idea that they could make an informed choice of participation, for example, having never read an ethnography and not understanding the scale or rather limited readership of a doctoral thesis. I fear that most, with a few exceptions, believed – despite my efforts of denial – that my PhD thesis would eventually end up as a widely distributed publication or give them some form of recognition and attention. My ethical responsibility of dissemination beyond disciplinary boundaries will be taken up in the final conclusion of the thesis.

Indeed, this did not solve all conundrums. Getting signed consent forms from my research participants as a potential requirement of publishers seemed a daunting exercise. Above all, while my presence seemed accepted, the idea of handing me (or anyone else for that matter) a signature under a document seemed an odd or even suspicious idea. This was understood and mistrusted as obscure German bureaucracy. It seems ironic that such requirements of informed consent are associated with German officialdom when Germany has such a poor record of ethical

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<sup>18</sup> See the next Chapter 3.1.

research scrutiny; not only are ethics committees missing in research institutions but even there exists no ethics code for anthropologists by the Germany Anthropological Society (DGV). When I discussed the issue signed consent, the general question was what this signature would be for. Many felt that they would “sign away” their rights rather than gain rights with their signature. I had to agree that this seemed the wrong way around, and the members of the self-help group and I negotiated what consent meant to them and in which way this could be formalised that they were comfortable with it. In the end, with the risk of not conforming to standardised ethical requirements, I gave my signature on a document which I handed to them. I stated to guarantee their anonymity and treat their information and data (such as photos) with confidentiality and respect.

### Chapter 3: Bio-anthropologies: theoretical framework

As a final part of this introductory section follows an overview of the body of literature in which I placed my research findings. Locating this thesis within medical anthropology rather than, perhaps, an anthropology of migration or diaspora should lay emphasis on experiences and practices of illness and body management. Migration and marginality should serve to focus the lens on how such experiences can be shaped in particular social scapes and interactions. At the centre of this thesis, therefore, is type 2 diabetes. Type 2 diabetes can mean many things. It is a malfunctioning pancreas, a body overwhelmed by high glucose concentration in its blood and organs that are damaged as a consequence. Type 2 diabetes is a range of faulty genes that can lie dormant until too indulgent food habits have challenged the body enough to make such defect relevant. Type 2 diabetes is a biomedical disease category that describes a metabolic disorder; although under different names, it has been known for thousands of years and its description can be found in ancient Greek and Sanskrit medical texts (Müller 1989; Schadewaldt 1989). Today diabetes is frequently part of “pop health” media coverage, usually mentioned in the same breath with escalating obesity rates. Type 2 diabetes also means a chronically ill life, an immediate physical, profoundly emotional and inherently social experience; experienced by those who receive its diagnosis, those sharing their lives, and those engaging professionally with diabetes. In short, diabetes is sweet blood and strained organs, faulty genes and a scientific medical category; it is a personal embodied and emotional lived experience of facing a life that requires the body to be controlled, and a collective social and societal experience. Neither is diabetes a mere biological entity, a scientific fact, nor can one reduce diabetes to be a social construct perpetuated by media coverage and public health campaigns that blames individuals or society of indulgence.

Social anthropological enquiry tends to focus on illness as an experience of suffering, the impact on social lives and roles and how it is dealt with by individuals or society. Medical anthropologists investigate sickness, medicines and medical systems. The focus, however, has widened and a renaming of this branch to the anthropology of health and illness aims to disentangle automatic connections of

illness and medicine and explore broader contexts and influences. Part of such development is also to discard a distinction of illness, as the anthropologically interesting lay experience, and disease, as the biomedical category diagnosed by health professionals (Eisenberg 1977; Ecks 2008: 87). The emergent science and technology studies found a special interest in unpacking such formerly black-boxed categories and the spaces in which they were formed and negotiated (Lock, Young and Cambrosio 2000). Furthermore, such studies started to explore experiences of bodies re-evaluated or even modified by new scientific technologies (e.g. Rabinow 1996b). Biology was no longer overlooked, ignored, left aside or dismissed. The following chapter should serve as an introduction to a range of “bio-anthropologies” and outline the theoretical framework of this thesis.

Most intriguing of such bio-contributions is the idea of biosociality. Rabinow (1996a) imagined – although never empirically explored – how biology, specifically new biologies created by biotechnology, could create social groups. In this thesis, there is the patient group of Turkish Berliners with diabetes, evoked by health professionals and activists in its immense size and challenge. Some of these patients are formally organised in a self-help group. As this is an unusual story of biosociality, one of marginalised people and fairly “low-tech”, this chapter will introduce previous accounts of biosociality and propose to widen the focus. First another “bio-literature” will be addressed. Michel Foucault was one of the first and most influential scholars to introduce “bio” into social theory. Perhaps most dominant and certainly most often adopted in numerous anthropological analyses of this kind is Foucault’s bio-power (1998 [1976]). The rigorous lifestyle disciplines of people with diabetes invites consideration of such institutionalised forms of bodily control as well as Foucault’s (1990 [1984]) later work on self-care (e.g. Ferzacca 2000). Here I am going to introduce his legacy in health research and their limitations in understanding contemporary experiences of health maintenance and self-care practices.

### 3.1 Beyond bio-power

#### *Bio-power*

The Foucauldian “bio” is concerned with the body and life. Michel Foucault’s concept of bio-power (1998 [1976]) envisions lives and bodies monitored and controlled in increasingly complex nation states that require more subtle and dispersed forms of power than the corporal punishment to which the sovereign powers of earlier centuries resorted. Governmentality, as he later coined this, is a form or art to govern the population with more than mere politics and laws but to assert control over populations and bodies through various disperse disciplines (Foucault 1991b, 2000: 201ff). Foucault’s legacy is immense and transcends disciplines and subject interests. For some, his later work on self-care seems more relevant or radical in thought, in which he imagined people with the freedom to engage in “technologies of the self” beyond bio-power (1997). This thesis addresses both, considering whether diabetes control can be understood as forms of bio-power that people experience or as technologies of the self that people practice autonomously, and asking if Foucault and his descendants raise relevant questions to address the experiences told in this ethnography.

Foucault’s famous works are histories (or what he called archaeologies and later, more Nietzschean, genealogies) of evolving state power and emerging institutions that had life and the body as their central focus. His seminal *Madness and Civilization* (1989 [1961]) is about the mad body and how it is controlled, and this work had a profound impact on the anti-psychiatry movement. Moving on to the generally ill, Foucault described the *Birth of the Clinic* (1986 [1963]) as the beginnings of institutionalised medicine and the medical profession. Most notably, this work is cited for Foucault’s notion of the “clinical gaze” (*regard*) that he conceptualised as an institutionalised and penetrating gaze of the medic on the patient body. This includes the technical, diagnostic, examining and intrusive gaze into the body as well as the administrative, monitoring, measuring and controlling gaze on health and illness states. Foucault then further developed these ideas of watching the – here criminal – body in his history of the prison. *Discipline and Punish* (1991a [1975]) starts with the graphic description of a brutal 18<sup>th</sup> century

public torture and execution scene. Foucault traced the historic development of sovereign power that inflicts such violent acts on the body to punish a crime, to the institutional, modern form of punishment that aims to discipline and reform the criminal in prisons. The body remains at the centre of punishment but its disciplining is achieved in form of constant surveillance. The Panopticon, the central watchtower that enables constant surveillance of the criminal, represents this idea of discipline (*surveillance*) and docile bodies that can be moulded as a result of internalising this discipline. In short, Foucault described how power transformed historically from a brutal force to more covert ways, aiming to control the body rather than destroying it.

This notion of controlling life and bodies was further developed in Foucault's *History of Sexuality (Volume I: The will to knowledge, 1998 [1976])* and his concept of bio-power. Again, Foucault scrutinised the emergent, enlightened modern state and its institutions – this time in light of a history of sexuality – and concluded that changing and expanding demographics required a more administrative and bureaucratic approach to govern the population than a direct rule of power. Placing the discipline of bodies and the regulation of the population at the core of power, institutions emerged. Military institutions, schools, universities, clinics would exert such discipline on individual bodies and demographic statistics were gathered that monitored the population in birth and mortality rates.

[T]his power over life evolved in two basic forms [...]. One of these poles – the first to be formed, it seems – centered on the body as a machine: its disciplining, the optimization of its capabilities, the extortion of its forces, the parallel increase of its usefulness and its docility, its integration into systems of efficient and economic controls, all this was ensured by the procedures of power that characterized the *disciplines: an anatomo-politics of the human body*. The second, formed somewhat later, focused on the species body, the body imbued with the mechanics of life and serving as the basis of the biological processes: propagation, births and mortality, the level of health, life expectancy and longevity, with all the conditions that can cause these to vary. Their supervision was effected through an entire series of interventions and *regulatory controls: a biopolitics of the population*. The disciplines of the body and the regulations of the population constituted the two poles around which the organization of power over life was deployed. (Foucault 1998 [1976]: 139; emphasis in the original)

Foucault called these two techniques of power – anatomo-politics and biopolitics – bio-power (ibid. 140). Bio-power is acting on populations and their individual bodies as a form of governing the masses.

This research project may be readily located with a body of literature on bio-power, as it looks at the public health issue of chronic illness in the population group of Turkish migrants. Foucault's legacy is immense and, although his own work remained in the realm of theoretical, philosophical enquiry, it provides the theoretical basis for a plethora of empirical research, for example on public health and healthcare. Foucault's popularity surely owes to a range of developments within the biomedical realm that his work pre-empted. On the one hand, biomedicine seems to have ever perfected the medical gaze and surveillance with its biotechnological advances in human genetics. On the other hand, biomedical resources are increasingly occupied with caring for chronic illness instead of curing infectious disease, so that prevention, the discipline of healthy living, have gained unprecedented significance.

Turner (1992) welcomed Foucault's endeavour of bringing the body into social theory. "Essentially the argument behind the sociology of the body is, first, that sociology is genuinely a sociology of action, and that the social actor is not a Cartesian subject divided into body and mind but an embodied actor whose practicality and knowledgeability involve precisely this embodiment." (Turner 1992: 170) As Foucault's frameworks offer such an abundant field of enquiry, the list of Foucault's legacy could continue endlessly. An interesting compilation is the edited volume of Petersen and Bunton (1997) that includes contribution by Turner alongside fascinating discussions, for example of surveillance in regard to menopause and hormone replacement therapy (Harding 1997), and an account of Brazilian health education as bio-power (Gastaldo 1997). Lupton's *The Imperative of Health* (1995) investigates the public health movement and health promotion through Foucault's lens. She discusses such issues as vaccine use and hygiene campaigns to "govern the masses", and how risk management, its measurement, estimation and eliminations, stands at the centre of "taming uncertainty". Health promotion aims to create wilful, docile bodies that refrain from risky sexual practices, extensive alcohol consumption or smoking.

The ethnography in this thesis, however, only speaks at first glance to the analytical framework of bio-power. While one may imagine institutionalised programmes to monitor the Turkish migrant population's burden of diabetes and to

“discipline” their bodies in health education, there was, at the time of this research, no epidemiological data on the diabetes prevalence of any minority groups in Germany, no interventions targeted at this patient group or official education offered in another language than German. That said, Turkish-origin doctors devised their own healthcare plans to care for their Turkish migrant clientele and Foucault (1998 [1976]) indeed conceptualised bio-power as dispersed in institutions and their representatives rather than centralised.

### *Power/knowledge*

Foucault (1998 [1976]) did not envision a “top-down” central power of direct rule, but a power that is local, diffuse and dispersed in various institutions, and that is represented in and reproduced through people. In this case of diabetes, bio-power would be asserted by the family doctor, the diabetes nurse, the newspaper health correspondent. Power, for Foucault (1980, 2000), is always intrinsically linked to knowledge; in fact, this link between systems of knowledge and power is so inevitable that he coined the term power/knowledge. Biomedicine, for example, is such a pervasive system of thought because it is represented in its various institutions of clinical spaces and by the medical profession that occupies such spaces and teaches patients how they should understand and treat their bodies (Lupton 1997: 99). In his essay *The government of the body* (ibid. 177-195), Turner parallels Weber’s sociologically more established concept of rationalisation and ascetic practices with Foucault’s power/knowledge relationship. Tracing the “subtle connections between the body, knowledge and power”, he unpacks medical regimes of diet and “anxieties about obesity and dieting, slimming and anorexia, eating and allergy” (ibid. 192). Such social, political practices of food are embedded in a knowledge system that regards the body as a machine that requires surveillance and management and that employs “science in the apparatus of social control” (ibid. 192).

This thesis will present ethnographic accounts on how knowledge on diabetes is negotiated by the research participants (Chapter 4). It will explore how diabetes self-management requires detailed knowledge on diabetes itself and strategies on how to conduct everyday lives in order to control diabetes well. In accordance to

Foucault's (1980) notion of power/knowledge, this diabetes knowledge is intrinsically linked to power relations. Many Turkish Berliners have no access to diabetes education that acknowledges their needs, for example in regard to language or diet. The Turkish-language education sessions offered by some Turkish-origin doctors guard knowledge in different ways, providing only very basic education for the alleged un-educated. Even within the self-help group power relations shape how knowledge is negotiated. Knowledge is, nonetheless, actively sought and challenged; knowledge is indeed "practice" rather than an abstract entity (Foucault (1990 [1984])).

### *Self-care*

In his last volume of the *History of Sexuality*, *The Care of the Self* (1990 [1984]), Foucault shifted his attention from the disciplining of docile bodies to agency of committed self-disciplining selves. Again exploring history, he investigated ancient Greco-Roman moral economies of self-care. He found that body maintenance is not necessarily subject to disciplinary biopolitical governing but could be "technologies of the self" (Foucault 1997). In the classical age the notion of self-care was a conscious, voluntary, personal and ethical/normative exercise. This "self-mastery" was about the exercise of freedom, rather than being constrained by power/knowledge (Foucault 1990 [1984]: 34). Freedom, in his view, was not considered a given, but would be individually achieved through practices (Foucault 1997). These ancient notions of "self-reliance" (Foucault 1990 [1984]: 100), as he quotes Celsus, on knowing about healthy living practices such as diets and physical activity, cultivating the self for a better life quality, seem very contemporary values. This later work started, although only as an emergent and unfinished new line of inquiry, to allow for a more complex understanding of body-politics and opened the floor for numerous contemporary readings of Foucault's work that included active selves in their bio-studies.

On self-care, the volume of Petersen and Bunton (1997) that was mentioned earlier includes an ethnographic study on self-starvation that Eckermann (1997) describes as a technology of the self. To mention a contribution on diabetes, Ferzacca's *Actually, I don't feel so bad* (2000) is a study on diabetes self-

management in a U.S. veteran clinic. Ferzacca suggests that strict diabetes management regimes should not be considered as bio-power. While doctors and patients share a normative idea of the cultivated self that leads a productive life, the veterans engaged in idiosyncratic technologies of the self in order to fulfil such expectation.

A study on Russian immigrants with diabetes in the U.S. argues that these patients were non-compliant patients, not because they rejected the proposed self-care recommendations but because they did not share the normative, neo-liberal ethics of productive, disciplined selves (Borovoy and Hine 2008). Here, there is no reference to Foucault's self-care that describes ancient body ethics as the effort towards a more philosophically better person. Instead, ethics are believed to be rooted in neo-liberalism, that means that capitalism has produced ethical norms of discipline and productivity. There is a whole range of literature that finds explanation in neo-liberalism and a capitalist logic of productivity. Ritenbaugh's study *Obesity as a Culture-bound Syndrome* (1982) explored American middle-class ideas about body control – mostly visible as a slim body shape – through physical exercise and certain dietary regimens. She argues that these are intrinsically Western concepts. A healthy lifestyle and a slim body has become a moral postulate in Western society and obesity, cardiovascular diseases and diabetes – all regarded as due to excessive calorie intake – are blamed on the patient's own bodily ill-management. I am, however, suspicious of a too limited focus on neo-liberal mechanisms in health and lifestyle practice, for one, as Foucault suggests with his history of ancient self-care that such practices can have nothing to do with modern neo-liberal capitalist morals of productivity (cf. Nehamas 2005, *The Art of Living*).

The ethnography in this thesis that looks at self-care practices resonates in some ways with a Foucauldian framework. Rather than subjects of bio-power, the Turkish Berliner's with diabetes engage in their own practices of disciplining their bodies. As official healthcare services do not acknowledge their special needs, they actively seek and negotiate education, knowledge and support in order to achieve better control over their illness (Chapter 4). Foucault offers us a scope of work that can help to understand contemporary examples of self-care. It enables us to ask as to whether the clinical ideal of an expert patient and diabetes self-management practices

should be understood as bio-power, or whether patients step outside biomedical power/knowledge and achieve autonomous techniques of self-care. While the Turkish-speaking self-help group rehearse text book answers and follow clinical recommendations, they have to negotiate access to such knowledge and amend clinical recommendations in order to make them relevant to their social lives that are not envisioned in such standardised advice.

This leads to another question. Would Foucault grant his criminals, mad and sick of his earlier work, which he mentions no longer in his later work, such individual, active assertion of freedom? I am raising this question because, unlike Foucault's previous work that mainly featured the controlled lives and bodies of marginalised people, the ill or criminal, the ethical quest of self-care was one of people from privileged backgrounds. By that I mean that the ancient texts he drew on featured men in ancient Greek and Roman society not women or slaves. Foucault did not address this himself (although this personal quest for freedom is deeply embedded in a society that tolerates slavery; Foucault 1990 [1984]). This present ethnography sits uncomfortably between Foucault's concept of bio-power that exerts an inescapable control over sick, marginal bodies and his notion of privileged bodily self-care that represents an ethical exercise towards a more perfect, "philosophic life" (ibid. 57). In this thesis I will not only argue that the marginalised can indeed engage in deliberate practices of self-care, mainly as bio-power seems to be largely uninterested in this population group. Moreover, such self-care is not based on ethical motivations but is a far more practical exercise, and concentrating the analytical perspective only on Foucauldian philosophical enquiry on freedom fails to address more immediate and thus relevant questions of bodily suffering.

Lupton (1995) scrutinised Foucault's idea of self-care and suggested that healthy living and sports can be personal and deliberate practice. But rather than understanding such practices as Foucault's ethical "technologies of the self" (1997), Lupton argued that such practices do not necessarily derive from an individual health awareness but simply create emotional, sensual pleasure (also in Lupton 1997). Such sensual experience can also be derived from resistance and non-compliance, for example from deliberate transgressions such as smoking (citing Klein 1993). Finally, Lupton alerted us to the possibility that health choices can be based on ideas of fate

rather than hegemonic health imperatives (Davison et al. 1992) and that factors such as social class should be taken into consideration when dissecting Foucault's docile bodies.

Contributions such as Lupton's (1995, 1997) stress the importance to move beyond Foucault's concepts of bio-power and self-care. As much as the concepts of bio-power and ethical self-care serve well to describe the systems of power/knowledge, institutions that patients seem to be at the mercy of, or personal standards they aspire to, such framework nonetheless limits possible avenues of understanding. While Foucault's later work moved towards a history of self-care, active selves and their technologies, everyday lived experience remained at the margin of his ideas. I agree with Lupton (1997) that health and illness is inevitably about emotions and embodied experience, which is something Foucault was not interested in despite his insistence of bringing the body into the equation. Anthropologies of the body consider physical, bodily experience, embodied knowledge, senses and emotions (see e.g. Fraser and Greco 2005). Millward and Kelly (2003) suggest that, although the experience of (chronic) illness is a social one, the physical world, the human body and its biological capacities and constrains is the backdrop to such social experience. They therefore postulate a "holistic account of the nature of human experience embracing the material world, the biological imperatives of the human body, the social world in which human bodies reside, and the mediating role of the individual's sense of self in this" (Millward and Kelly 2003: 157).

In this thesis I argue that in order to understand why people engage in practices of body maintenance for diabetes control more questions are relevant to ask. No doubt, it is an intriguing and valid question to ask if subjects can achieve freedom through techniques of self-care. And can anyone truly act outside Foucault's power/knowledge? However, these questions might not represent lived experience very well, nor serve to understand it. I suggest that this thesis does not contain narratives of dominance, resistance or pursuit of freedom, but here bodies are docile or practiced on to be liveable (Chapter 6). By that I mean that bodies are disciplined to be pain-free, sensible and functional. Discipline and self-care can be neither about a governing, pervasive power, nor an ethical, normative exercise, but about

practicalities of life, influenced by interpersonal relations, as much as social class, age, gender or ethnicity (Lupton 1997). This is not to say that achieving a body that is more in control, is less inconvenient and self-destructing, and doing so on their own terms cannot also be a sign of achieving freedom on a more abstract level.

In order to seek a better representation of the deliberate practices of diabetes self-care of Turkish Berliners and go beyond a Foucauldian framework, I turn towards a perhaps unusual scholar who did not write about “bio” and bodies. He did, however, write about everyday lives of the ordinary, less privileged. De Certeau, in his *Everyday Practices of Life* (1984), emphasised the agency of the ordinary person. He explored how ordinary people manoeuvre through ordinary situation of living, for example the work place or walking through urban spaces. While “strategies” are devised in institutions, much like Foucault’s power/knowledge, de Certeau understands “tactics” as the practices of ordinary people to make such strategies “habitable” in their everyday lives (ibid. 34ff). In his approach, de Certeau considers “tactics” as tools of the weak, as forms of subversion or resistance. Admittedly, Foucault’s early work also allowed for the possibility of resistance (Lupton 1997: 102) and he saw power as something collaborative, though only later did “agency” enter his work. To revisit the previous discussion, I draw upon de Certeau for his acknowledgement of agency in the ordinary person, while remaining with the argument that daily practices of diabetes control should not be foremost understood as forms of resistance but are simply practical exercises of making illness and ill bodies liveable. De Certeau may at first glance not help to understand the biological dimension of diabetes management but his account describes how chronically ill bodies are disciplines not for ethical reasons, striving for a “good” life, but for practical reasons, striving for a liveable life. I thus propose to call Turkish Berliners practices of diabetes self-care “bio-tactics” as an extension of de Certeau’s idea (Chapter 6).

On a final note, revisiting both Foucault’s (1990 [1984]) account of an ancient ethical quest of body control, and the studies by Borovoy and Hine (2008) on Russian immigrants and by Ritenbaugh (1982) on American middle-class women alert to something else in regards to marginalised population groups. Both Foucauldian Greco-Roman and neoliberal self-care of exercise and healthy eating,

although with different motivation, describe a very ethnocentric, Western notion. Self-care, however, varies across history and cultures. The seemingly opposing value of “big is beautiful”, shared in many low- and middle-income countries (and by many of my research participants), cannot be understood as resisting or ignoring self-care or health maintenance. Rather, aspiring to a larger body figure can be explored as self-care in its own right in societies where poverty and infectious diseases can be fatal for skinny people.

### 3.2 Beyond biosociality

#### *Rabinow’s biosociality*

The other body of literature that is discussed in this chapter is “biosociality”, moving from self-care to self-care groups. Paul Rabinow once summarised Foucault’s bio-power as a relationship of “letting die” and “making live” (Rabinow and Rose 2006). His own work on new biotechnologies and human genetics seemed to have taken him one step further towards “making life”. Rabinow (1996a) argued that new biotechnologies revise perceptions of biologies and create new socialities that he coined “biosocialities”. Rabinow, though, showed less interest in such biosocial lives than in what he regarded as the cradle of biosociality: the science laboratories in which life is “in the making”.

Rabinow’s research interest lies in new modern venues of life: the exploration of biotechnological advances in human genetics, specifically the technology of polymerase chain reaction (*Making PCR: A story of biotechnology* 1996b) and recombinant DNA (*French DNA: Trouble in purgatory* 1999). These new technologies represent major developments in human genetics that fundamentally changed how the human body is understood and how certain diseases are classified. Such biotechnologies profoundly shape identities and can form collective selves and activism (Gibbon and Novas 2008: 2). Stating in his essay *Artificiality and Enlightenment*:

There are already [...] groups whose members meet to share their experiences, lobby for their disease, educate their children, redo their home environment, and so on. That is what I mean by biosociality. [...] It is not hard to imagine

groups formed around the chromosome 17, locus 16,256, site 654,376 allele variant with a guanine substitution. Such groups will have medical specialists, laboratories, narratives, traditions, and a heavy panoply of pastoral keepers to help them experience, share, intervene, and “understand” their fate. (Rabinow 1996a: 102)

In short, contemporary biotechnological diagnostic and therapeutic tools create new kind of patients, or patients to-be through genetic illness susceptibility, that form groups of solidarity based on such emergent biological identities. While biosocialities are no radically new idea – “traditional” biosocialities are based on age, gender or ethnicity – Rabinow added more complexity. Rabinow’s “biosociality” describes how biology, for example a faulty gene, creates sociality, an interest groups of those affected, that share their experiences via Internet chat rooms, engage in fund raising and lobby for scientific research. In doing so, Rabinow broadened the exploration of “life” exploring domains of state, science, venture capital, ethics and consumerism.

Despite such broad scope, however, biosociality seems to refer to the patient in particular, while Rabinow’s work largely focuses on the scientist. Following Latour’s *Laboratory Life* (with Woolgar 1986), Rabinow chose to explore formerly often black-boxed sites as his setting of ethnographic research. Although he considered the implications beyond the laboratory – namely in the formation of biosociality – he privileged these biotechnological spaces as sites of knowledge production, practice and negotiations (Rabinow 1999). He agreed with Latour (1987) that, while social theory was traditionally interested in the societal responses to illness or science, spaces of sciences are equally contested and contesting spheres. These are the sites where ideas of nature and culture are challenged, where he can witness “life in the making” (Rabinow 1996b: 2). His fascination with biotechnology arose not only from its impact on social discourse and identity but its equally shaping, creative power over biology. Rabinow’s science ethnographies were not actually interested in tracing the biosocial lives created by these technologies. His work has a strong focus on biotechnologies, how they transform nature as we know and perceive it, thus change identities and personhood and create social momentum. Biosociality means both the reinvention of nature, as previously personified in Haraway’s cyborg (1991) that is a hybrid of nature and technology, and the

formation of collective identity and activism by such transformed perceptions of biology.

*Ethnographies of biosociality*

Rabinow did not actually produce ethnographies of biosociality and this thesis is a contribution to a growing body of literature that aims to explore lived experiences of biosociality. While Rabinow is only tangentially interested in actual self-help practices of biosocial groups, his contemporaries and students continue this line of inquiry in a fast moving scientific age and exploring their making and transformations. The concept of biosociality is immensely popular and ethnographic studies that describe biosocial groups plentiful.

The edited volume by Gibbon and Novas (2008), for example, collected studies of biosociality. Roberts (2008) explores the impact of IVF technology in Ecuador. While this technology brings hope of a “modern” solution to the “modern problem” of infertility, it also profoundly alters how middle class women experience their bodies as generally faulty and readily accept intrusive procedures to rectify this short-coming. Sahra Gibbon (2008) writes about the biosociality of cancer charity activism that engages in fundraising for molecular research, in accordance with Rabinow’s original idea of an interest group that articulates its motivation in conjunction with science and technology. New medical knowledge and diagnostic technology, namely the identification of the breast cancer gene (marker), enables to identify candidates, future patients, and repositions activism by placing a newly formulated hope in basic science. However, such technological innovation does not always seem to create sociality. Lock’s study on genetic testing for Alzheimer’s susceptibility (2008) could not find the same significance as Gibbon (2008). The results of genetic testing for Alzheimer’s had little impact on those exposed to these new possible identities as candidates or risk bearers. Lock (2008) cautions that these novel technologies with the power to reshape and recreate biologies might not automatically change how such biologies are perceived.

Recent work increasingly provided such critiques to the concept of biosociality. Kaushik Sunder Rajan (2006, 2008) ethnographically explored the political economy of genomic research and drug development. While Rabinow only

alluded to economic factors in his work on biosociality, others concentrated their explorations on venture capital in emergent biotechnological markets. In his multi-sited ethnography *Biocapital* (2006), Sunder Rajan explores pharmaceutical companies in the United States and India and argues that new biotechnologies shape a new age of capitalism or rather, that this new biocapitalism cannot be understood in isolation from biotechnological developments and scientific knowledge. He examines the practices involved in this global flow of ideas, information and capital. In a “melding together of new forms of biomedical and corporate enterprise”, the global and local players involved represented science, economy and the state (Sunder Rajan 2008: 158). In his paper on biocapital and biosociality (in the edited volume Gibbon and Novas 2008) Sunder Rajan adds a discussion of those who fall victim to such biocapitalistic transformation. Highlighting the bioethics at stake and considering identity formation in biocapitalism, he explores the experiences of former mill workers in Bombay. The mill workers faced unemployment when they lost out in the relocation of state funding from the textile industry to pharmacogenomics. Sunder Rajan (2008) describes how they became victims to biocapital as deprivation forced them to become experimental subjects of clinical trials.

Similarly, Aditya Bharadwaj (2008) ethnographically explored the political economies of IVF and stem cell technologies and practices in India and considered the impact in local contexts of deprivation and inequality. Bharadwaj argues that global biotechnologies stand in stark contrast to local realities of poverty that “asphyxiates, often prematurely, both the ‘bio’ and any semblance of ‘sociality’” (ibid. 100). Suggesting that biosociality would be an inappropriate conceptualisation of such experiences, he instead speaks of bioavailability (borrowing from Lawrence Cohen (2005)’s terminology in regard to organ transplantation in India). Actors in Indian IVF and stem cell clinics are bioavailable (e.g. providing embryos) to science and available for biocrossings (of biotechnological procedures). As biocrossings he understands assemblages of bio and social, unpredictable and varied crossings of hormones, sperm, embryos, stem cells made in social spaces. In short, local health inequalities in neo-liberal global markets produce poor patients who, rather than being biosocial, are merely bioavailable and endure biocrossings.

*The biosocial lives of Turkish Berliners*

My ethnography diverts from most existing ethnographies on biosociality in several ways. Those ethnographies of biosociality that look outside the laboratory and investigate practices of biosociality still do not step outside the realm of biotechnologies. I show in this thesis that there are biosocialities, here Turkish Berliners with diabetes, that are not driven by high-tech science and innovation. They find social momentum elsewhere. Second, there seems to be the assumption that biosociality requires capital (Bharadwaj 2008; Sunder Rajan 2008). I argue that biosociality can also happen outside bio-capital, marginalised can be bio-social not just bio-available (see Cohen 2005); indeed, it is the relative position of marginality that creates social momentum. Finally, this thesis gives an ethnographic account of the kind of biosociality that is Berlin's informal Turkish diabetes care that acknowledges how social, political, economic and moral lives are intricately linked.

Social momentum and emergent biosocialities might not always require such baffling technologies. While “bio” to Foucault meant life and the body, Rabinow explores “bio” in regards to life-sciences and bio-tech. Biosocialities in his view gain their social momentum in biotechnologies and scientific innovation. This thesis aims to show that biosociality does not necessarily emerge out of technology. I argue that “low-tech” biologies can have the same impact of shaping identity, group activity, political and commercial interest, and similarly, such sociality can be fairly unaided by technologies. By that I mean, that there has been no breakthrough in discovering a diabetes gene marker, there are no radically new diagnostic or therapeutic tools in the making, nor is the field of diabetes care in Berlin one of virtual chat-rooms and email networking. However, diabetes (and obesity) is a popular topic within local public health circles, gains increasingly coverage by local media, including the Turkish-language TV and radio stations, and the migrant population has entered the (economic) focus of health insurances and private care services. Emily Martin's (2007) ethnographic investigation of bipolar support groups is a recent example of biosociality, not created through biotechnological breakthroughs but alongside a (novel) societal fascination with bipolar disorder. Although not conceptualised as a study of biosociality, her *Bipolar Expeditions* (2007) explore experience of mental

illness, collective negotiations of such experience and the backdrop of scientific knowledge, social discourse and economic interests.

Similarly, a sociality of “Turkish diabetes” had emerged in recent years. In contrast to Martins’s (2007) work, biosociality or bio-activism does not necessarily require privileged status, access to capital and mainstream societal belonging but, conversely, marginality and deprivation can create momentum to form socialities. The Turkish self-help group in Berlin is constantly struggling for funding, and its members are largely from lower socio-economic backgrounds and challenged by daily social deprivation. The group was indeed founded because funding for more formalised Turkish-language healthcare ended, and members join as their marginal status in formal German healthcare impedes adequate care. The self-help group now offers the opportunity for social participation and to claim services and support (Chapter 7). In *Life Exposed: Biological Citizens after Chernobyl* (2002), Adriana Petryna explored how Ukrainian citizens deal with emerging social problems in the aftermath of socialism and emerging long-term health problems of the Chernobyl reactor explosion. In this context, Petryna coined the term “biological citizenship” to express how “the damaged biology of a population has become the grounds for social membership and the basis for staking citizenship claims” (ibid. 5). Unlike Rabinow’s biosociality, sociality here does not mean reshaped identities of patient groups, organised in emotional support networks, or activism for scientific research or access to pharmaceuticals or diagnostic testing. Petryna’s biological citizenship is about the reclaiming of citizen’s rights within a reshaping political system, yet based on damaged biologies rather than based on the mistreated and then abandoned social/civic lives. This concept of biological citizenship is also formulated by Nikolas Rose. In his *Politics of Life Itself* (2007: 133), he envisions citizens not defined by national boundaries but in biological terms, and, for example, holding “biological responsibilities [...] embodied in contemporary norms of health and practices of health education”.

Rose’s conceptualisations of biological citizenship (2007: 131-154), neurochemical selves (ibid. 187-223) or somatic ethics (ibid. 252-259), unfortunately, were not ethnographically explored, and one is left wondering if such concepts can describe a plethora of phenomena and be readily lifted into other

contexts, at least without presenting ethnographic evidence. Petryna's (2002) ethnography not only describes that the disadvantaged and deprived can find their voice in bio-social action but she also fleshes out the delicate interplay of political turmoil, biological catastrophes and emergent market economies. The thesis also aims to present an ethnographic account that acknowledges the complex political, economic, social and moral dimensions that lie beneath biosociality. While Rabinow (1996a) and others (e.g. Bharadwaj 2008; Gibbon 2008; Sunder Rajan 2008) saw links between science, technology and capital and envisioned patients-cum-activists or scientists-cum-entrepreneurs, this thesis will explore how people like the self-help group leader acts as student and teacher, patient and consultant, activist and businessman (Chapter 8). People in Berlin's field of Turkish diabetes care occupy multiple roles and position themselves fluently within social, economic and political interests. Diabetes management, both as a communal provision effort and a personal self-care practice, is thus affected by the social relations, micro-politics and -economics that these roles create.

In conclusion, in this chapter I aimed to summarise key theoretical concepts that will be revisited in this thesis – namely Foucault's bio-power and technologies of the self and Rabinow's notion of biosociality – and how they were adopted in contemporary ethnographic accounts. I asked how such concepts can serve to understand this ethnography on Turkish Berliners with diabetes and suggested that some of the ethnographic material in this thesis helps to challenge some assumptions that seem to resonate with the concepts. Mainly, I seek to take marginality and inequality into account that, rather than disqualify people from social participation or self-care, can provide its own momentum.

## SECTION 2

### Practices of diabetes control: Beyond bio-power

I'm arriving late at today's diabetes self-help group meeting but Mr Yılmaz has not yet turned up himself. There are only a few people seated already and I announce a general "*Merhaba! Nasılsınız?*" ["Hello! How are you?"] In the second row a woman with dark shortish curly hair replies "*Iyimim. Siz nasılsınız?*" ["I'm fine. And how are you?"] and comments my "*ben de iyim*" ["I'm fine, too"] with a pleased "*çok güzel*" ["very good"]. I'm not quite sure if she commends my Turkish or my good health but I cheerfully take a seat two rows behind her.

A young woman – in her 30s, or maybe early 40s – with long blond hair tied in the back to a ponytail comes in and says hi to everyone. She especially greets the woman I've just spoken to and scans the room for familiar faces. I smile at her and she starts chatting with me in Turkish – whether I'm new, that she hasn't seen me before, etc. I try to reply in my best Turkish that I have been here before, doing my PhD research. The older woman helps me piecing the words together and finally I switch into German to make myself better understood. The blond woman replies in fluent German with a heavy Berlin accent. She finds my research all very interesting but wonders how I'm holding up with the Turkish. I explain that I tend to understand quite a lot but struggle with speaking – especially if asked too quickly. She laughs and exclaims to the older woman next to her: "That's just like with you and German." The older woman also laughs and starts talking in slow yet quite good German that she is sometimes too embarrassed to speak German but does understand quite a lot. I am surprised to hear that as I remember this woman from previous sessions as one of the women who always looks very involved, engaged, independent. I have assumed that she must speak perfect German and probably has a well-paid fulltime job.

I seem to have made her more confident speaking in German [...] so she starts telling me about herself. The blond woman has told her about this self-help group and after some time she finally agreed to come along one day. She thought she would only attend the meetings every other month but ended up becoming a regular. Indeed she has caught my attention before as she is very knowledgeable and involved in the meetings. I ask her about her diabetes and she says that she has had diabetes for about 15 years but only heard of the group two years ago. Her diabetes control used to be atrocious but now she is very confident and finds it easy to manage her diabetes on her own. She smiles at a man in the group who is reading tentatively through nutrition tables and seems quite obviously confused. "It's all a matter of the right information", she explains. Her doctor never explained much to her so she did not know how to deal with her illness before. "For example my cholesterol. I got these tablets and my hair got thinner and thinner. So I just stopped taking the tablets at all. Now I found better tablets and also know how to make dietary changes to lower my cholesterol." She also feels much more empowered through the self-help group in looking for the right help. "If

my [family] doctor now doesn't have time for me I just tell him that I'll go and see my diabetologist instead.”

These excerpts from my field notes (03.02.2007) document my first conversation with Rana and Sevim, regular members of Berlin's self-help group of Turkish-speaking diabetics (*Türk Şeker Hastaları Öz Yardım Derneği*), who became two of my closest informants. Rana, a 60-some-year-old mother and grandmother, had joined the self-help group about two years ago. During group meetings the small, youthful looking woman with short brown wavy hair and sporty clothes was always decidedly interested, remarkably knowledgeable and, above all, good-humoured, sympathetic and thus much liked by everyone. I noticed her right from the start during my early days of participant observation with the group and she soon became one of my first contacts within the group as she always had a friendly word for me. She had been living with diabetes for over ten years when she got acquainted with a woman whose husband's family lived in Rana's Turkish hometown and had known her diseased mother. The 40-some woman, Sevim, who always had her blond hair tied back and wearing the practical casual clothes of a mother of three, had diabetes herself and had already been a regular member of the self-help group when she tried to recruit her new friend. It took quite some convincing but finally Rana came along and soon joined the small group of knowledgeable regulars. There, she learned about the complex workings of the body altered and challenged by diabetes, and how a balanced diet (*mutfak*), physical activity (*hareket*) and medication (*ilaç*) can manage her diabetes. Both Sevim and Rana had spent the last couple of years putting their newly acquired knowledge into practice, monitoring and listening to their bodies and re-arranging their lives around these new practices.

This section will explore individual experiences of living with diabetes. A study of chronic illness invites investigating the “expert patient” (Lupton 1995; Nettleton 1997), which is not only the clinical ideal of a patient who responsibly acquires knowledge and skills to “professionally” self-manage chronic illness in everyday life, but it is indeed the very real everyday lived experience of diabetes' impact on individual practices, bodies and personhoods. I will write about those who share the label “diabetes patient” and the everyday experience that comes with it.

During my fieldwork I joined them on their daily endeavour of “learning”, “monitoring”, and ultimately “manoeuvring” diabetes.

Although it is the last section of this thesis that will investigate diabetes as a communal and political experience, the politics and economy of diabetes, and the groups invested in such interests, this section cannot be free from politics and sociality. Yet the focus is less how such politics are shaped within a wider context of local diabetes care provision but how politics shape individual experiences of diabetes care. The experience of diabetes as a Turkish migrant in Berlin should be neither understood as a story of domination, submission and resistance, nor is it an experience that can be understood in a framework that suggests a space free of politics. Rather, there are other aspects, for example emotive effects of bodily experience that add to the understanding of practices of diabetes control among my research participants. Chapter 4 will explore how knowledge, as I encountered it, is more than an abstract entity that is held and withheld, disseminated or limited. Knowledge is intrinsically linked to power position in Foucault’s power/knowledge account, yet is also actively sought and reclaimed. Knowledge is practically acquired, made sense of through practical experience. Chapter 5 will describe how monitoring diabetes is more than the “clinical gaze” entering homes but a tool of making sense of an illness experience that often lacks an immediate bodily encounter, framing the parameters of illness and risk, seeking security and sometimes gaining anxieties in return. Thus on a daily basis, knowledge and skills are tactically employed in order to achieve an individual grade of diabetes control. They do so on their own terms, as Chapter 6 will finally investigate, neither blindly subjecting themselves to some sort of biomedical hegemony of “healthy living” that demands a certain diet nor representing inert, disadvantaged migrant patients that do not understand or somehow “resist” such dietary recommendations. Rather, such tactics of diabetes control follow an immediate demand of managing complexities in lives that are often outside concerns directly linked to diabetes. This section thus aims to look beyond notions of bio-power (Foucault 1898 [1976]) to understand highly disciplined practices of body maintenance.

As a final note, I mostly refer to diabetes *control* instead of diabetes management or care. I chose it as the clinical term “diabetes control” incorporates a

whole range of meanings and therefore seems to be simply much more interesting. Diabetes control refers to the process of managing diabetes; it also denotes the patient's illness status (an average blood glucose level of 7 certifies "good diabetes control" as opposed to 10, which would mean very poor health); and it therefore records achievement (or failure in the case of "poor diabetes control") and alludes to the ability and accomplishment of both patient and doctor.

## Chapter 4: Learning diabetes

Diabetes control requires knowledge. People who are faced with the diagnosis of diabetes often seek information as a first coping strategy to make sense of the news and grasp how their lives might change (Peel et al. 2004). Such knowledge seeking is indeed part of the first therapeutic strategy from a clinical perspective (Day 2004). In diabetes patient education sessions, people (ideally newly) diagnosed with diabetes learn a range of expertise, from basic anatomy and organ function to the complex biochemical workings of pancreatic cells and the glucose metabolism. Nutrition is at the centre of diabetics' skills as a careful diet (plus physical activity) is an important element of diabetes control. People with diabetes also need to acquire knowledge on medication and, if required, insulin, dose adjustment, blood glucose monitoring, to read test results, and to detect complications. Equally, it is important to learn what services they need, and which ones they are entitled to. Considering the complexities of diabetes and its care, diabetes patient education is part of any clinical diabetes care plan and is considered imperative to diabetes treatment. Diabetes education's aim is to create "self-sufficient", "responsible" patients and is often framed around notions of "empowerment" and "expert patients" (Lupton 1995; Nettleton 1997). Such expertise is required as diabetes control is not only complex and complicated, but most crucially as diabetes control is a self-management exercise in the hands of the patients. This self-management often means a complete change in lifestyle, immensely amended diets, cooking practices and consumption patterns, adoption of physical activity in formerly often sedentary lives, and alterations to sociality and socialising. Aside from providing (admittedly often quite crucial) medication and screening for and managing complications, the clinical responsibility in diabetes care is thus confined to the rather low-tech role to offer education on how to go about such self-management.

This thesis also starts its analysis with knowledge, as diabetes education appears to be the main provision gap for the Turkish diabetic population in Berlin. To put it simply, most education is provided in a foreign language for these patients. However, the issue of knowledge is more complex than lacking translation services or native language provision. This chapter looks at patient education and the self-

help group's peer education and explores that there are all kinds of knowledge and levels of knowledge, and that these are inevitably linked to power relations, are guarded or deliberately sought. Knowledge, here, is not merely an abstract entity that we have or not, are given or refused, but it is a practical and social engagement of seeking knowledge, making sense of it within the group and applying knowledge in the everyday.

The first subchapter examines the avenues to access to knowledge and the demanding exercise of acquiring knowledge when it is guarded. In doing so, I will particularly focus on the members of the Turkish-language diabetes self-help group who succeeded to assume the role of expert patients. Guarded education provision evokes Foucault's concept power/knowledge (1980), and the way this self-help group contest this, suggests that "the ill" can challenge authority over knowledge. In light of that, the other subchapter then has a closer look at how knowledge itself is negotiated and considered practical in the everyday by these well-informed patients. Here, the emphasis is on knowledge as practice, rather than separating knowledge from action (cf. Mol and Law 2004). It will explore the different kinds of knowledge, clinical, lay, unorthodox, Turkish, embodied knowledge, that are relevant to diabetes control, and the practical engagement with knowledge that gives meaning to one's experience and that makes knowledge itself meaningful.

#### 4.1 Accessing knowledge

During one of my first interviews with a family doctor I was shown a chart he frequently used for his Turkish-language diabetes patient education sessions. The chart took me by surprise and I tried to hide delicately that I was choking on my coffee while the doctor elaborated on the usefulness of illustrative teaching material in the case of illiterate, uneducated patients. The chart depicted what can only be described as a Mussulman, a crude drawing of a red-nosed, big-moustached man in bulky trousers, waistcoat and red fez hat, holding prayer beads and looking somewhat dim-witted. I was still trying to figure out if this Turkish-origin doctor, who previously complained about the xenophobic culture in Germany's society, had

any reservations about this clearly racist (or in his case class-snobbish?) depiction of a Turk so generously provided by a Swiss drug company, while he pointed out the separately drawn organs heart, kidneys and brain, as well as eyes, an “opened leg” exposing its arteries and nerves, and a foot covered in yellow stars that should represent tingling nerve pain. With this illustration, he continued explaining, he could teach about the secondary complications of diabetes.



It remained beyond me as to why illiterate patients would need the help of a Mussulman to understand the information given to them. Later, that drug company sent me their “target-group appropriate” training pack for diabetes educators that explained that this *Temel Amca* (uncle *Temel*) was a Turkish cartoon character that at least older Turkish migrant patients should recognise.<sup>19</sup> I could not help but doubt that this attempt of cultural reference would go down well with your average Turkish-origin patient. Then again it might be my anthropologist’s oversensitivity towards what might in fact be a rather humorous contribution to otherwise dull patient education. Rather more significant is the fact that the knowledge provided to patients in order to understand their illness and master its management is shaped and skewed by assumptions about these patients, their lives and experiences.

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<sup>19</sup> I asked the company employee who sent me the material for permission to use it in this thesis but chose not to disclose the company’s name as I use the illustration as a negative example rather than the positive one that the company might expect.

My aim in this subchapter is to trace the discrepancies between the ideal of the empowered expert patient and the way access to education is guarded and limited. Certain marginalised patient groups seem to be excluded from the expert patient ideal. It should be explored how knowledge is made accessible and under which assumptions. At first sight, this is in accordance to Foucault's concept power/knowledge (1980) and his idea that knowledge is always intrinsically linked to power, for example that medical knowledge is produced, guarded and disseminated by medical institutions and professions. However, seeking access to restricted knowledge is not only a matter of power and domination but becomes a practical pragmatic exercise. Being challenged by and challenging the barriers and gate-keeping of knowledge, my research participants were constantly actively engaged in knowledge acquisition, production and negotiation. In self- and peer-education they assume their own active roles in the relations of power/knowledge.

#### *Educating patients*

Part and parcel of every diabetes diagnosis is the subsequent offer to undergo diabetes education. The newly diagnosed should learn that diabetes is a chronic illness that can only be "managed" rather than "cured", and that this means lifestyle management rather than medical intervention. They are confronted with the prospect that medication – and in severe cases insulin – does not suffice without dietary discipline, while a carefully devised nutrition could altogether supplant any medication.

A diabetes consultant explained to me that in the German healthcare system every diabetes patient has the right to education and that any general health practice can refer their patients in case they are not able to offer such education session themselves (interview transcripts 26.06.2007). Germany has an insurance-based social security system in which all employed residents (including students, retired and those on social and unemployment benefits, and non-citizens) are covered by a state health insurance while self-employed, high earners (and civil servants) are "opting out" into a private health insurance. As much as this system has always spurred debates of a two-class-system which provides better services to those who can afford the more comprehensive insurer, it nonetheless offers basic healthcare

(including dental and various complementary medicines) to every person. Recent health reforms have attempted to rectify the problem that rising healthcare costs challenge this solidarity-based insurance system (the healthy pay into a health insurance to finance today's ill – and expect their costs covered once in need) by introducing “out-of-pocket” contributions for certain services. In return, structured care schemes for those with chronic illness have been developed that would exempt from contributions to reflect their more serious and frequent care demand. Undeniably, any discussion on health inequalities seem to falter in the light of a system that at least sets out to provide comprehensive if basic diabetes care to every patient regardless of their funds – at least in comparison to settings where the poor are denied access to help. The devil, of course, is in the detail.

The diabetes consultant, who advised me about the German diabetes care provision, offered patient education sessions in two general health practices in Berlin, in a middle-class suburb and a socially-deprived, multi-ethnic district. From the very beginning of her career she realised that as much as diabetes care provision is guaranteed on paper, it is exclusively targeted at a “model patient” that she hardly encountered in Berlin's urban landscape. Only her middle-class patients in the shiny, newly refurbished practice complex responded to her state-of-the-art teaching material straight from the Diabetes Union's educational repertoire. The most obvious problem – a daily occurrence during her work – at the her council estate surgery turned out to be that educating in a language that is not native to the patient or advising Muslim migrants against too many pork sausages, schnitzel and potatoes yielded only limited success. She became involved in founding a working group for migrants and diabetes at the national diabetes union that set out to train educators with migrant backgrounds and language skills and raise awareness among practitioners about the need to consider patients' heterogeneous backgrounds (from interview transcripts 26.06.2007).

#### *Negotiating formal education: Turkish-language patient sessions*

Berlin's by now numerous Turkish-origin family doctors have started a similar project in recent years to provide more appropriate patient education sessions. Their efforts to account for “ethnic diversity” or “cultural sensitivity” were certainly more

practicable than the clumsy if commendable attempts of the German Diabetes Union. It did not, however, prevent a stereotyping that I encountered again and again when speaking with health professionals about their working class patients (which might explain the uncritical use of the above shown Uncle Temel). I was invited to attend a medical conference when I first met Dr. Zahedi who was recommended to me for his interest in diabetes care. Some weeks later he spoke at another congress on Diabetes Day on his work on diabetes education, migrants and illiteracy. He introduced himself as the son of an Iranian father and a Turkish mother who had arrived in Germany as a little boy when there were not even 300 Turks living in Berlin. In his talk Zahedi presented statistics on Berlin's heterogeneous residents, and epidemiological data that suggest over-proportionally high rates of obesity among Turkish-origin children and of diabetes among Turkish adults. Even more alarming, he emphasised, were the fact that 70 per cent of Turkish diabetes patients were badly cared for with blood glucose control much worse than the German average. The remedy for such atrocious health inequalities would be more appropriate patient education that should not only take into account the patients' Turkish language, diet and lifestyle but also the very low educational levels and often illiteracy of these first generation immigrants from rural Turkey.

Two months later I sat in Dr. Zahedi's practice awaiting the start of his patient education session. A nurse, a young Turkish-origin woman casually dressed in jeans and a woollen jumper, led us in into a tiny box room filled with education charts and material such as plastic food. Next to me squeezed four men and three women (some in traditional clothing with head scarves) into the little space. This first lesson featured basic knowledge about diabetes: what is diabetes, what symptoms are common and which co-morbidities are expected. The nurse used very illustrative language, for example explained the difference of type 1 and 2 diabetes in terms of a factory. We should imagine the pancreas to be a factory and the insulin producing islet cells to be the machinery. With type 1 diabetes the whole factory is not working at all. Their condition, type 2, means that only some machines do not work properly – and probably different machines depending on each person in the room. With good nutrition and exercise one can improve how well the machines are working. Despite the easy language, the nurse gave quite detailed information

within the course of one hour: why we need insulin, how insulin helps to get sugar into our cells, the types of cells that need sugar, the various involved organs and why they feel thirsty and have to urinate so frequently as their kidney registers far too much glucose. After the session, I commended her on her teaching style, how she managed to put complex issues into simple language. She was pleased and explained:

“Many of these people will have worked in a factory, you know, so they can relate to this kind of language. Many have little education and come from rural backgrounds – some are Kurdish. They have difficulties understanding complex issues and even ‘high Turkish’.” And closing the door, she added:

“Most doctors, you know, don’t explain anything to their patients. They don’t have time but they also couldn’t care less – find it tiresome. They think these patients wouldn’t understand it anyway. But you know, these people aren’t stupid. They can understand if you take the time to explain everything in simple language with many examples. I think that is the least one can do. You present these patients with the diagnosis of diabetes and then leave them alone with it. That’s inhumane!” [Field notes 22.01.2007]

The nurse explained that she was trained at the German Diabetes Union and tried to combine both German and Turkish approaches. Turkish seems to be very authoritative, the “German way” is much more interactive; but she also considered that Turks do not read much, many are illiterate and that she had to consider this special “consumer group”.

Over the course of the week this group of patients attended three more hours of teaching to cover a whole range of topics, learning about diet, the importance of regular check-ups, how to detect bodily changes that suggest the onset of complications, and how to handle insulin injections and blood glucose monitoring. People attended eagerly, participated admirably but had far more questions than the daily hour in Zahedi’s practice could answer. It left a sour taste of introducing people to a whole new world and leaving them to explore it without any further guidance. In fact, many doctors complained to me that a one-off module of patient education that a state health insurance would cover has little impact on most patients’ ability to manage their diabetes.

Dr. K: I always struggle against beliefs people bring to the sessions. This wrong knowledge is much more persistent than attempting a one-off education. If you teach 100% during an education session, the patient will only remember 20%, tops. Knowledge from outside sticks around.

C: What do you mean *from outside*? Where does this knowledge come from?

Dr. K: From everywhere. Pubs – men really from pubs, from the neighbourhood. There are always ill people in the neighbourhood. Here and there was said this and that. All hearsay.

C: And what is it about? Nutrition, medication?

Dr. K: Also medication: that [they heard that] another medication would be better. Or nutrition: can't you do it like this too? They get it all mixed up. That's why during patient education session... the lecturer [at the training workshop] said: you shouldn't be upset if people don't get it, if they only remember 30% - although even that's hardly the case – at least you've done something.

C: And how do you do your patient education sessions?

Dr. K: You are only allowed to do patient education once [per patient] – but I spread them over five sessions. You can't cramp all the learning material into one session. That's not possible. Five times. But only one [module] per case [is covered by the health insurance].

[Interview transcript 17.10.2006]

There is an obvious discrepancy between the commonly shared opinion that patient-led illness management, and therefore patient education, lies at the heart of diabetes care and the limited resources and time allocated to such education. A paradigm of healthcare that hands responsibility and therapeutic power to an informed “expert” patient also presumes the patients' ability to obtain the necessary knowledge to be an “expert” largely on their own, ideally after the initial guidance of a patient education module. This shows that the “expert patient” is a highly problematic notion.

### *Guarding knowledge*

There are two specific problems with above described Turkish-language diabetes education (besides the rather limited time frame to deliver such education). First, Turkish education sessions are barely available, and second, if education was available the content was very basic.

Several Turkish-origin doctors told me about diabetes education in their practice – no doubt a very low number considering the estimated 20,000 Turkish Berliners with diabetes<sup>20</sup> – and although all invited me to participate, I was cautioned that they would currently not be available due to staff shortage or time constraints. To

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<sup>20</sup> Various health professionals and charity workers in Berlin shared this estimation with me: they take the about 200,000 Turkish Berliners and the (conservative, estimated) diabetes prevalence rate of 10%.

my and, more importantly, many patients' annoyance, a practice's autumn education sessions were repeatedly postponed due to illness (we were only told after turning up at the practice at the given times) and the whole module was finally called off altogether. In fact, only Zahedi's practice (which had a good reputation for their education programme) finally provided me with the opportunity to participate in a series of sessions.

My research participants from the self-help group shared many stories of frustration with me. Their illness narratives contained mere side notes of their initial patient education sessions – if they had attended one at all. Their lives with diabetes began with the diagnosis which was only in some cases precluded by more or less discomfiting symptoms. Rana told me that she could not really remember anymore what it was like to receive the diabetes diagnosis. It had been over ten years ago and at first she did not really know how to deal with it anyway. She commented, “My doctor was quite useless. He didn't even tell me that there are diabetes specialists! Can you imagine?” (Field notes 13.03.2007) Similarly, her self-help group colleague Mehtap did not receive any patient education sessions. After her diagnosis seven years ago, she got several oral drugs but did not feel well controlled at all. She did not receive any education sessions. Finally an acquaintance advised her to go to a diabetologist where she found the help she needed. The specialist referred her to a nutritionist who, as Mehtap noted, only spoke German but tried very hard to explain well in plain German. Sevim told me a similar story and highlighted the difference her final contact with the self-help group made. Sevim had to go to hospital because of a hernia and after that she felt quite tired, thirsty and had to urinate frequently. With these symptoms she went to see her family doctor – a Turk – who diagnosed diabetes and prescribed her oral medication. Because of the hernia she was on sick leave anyway and was sent into rehab (*Kur*<sup>21</sup>) and at the health spa she also received some diabetes education sessions. “I didn't really pay much attention”, she told me. “There were some quite boring talks on diabetes – and there were nutritionists telling us about diet. It wasn't very appropriate anyway – the wrong kind of foods, you

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<sup>21</sup> Part of Germany's post-war social welfare provision are health spa holidays (*Kur*) every citizen is entitled to on a regular basis, e.g. mother (or father)-child-rehab, that is based on a rehabilitation medicine of bathing, relaxation and environmental stimuli (Maretzki 1987).

know – potatoes and schnitzel.” I later found out that diabetes did not really come as such a surprise as she had “a touch of sugar” during her pregnancies – the last one was ten years ago – but she “always got it down again – just reduced my sugar intake”. Her family doctor was not too helpful though. She had never been offered education sessions, he had never explained much to her. “All he did was giving me medication.” (Field notes 17.05.2007)

Those people who have the rare opportunity to attend Turkish-language patient education, experience a second kind of “provision gap”. They seem to receive a very basic form of diabetes education, one that could raise the concern as to whether it is “expert knowledge” that is taught. Many doctors expressed their concern to me that particularly the group of first generation Turkish migrants from rural backgrounds lacked basic understanding of their bodies, and even the language to refer to their body parts. As a result “appropriate” knowledge for these patients’ education was identified as on a very basic level.

Dr. B [Turkish-origin family doctor]: Well, my personal...well...speculation, I can only call it as it is not at all scientific, I mean, I can’t show you any hard evidence for this...but in Turkish we only know few terms regarding the body. It’s not an issue for a German – even for your average Joe – it’s not too difficult to apprehend his body, its “content” and topography. Let’s say we say cheekbone, a German knows what that is and where in his body to find it. But that is not really the case with Turks. [...]

In Turkish there are not that many [terms for body parts or organs] and there are regional differences. Let’s say, a term used at the Black Sea coast for “thigh”, is used to refer to the lower leg in the North East regions. That’s why such words are not consistent and that’s why a Turk doesn’t know his body. And especially with diabetes you have to know your body well. If we consider what is standard education material in Germany. A patient will learn about mechanisms, a little bit of anatomy, a little bit of physiology. Let’s say we mention the pancreas – no one [no Turk] will know what that is or where it is. There is no word for this in Turkish – just “*pankreas*”. There is no other term. That’s why it’s hard. You can, of course, teach all this but it takes a lot of time and effort.

[Interview transcript 28.06.2007]

Such clinical preconceptions of patients’ knowledge bases and learning abilities seemed to stem from a combination of stereotyping the rural migrant labourer and actual experience with patients. Those diabetes educators who told me that they aimed to account for common problems of illiteracy, limited active vocabulary or

anatomical understanding envisioned a limited yet well understood knowledge base for their patients assuming and therefore rendering more complex comprehension unfeasible. Diabetes education could therefore take on a range of “learning outcomes” and indeed would convey very different forms of knowledge and therefore often limited understandings of diabetes. It certainly raises doubts if the object of this education is to qualify “expert patients” that could confidently self-manage their illness. In any case, it seems to be the doctor’s individual decision what patient expertise should be.

That knowledge or expertise is a contested category, has been addressed elsewhere in similar contexts. Karen Lutfey (2005) conducted ethnographic fieldwork in two American diabetes clinics exploring notions of “good doctoring” of ensuring patient adherence. The study reveals that practitioners regard themselves as “educators” and “salesmen” who consider it pivotal for complex diabetes management to have informed and autonomous patients. Patients should actively learn to become experts of their condition. However, not all information is considered good. Patients are expected to subscribe to the biomedical model of diabetes care. For practitioners, those patients resisting this imperative are acting “irrationally by not protecting one’s health and best interests” whereas “good patients” are “acting intelligently” (Lutfey 2005: 438). Lutfey’s (2005) study shows that as much as it is desired by medical professionals to acquire expertise as a patient, it has to be the right kind of expertise. While knowledge is normatively scrutinised in terms of right and wrong information and beliefs, there is then a choice of what levels of right or good knowledge should be considered or conveyed. And this choice is locally and idiosyncratically negotiated by healthcare professionals. Carter (1995: 139), for example, explored the technological culture of risk assessment in clinical settings, looking at cholesterol screening and how scientific knowledge is permeated by social meaning. He suggested that it is local, individual and informal choices that decide on what passes as “expert”, “formal” knowledge (ibid. 138).

In the case of Turkish Berliners, rather worryingly, such choices seem to be made on the basis of ability to understand knowledge rather than “gold standards” of knowledge. Insofar as knowledge is highly guarded, structured and limited according

to perceived capacities of patients, this invites Francis Bacon's "knowledge is power" (1612) taken up among many including Foucault and his conceptualisation of power/knowledge (1980). Following Nietzsche (1969 [1887]) in his opposition to Kant's understanding that there is a universal essence of knowledge, Foucault (1998 [1976], 2000) explores knowledge (and power) in its historic, institutional and ideological context. For him, knowledge is relational and intrinsically linked to power structures and can thus be not understood as a separate phenomenon. Medicine is a prominent example for such power/knowledge, as populations' bodies are controlled and monitored by medicine and its institutions and representatives that produce, utilise and disseminate medical knowledge (cf. Lupton 1997). Knowledge about diabetes control, here, is clearly shaped and withheld according to local assumptions and without consultation with patients; even though it is the patients that are required by the same ideological structures to adopt such expert status. The tension lies both in theory and practice. Although Foucault does not separate theory and practice but considers theory as practice (O'Farrell 2005: 71), his idea of power/knowledge separates the doctor who represents medicine and medical knowledge from the patient who is subject to medical knowledge and practice. Yet even contemporary notions of expert patients are formed within the medical realm, according to a clinical model of what constitutes patient expertise. In the above ethnography, patient expertise seems to be an altogether contested idea in the case of migrant patients: either medical knowledge is entirely unavailable (in mainstream diabetes education that is in the wrong language to teach expertise) or "dumbed down" for illiterate, un-educated migrant "expert" patients.

#### *Challenging expertise: the self-help group*

However, the story of diabetes power/knowledge is more complex. My evaluation of such simplified education sessions may seem harsh, but the immediate comparison with the peer education in the self-help group made me question the value of limiting knowledge for certain patient groups. The self-help group – in the true fashion of patient-led support groups (Nettleton 1995) – actively pursued access to the kind of detailed knowledge that some health professionals had presumed this patient group incapable of understanding. The education about cholesterol is an example for such

pluralities of knowledge and will be used for the following description of a typical self-help group meeting.

The self-help group gathered every Saturday afternoon for two hours in the small lecture hall in the dialysis centre of a private hospital. After people found their seats and exchanged some words with other members, Yılmaz would ask for their attention and start with a general chat with everyone. How was everyone doing; did anyone have any questions or concerns? At this point people would share their experience about recent doctor's appointments, possible set-back or success, and often, latest test results were discussed. People would, for example, read their current cholesterol levels to the group from their latest doctor's letter (*Arztbrief*). They may double-check that they read the results correctly and inquire how their results compare to the clinical cut-off points of their "good" and "bad" cholesterol; they may ask for advice with levels have worsened or welcome the group's praise if levels have improved. As diabetes increases risks for cardio-vascular diseases, people with diabetes should watch their cholesterol levels. The patients of Zahedi's "illiteracy-sensitive" lessons mainly learned that it is as necessary to avoid fatty meals as sugary or starchy foods (field notes 22.01.2007). A short discussion aimed towards a distinction of "good" and "bad" fats created much confusion among the attendees. At the German "gold standard" middle-class patient education session of my diabetes consultant informant a much longer time slot was allocated to cholesterol and included much more refined teachings of "good" and "bad" cholesterol and, accordingly, how to read and assess blood results (from field notes 26.06.2007). In general, the time constraints of any patient education session added to quite limiting considerations, yet I could not help noticing that some patients received more complex explanations than others. My initial approval that maybe one should not overcomplicate already quite alien clinical information soon faltered after experiencing how the un- or low-(school-)educated self-help group members juggled clinical knowledge, and as a result, managed to understand the clinical information given about their health status.

The self-help group leader actively sought out detailed and current clinical knowledge. After the initial question and answer session at each self-help group meeting, Yılmaz then gave a lecture on a specific topic such as cholesterol. The

members learned, for example, that there are good fats (vegetable and fish oils) and bad fats (mainly animal, saturated fats), which produce bad cholesterol (*kötü kolesterol*) LDL (which should be lower than 100 mg/dL as it clots blood vessels) and good cholesterol (*iyi kolesterol*) HDL (which should be over 45 mg/dL; it releases fatty deposits in blood vessels and transports them back to the liver). Such clinical cut-off points of cholesterol levels were rehearsed on a regular basis, individual test results discussed within the group and contextualised with the kind of diet or social events that preceded such test results. Knowing to avoid fat as well as refined carbohydrates is one step towards controlling diabetes but it only paints half the picture. Understanding that not every kind of fat has adverse health effects and learning which types are beneficial (after all it is the type of fat so frequently used in their regional cooking), added a whole other way of understanding their body. Moreover it enabled the members of the self-help group to read further information material, to discuss test results with health professionals, and ultimately and very practically to manage their bodies and keeping (bad) cholesterol levels low. This meant to avoid further clinical intervention in the form of medication and ultimately further illness.

Yılmaz lectures were often intense and tiring. After an hour of group meeting, he would call for a break (that he and many of the male members used for a cigarette outside). During breaks the group members shared snacks such as fruit and cakes with each other. While this part of the group meeting was a nice respite from learning and a chance to catch up on latest gossip, group members also used this time to have more private conversations about how they were doing, possible emotional or physical struggles. Also, women would share their recipes – especially of the cakes they brought in, baked with spelt flour or fruit sugar – or other practical experiences that they had made in their attempt to implement newly acquired knowledge. Becoming members of the self-help group had surely turned my research participants' experience with diabetes around. The self-help group members have gained access to a combined wealth of knowledge of peers with similar experience and the trained support of the group's leader Yılmaz. Such education was available on a weekly basis with the opportunity to revise, rehearse and question without time constraints. What health professionals liked to flag as a patient's right – the right to

knowledge – turned in clinical practice much more into a duty to comply and be satisfied with the limited offer provided by resource-constrained family doctors. The self-help group offered knowledge and, first of all, access to it on a much more egalitarian basis. Rana, Sevim and her colleagues at the Turkish-language self-help group had come a long way from their first encounter with diabetes at the time of diagnosis to their present relation to their illness and care.

Having described their way of social learning (Wenger 1998) within the group as more egalitarian as the severely restricted knowledge offered during the “illiteracy-friendly” patient education session, to an outsider, the group meetings may have appeared far from egalitarian but very authoritarian in style. Yılmaz led the group meetings with a strict hand, swiftly silencing conversations during his lectures which were typically held in a didactic style. After the break, he often allowed for more interaction and involved the group members much more. Sevim was sometimes a bit intimidated during group meetings: “I sometimes just wait until Yılmaz points at me and says: Sevim *hanım*, tell us what’s this and that... and I freeze.” She was very impressed how some group members such as Sadık always had an answer and could answer so eloquently: “As if he were reading it from a book.” (Field notes 17.05.2007) Sevim had heard of the self-help group through the local Turkish TV station. That was quite a lucky coincidence as the family usually watched satellite TV from Turkey and not Berlin’s local Turkish-language TV. But she watched the health programme with Mr Yılmaz – twice. The second time, Sadık – a devoted regular – was accompanying Yılmaz. He had brought his scales and was telling people how he managed his diabetes. She was so impressed that she decided to come to the group meetings. She had been a member for three years when I met her at the group. Sadık, a 75 year old widower, was a great role model for many in the group and always impressed with his knowledge.

I was at first surprised by this perhaps unusual self-help group model that featured Yılmaz’s lecturing style, as I imagined chairs arranged in a circle as it is often portrayed in film. Newcomers to the group, however, did not share my initial puzzlement. In several conversation, health professionals later explained to me, that it is quite a “Turkish way” to learn this way, as for example the diabetes nurse at Zahedi’s practice Turkish explained her blend of the “German” interactive and the

“Turkish” authoritative education model (from field notes 22.01.2007). The more I got used to this self-help group format, I also realised that a large part of the two hours of meeting were indeed devoted to sharing experiences within the whole group rather than simply learning new information from Yılmaz. This is not to say, though, that Yılmaz did not claim authority on this information, as Rana experienced later that year when she challenges this authority by suggesting alternative information on blood sugar test strips; a conflict that only resolved when she left the group. This incident will be discussed in more detail in Chapter 5.1 and Chapter 8.2 that will revisit how power relations and authority intrinsically shape social experiences with diabetes.

### *Power/knowledge*

Summing up, knowledge is a central requisite of experiencing diabetes. Knowledge acquisition is considered essential from a clinical perspective in order to manage diabetes, and therefore educating about diabetes – rather than medicating it – is at the heart of clinical intervention and belongs to “best practice” standards (IDF 2005). Knowledge, however, is locally and idiosyncratically negotiated and shaped and intrinsically linked to power relations (cf. Foucault 1980). What kind of knowledge is made available seems to depend on the ability ascribed to the patient or patient group that should attain such body of expertise – a judgment often left to and cast by the health professionals who put such patient education into practice. While some doctors expressed their view to me that information brochures, translated to accommodate those patient groups who do not share the healthcare provider’s language, fulfil the requirement of educating the patient, others resort to other measures. Some of those health professionals who shared the native language of their migrant patients amended patient education sessions, which every patient should have rightful access to, as they believed that this right included that such sessions should be in a format that is accommodating to patients’ specific needs. This might have been, in theory, a commendable exercise, though did patients seem to have traded their “foreign”, non-native speaking status for that of the uneducated rural dweller. Instead of being confronted with German, they were in turned considered challenged by “standard” (urban Western) Turkish and lacking knowledge such as

human biology (without considering that former farmer might have a fairly good grasp of organ anatomy as opposed to urban middle-class academics). Accordingly, the (potential or alleged) illiterate patient received a “dumbed down” version of diabetes knowledge, yet these patients’ “failure” to prove “patient expertise” was put in causal relation to the initial educational gap rather than the limited information provided.

In the light of such access constraints, patients of the self-help group actively sought access to a much more sophisticated and in-depth body of knowledge. Quite contrary to what was assumed about their capabilities to handle such knowledge, they actively engaged in practices of making sense of such information and giving them meaning in their personal illness experience. The group’s success of fostering active self-management was most evidently due to their intense way of group learning, repeatedly hearing information (not facing the same structural constraints of practice hours and staff availability as formal healthcare provision did to provide education), being able to ask many questions, comparing such information with their own test results and attempts of implementation, sharing positive and negative experiences as well as advice and emotional support. The next subchapter explores this practical and social aspect of knowledge. However, while knowledge acquisition was a group effort, within the self-help group knowledge transfer was also shaped by and negotiated through power relations. Yılmaz claimed authority over the clinical knowledge (not so much the women’s knowledge over recipes) and his style of leading the group meetings reflected this hierarchy.

Finally, the group members also assumed an authoritative role due to their expertise and engaged in the negotiation of “appropriate” knowledge – although this was not used in order to produce or guard knowledge. They may have shared the experiences of many Berliners living with diabetes who were automatically subsumed under a patient group that is deemed (or doomed?) challenged by their low socio-economic status and education levels and by their foreign native language. Indeed their biographies were largely marked by hard labour, low household income and cramped living conditions in an environment that was not always welcoming or warm-hearted. And yet in becoming knowledgeable expert patients, they assume a position of power compared to those Turkish Berliners who are largely excluded

from diabetes education. Sevim told me about her own way towards becoming a diabetes expert and she pointed out that those who did not undergo equally intensive tuition were easily spotted, especially as sharing diabetes experience among the more “expert” patients was a specialist’s affair. She could immediately identify the untrained, for example, by inquiring about one’s diabetes status. Among Sevim and her “diabetes colleagues” this is routinely done in terms of HbA1c-levels, the long-term measure for blood glucose levels.<sup>22</sup> Asking new faces at the community information events about their HbA1c, Sevim explained to me, she would know: “If people answer 8 or 9 or something, they got it – but if they answer 200, then it’s clear they don’t know anything about HbA1c.” (Field notes 17.08.2007) Her own knowledge separates her from others, and towards these unknowledgeable others, she is assuming a position of power/knowledge (Foucault 1980).

#### 4.2 Practising knowledge

By seeking their own way of accessing knowledge that was otherwise rationed and guarded in the clinical context, the members of the Turkish-language diabetes self-help group arrived at different, more advanced, understandings of diabetes control than their fellow Turkish Berliners with diabetes. Yet while the group as a whole represented a fairly unproblematic success story, individual narratives of members were hardly as straightforward. Personal journeys towards their present status in the group and in their illness were much more complicated. Knowledge acquired in the group was not necessarily actively sought in the beginning and much of what was learned only really made gradually sense through first attempts of implementing the learned into their everyday lives. Only with the lived experience of the practicality of knowledge, of tangible changes of their health, it was traced, negotiated and applied. They then would utilise diabetes education’s generalised recommendations to their own ends and manoeuvring health advice in response to their individual experiences and social lives. This subchapter aims to trace such journeys of making sense of knowledge through its practicality in everyday life and thus ultimately making sense

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<sup>22</sup> For a more detailed explanation see Chapter 5.

to everyday experience through knowledge. Knowledge is not an abstract entity but is learned within a social group, is made sense of and practiced in social lives. Treating knowledge as action, more specifically “knowing as practice”, I follow Mol and Law (2004: 46). I will ask how practical knowledge is evaluated, and why and what kind of knowledge is perceived or made practical. The short answer is that the newly acquired knowledge has to work and make sense in their social worlds, or help to make sense of their (diabetes challenged) social lives.

*Accessing but not appreciating knowledge?*

A common public health riddle is that even when “appropriate” access to knowledge is offered, that means if services for example consider native language, gender issues or transport concerns, patients nonetheless often only reluctantly make use of such services. I met Kristina, a Master’s student who was researching for her dissertation, at a community diabetes event (from field notes 31.03.2007). The self-help group held these events on a regular basis in town halls as a sort of “community outreach” awareness raising and information event that should attract further members to their group. Kristina was writing her Master’s dissertation on ethno-marketing to migrant diabetes patients as part of a work placement with a major drug company. She did not seem aware of any ethical implications that her employment might raise, and justified her interest and expertise in terms of her own migrant background and type 1 diabetes. The starting point of her research was a paper that explained that, as part of a prevalence study (the inevitable Laube et al. 2001), newly diagnosed Turkish migrants with diabetes were offered follow up care in their native language. To the researchers’ amazement only a small percentage of study participants returned for care.

There were numerous tales of such recruitment problems. At the community event I chatted to one of its regular participants, a young Turkish-origin drug rep. He explained that according to city statistics there were about 203,000 Turks in Berlin and if diabetes statistics are applied to these numbers, about 20,000 people within this Turkish community lived with diabetes.

You could call that a market. [... But considering that] this event has been advertised on [local Turkish-language] radio all week it’s quite a

disappointing turn-out if only seventy people have bothered to turn up. Even considering the nice weather.”

Immediately the drug rep also offered an explanation that resonated with the opinions of several of the – mostly Turkish-origin – doctors I had met:

“It’s quite typical, really. That’s the Turkish mentality – or southern mentality...this siesta mentality, not showing enthusiasm or interest in something, being sluggish and lazy. I mean, this self-help group is quite well-known but – how many members are there?” [Field notes 31.03.2007]

While access to knowledge about diabetes was generally well guarded and not exactly liberally offered to a heterogeneous patient population in Berlin, the self-help group aimed to provide diabetes education more generously at their community events and the weekly self-help group meetings. Yet people seemed to struggle to appreciate the offer. For example, almost all the research participants told me that it took them months from their first attendance of the self-help group or community events to become regulars.

All of them could recall their first contact with the group and how their lives finally transformed through getting a grip of their illness. These stories all have in common that it took some convincing and arm-twisting to meet the self-help group and turn first attendance into a regular habit. It was not so much the final access to knowledge through their first encounters with the group that changed their perspective on their illness, than the realisation of what a difference it was to approach illness management as a group and, ultimately, how much influence and control can be asserted on their illness. Abstract knowledge had to be acquired, understood, but most importantly, put into practice. Only after successfully achieving this conversion, the real benefit of being knowledgeable could be experienced. It was the very experience of enacting knowledge, for example experiencing improved eye sight, that acknowledged the utility of knowledge in their social lives. Mainly, of course, the crux lies in the matter of fact. Learning about diabetes requires time and dedication; it is complicated, complex, confusing and, frankly, boring. Sharing this task within a group that provide regular support helps. Finally, it takes equal dedication to make severe life choices to implement any of the learnt and experience its benefits. This is not an easy task as social lives are complex and involve more

people than the individual that attempts such lifestyle changes. Only then knowledge receives its utility and thus beneficence to its owner.

### *Experiencing the practicality of knowledge*

My research participants were quite aware of what separated their lives with diabetes from those of so many in their “community”; it was “knowing diabetes” that gave them the head start out of a seeming marginal position of health(care) inequality. They were not inert pupils of refined teaching programmes, above all, as such formalised and carefully drawn up strategies are rarely accordingly put into practice. What they had understood was that knowledge about diabetes is more than abstract clinical terminology but that it is instrumental, practical and pragmatic. They had experienced, literally on their own bodies, in what way being knowledgeable can make a difference in their lives. Their eye sight improved, they felt less tired or restless, or tingling in hand or feet disappeared. They could share these experiences with the other group members and hear about experiences not made themselves.

Such appreciation of benefits also extended from immediate bodily experiences and the group context. Sevim once explained to me how essential it was to be knowledgeable about diabetes and learn about the causes, symptoms and management of diabetes and derived this insight from her own family history. Her mother had just passed away in 2000; it was her diabetes that caused her premature death:

You know, my mother didn't know anything about diabetes. She just took the medication she was given, she didn't really change her diet, had scales or anything. She never knew her diabetes control – and neither did I. Just imagine! How much I know and how much I could have helped her. But I didn't know anything about diabetes then either. And I didn't take her along to information events either.” [Field notes 17.05.2007]

Rana, Sevim and their colleagues in the self-help group had reached a turning point in their illness experience. With the experience of the practicality and effectiveness of their newly acquired knowledge came also novel confidence and assertiveness. Revisiting the field note excerpts quoted in the introductory paragraph of this section, Rana proudly told me at our first meeting that she would now feel confident to request the expert help of a specialist – knowing her state health

insurance would cover this service – if her family doctor did not grant her enough time. Several months later her treatment was switched from oral medication to insulin and I offered to assist her in gaining more information about insulin injection. With a wave of a hand she reassured me that she had acquired a whole range of insulin brochures from her local pharmacy on the day of her treatment switch to bridge the time to an insulin education session scheduled for the following week upon her request. Being assertive in demanding access to knowledge was not only taught but regularly rehearsed and rewarded in self-help group meetings. Their weekly routine included discussing each other's doctor's notes and test results. Requesting copies of such documents presented a daunting step for many but the backing and encouragement of the group transformed it into an ordinary practice and such initial bravery was rewarded by the communal making-sense of cryptic clinical records. Being knowledgeable had started to bring real benefits. This “empowerment” to be assertive will be further discussed in Chapter 7.2.

The benefit, here, is about gaining power in negotiating the clinical encounter, which is quite possibly not intended in notions of the expert patient that focuses more on the “care at home”. This instrumental quality of knowledge of challenging orthodox power relations of course lie at the heart of the paradox between clinical efforts to educate while at the same time severely rationing access to education and patients' endeavours to negotiate education. While knowledge transfer is strategically employed in order to transform bodies into effective patients, authority over the ill body must be retained and this authority is legitimised as the source and interpreter of knowledge. The patient seems to seek knowledge exactly for the same purpose, in order to acquire a position of more equal negotiation (among experts), as Rana's case shows. This was discussed in the previous subchapter; important here is, that the acquisition of knowledge and subsequently a more powerful position came with the realisation that clinical encounters and self-care were rendered much more workable or manageable. Furthermore, the self-help group members experienced that knowledge helps to make their illness experience meaningful, to understand why their bodies were behaving in certain ways, why their well-being was interrupted or improved – in short, in order to be able to look at diabetes with a steady gaze.

Philosophy's preoccupation with knowledge has generated a plethora of approaches to answer questions about what knowledge is and what our motivation to acquire it is. Habermas' (1972 [1968]) work *Human Interest and Knowledge*, for example, concerns itself with the drive for knowledge rather than knowledge itself. German-language philosophers distinguish two words and thus two sets of ideas with knowledge: *Wissen* (knowledge itself, the content known) and *Erkenntnis* (insight, cognition, or the drive for knowledge) (e.g. Nietzsche 1969 [1887]). Habermas would argue that it is social interest and experience that fuels a drive for knowledge (*Erkenntnis*) which then ultimately leads to the acquisition of knowledge. Foucault (2000: 13) also emphasises Nietzsche's understanding of knowledge as "an event that falls under the category of activity". In the case of Rana and her colleagues, they first had to acquire a certain level of knowledge, but it was the practical experience of the benefits of knowledge in its use that provided them with means to make sense of her illness experience – as Law (1994: 29) points out that in social theory and philosophy knowledge is treated "as a contexted product whose status depends upon its workability". This initial understanding and identifying the practicality of what the group members had learned thereby produced an interest, a drive for acquiring more knowledge.

#### *Various knowledges*

What makes knowledge valuable was recognised in the experience of how knowledge plays out in the everyday and makes sense in their social worlds. This leaves the question of what kind of knowledge was evaluated as practical or efficacious. Exploring various knowledges invites several disjunctions. In this chapter, knowledge so far refers to clinical information on diabetes, textbook definitions and current therapeutic standards. Diabetes education as self-taught in the self-help group largely followed such clinical standards, often uncritical. Nonetheless, such knowledge was scrutinised for its practicality.

Central to this practicality – and in opposition to standard clinical knowledge – was "*Turkish*" information. By that I mean information that concerned their social lives that often varied from the realities their doctor's orders assumed. The self-help group members, for example, were given a so-called "carbohydrate conversion

table”, with which one can tell from a long list how much pasta would equal how many potatoes. Unlike those exchange tables given out by doctors or in regular education sessions, the self-help group’s table includes a long list of Turkish foods such as *bulgur* (dried crushed wheat), *pirinç* (rice), *pilav* (cooked, prepared rice), *nohut* (chickpeas), *mercimek* (lentils) or *bakla* (broad bean). Dr. Zahedi’s education session, to my surprise, only provided its attendees with German brochures, nonetheless Turkish diets – and more importantly various regional differences – were a central feature of such Turkish-language education sessions. Many of Zahedi’s Turkish-origin colleagues showed me their course material that tried to accommodate their Turkish clientele by featuring photos of Turkish meals or food products.

“Turkish-specific” knowledge, which is altogether absent from any German mainstream public health information, also shaped many of the big community information events that the self-help group hosted on a regular basis. In September fasting during Ramadan was discussed, in early summer the dangers of walking barefoot on the beach, the effect of sweating on glucose-levels, and how to store insulin in the soaring Turkish summer heat. Other seasonal advice was, for example, on the kinds of food people would be likely to eat during their summer stay in Turkey, especially identifying the fructose content of typical summer fruit. Moreover, community events tried to convey information about the German social system. The patient consultant Hilal regularly held talks on German bureaucratic procedures of applying for benefits, services and health insurance entitlements. She also assisted Yılmaz to keep the self-help group up to date with latest healthcare reforms and procedural changes. Topical knowledge about citizen’s rights and, above all, financial entitlements was considered as valuable to the group as information about diabetes and could usually not be attained through clinical-based patient education.<sup>23</sup> Hilal also believed strongly that patients need to learn how to be demanding and critical, something quite alien, in her opinion, to her mother’s generation of low-educated, hard-working modest people. That is not to say that at her work she frequently met patients who requested, for example, a level of care that the German social system did not attend to. In any case it was the fragmented understanding of the social system they were living in that impacted on her patients’

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<sup>23</sup> For a discussion on learning about citizen rights and entitlements see Chapter 7.

well-being, something that could be remedied with knowledge transfer and the support to apply it.

In contrast to clinical knowledge, there is *lay knowledge*, for example on nutrition and cooking. Family doctors would omit such competence and only occasionally appreciate the habit of many families to eat sit-down, cooked-from-scratch menus. Lay knowledge was mainly understood as negative information, gathered from family, friends and neighbours, for example on medication, that is then requested during consultations although inappropriate for this particular patient. Further examples for lay beliefs as education gaps that were frequently mentioned were notions of “chubby is healthy” or “resting helps recuperation”. Lay knowledge in accordance to clinical recommendations, on the other hand, for example extensive cooking skills, were duly unremarked upon by most doctors. Another example is the doctor’s widely shared assumption that their patients lacked any kind of clinical knowledge of their bodies, when these originally rural, farm-working people probably had some grasp on (their animals’) organs. Firmly situated in the medical realm, these doctors followed its distinction of knowledge and lay beliefs. Pelto and Pelto (1997) argue that medical anthropologists struggle time and again with health professionals’ stern conceptualisation of regarding knowledge as what are, to them, “objective”, evidence-based, scientific facts and regard them as in opposition to “subjective”, untenable lay beliefs. A dichotomy of lay belief versus (expert) knowledge, however, is increasingly a problematic one, even within the medical realm. Today, evidence-based medicine, the practice of large evidence reviews, is increasingly important in clinical practice and challenges doctors’ knowledge as merely experiential (cf. Ecks 2008).

That said, not all health professionals regarded lay or experiential knowledge as unhelpful. Several diabetes consultants told me that key to their work was drawing on their patients’ pre-existing knowledge. These diabetes consultants were nutritionists or practice nurses, often young women, who appreciated their (female and older) patients’ wealth of knowledge particularly on food and cooking. They understood that information that was given with the patients’ often elaborate knowledge on food products and food preparation in mind was easily adopted and integrated into pre-existing food practices. This was also the key to the “peer-

education” principle of the self-help group which was a valued platform for such knowledge exchange.

Another set of knowledge that remained at the fringes of mainstream clinical teaching was, in true self-help group fashion, latest research findings and sometimes *unorthodox information*. Yılmaz made a real effort to gather such information and present new and current issues. Members of the self-help group appreciated his resourcefulness, “he surfs the Internet for us” several people told me proudly, translating brochures and news items for them. The group discussed heatedly potential glucose-lowering effects of grapefruit or cinnamon, although Yılmaz preferred debates on less obscure news items. A central discussion during my stay at the self-help group was the news about high cholesterol levels in some margarines. I spent much time with Rana and was frequently spoiled by her fantastic cooking. She told me that she consciously used olive oil in her Aegean cooking and avoided too much use of butter (fat) as it is more common in the Eastern Anatolian region. She was surprised, however, when Yılmaz told the group that scientists have found out that some margarine can elevate bad cholesterol levels more than butter. Such margarines have even been banned in some European countries such as Sweden.

“[Yılmaz] just knows things you haven’t heard of yet. That margarine can be worse than butter! Who knew?! Already in [my hometown] in the 60s everybody started buying margarine. Although – in our family we only ate olive oil. We had olive trees in our garden. I still have margarine in the fridge – just bought it last week – but now I don’t want to open it.” [Field notes 13.03.2007]

Well aware about the rapid changes within scientific knowledge, Rana liked telling the following story. Both she and her husband suffered from bad stomach aches in the beginning of their life in Germany and went to see a doctor about it. The doctor’s advice in the 1960s was that it must be the olive oil [*sic*] and suggested not to eat it anymore. As Rana commented on medicine’s own struggle with evolving knowledge, food is indeed a complex body of knowledge that never seems to provide easy guidelines and frequent subject of news and advice items. So would Yılmaz end any debates on fats with the caution that olive oil should not get too hot and instead use sunflower oil for frying, as he had recently read in some brochure.

### *Knowledgeable bodies*

There was, however, another set of knowledge, the self-help group members had begun to draw on. The self-help group members had lived with their diabetic bodies for many years and had experienced how their body was “doing diabetes control”, their glucose levels reacting to certain diets, activities, stress. This accumulated tacit *embodied knowledge* could be drawn upon with any new technique or skill acquired in the process of learning formally about their illness. “Knowledgeable” self-help group members would merge clinical knowledge with practical knowledge, for example on food and cooking, and embodied knowledge of “feeling” its impact on their body and thus become successful tacticians of diabetes control.

Diabetes knowledge therefore can be embodied, and diabetic bodies can be knowledgeable. Mol and Law (2004: 50) describe how bodies act and are enacted. Exploring hypoglycaemia (dangerously low blood sugar levels), Mol and Law (2004) suggest not to consider it just as a state but a practice: avoiding, measuring, countering – and feeling, as bodies can be themselves knowledgeable of approaching risk. While the body has not yet been explicitly mentioned in this chapter, diabetes knowledge is, of course, about the body. Earlier I argued that diabetes knowledge is very practical. A very important indicator for practicality is when this is felt with or in the body. When feeling how a change in diet alleviates diabetes complications (for example regaining sensation in feet and hands), dietary restrictions start making sense. Such “feeling diabetes” is another type of knowledge patients begin to gain.

Notions of embodied knowledge, thus, also resonate with philosophical approaches to knowledge such as Habermas’ (1968) conceptualisation that knowledge stems from social experience, from habit and exercise. Accordingly, knowledge is not about abstract, intangible truism, but is closely tied into social life and lived experience. In his work on self-care Foucault (1990 [1984]) also suggests that individual practice produces knowledge instead of the other way round. Bryan Turner (1992), following Foucault (1991 [1975]), postulates the recognition of the body in social action. Instead of a Cartesian separation of body and mind in the social actor, Turner proposes to consider embodied “practicality and knowledgeability” (Turner 1992: 170). Finally, Mol and Law (2004: 46) postulate

that “knowing is a practice”, and suggest that exploring “knowledge about a body-we-do” should take priority over “knowledge about a body-we-have”.

*Discussion: on practical knowledge and social learning*

To sum up the whole of Chapter 4, patient education in particular and knowledge more generally was discussed as it stands central to patient-led diabetes control. Diabetes knowledge is held and withheld, shaped and evaluated. Foucault’s notion of power/knowledge (1980) sees knowledge as relations and power as relations, closely intertwined with each other. Exploring diabetes patient education in Berlin, Turkish migrant patients were largely subsumed as an uneducated and challenged group. Assuming such marginal position allowed for both more specific provision, in the form of native language education, but also for worse provision, as education content was often actively “dumbed down” by local health professionals. Diabetes education – rather than being clinically standardised – contains a plurality of knowledge, often along a trajectory from simplified to complex knowledge according to perceived patient ability, local social context and resource constraint. Even within the self-help group power relations shaped how knowledge was negotiated.

However, education may always involve a certain subordination on behalf of the student, and there is more to knowledge acquisition than its interlocution with power. Insofar as the self-help group actively sought knowledge whose availability was limited, invites Foucault’s notion of “technologies of the self” (1990). The self-help group engaged in the practical exercise of making knowledge available and comprehensible. In doing so they had actively become “expert patients” in its notion of “empowerment” and “patient-centred care” as it has been envisioned in modern biomedical healthcare (Lupton 1995, Nettleton 1997). Yet, the “expert patient” is a problematic term in its normative moral economy of what constitutes a “good”, compliant patient and in its locality and sociality. There are patient groups such as my research participants that were not necessarily in mind for such a role as their healthcare providers made clear.

Nonetheless, despite belonging to a deemed disadvantaged group of patients (demographically speaking, in terms of birth place, education levels, socio-economic status), many self-help group members considered themselves indeed experts of their

diabetes and showed understandings of their illness and experience that seemed envisioned in glossy state-of-the-art patient education guidelines. While diabetes education mostly conveys clinical, and arguably abstract, knowledge, this is not to say that it only receives significance within abstract concepts of learning or epistemology. Instead, the self-help group's success can be understood in their approach to knowledge. Knowledge was placed in the social, as Etienne Wenger (1998: 3), in his study of communities of learning, situated "learning in its context of lived experience of participation in the world". Learning happened within a group context and information was understood and rehearsed with the support of the group. Then, knowledge was put into practice – again with the support of the group. Practical knowledge, then, meant that it explained both public clinical language and private illness experience and that it addressed social worlds that were not acknowledged in other formalised education. It also meant that knowledge had to be actively made practical and workable. General nutritional information in the form of food tables had to be amended to address Turkish meals, information had to accommodate religious practice and migrant lives partly lived abroad in different climate and environment. This shows that knowledge is not intrinsically abstract and its application translates into practice. My research participants also drew from a different body of knowledge that is not confined to clinical spaces and sciences. Indeed this clinical, textbook knowledge is only gainful if combined with much more practical social knowledge. Patients, for example, tapped into rich knowledge, skills and experience on cooking when implementing diabetes dietary advice. Another set of knowledge is acquired through experiencing their illness, the embodied knowledge of diabetes, the body's stress reaction to dangerously low blood-sugar levels, or the subtle and yet unsettling signs of too high levels that jeopardise eyesight or organ health. Bodies also "do diabetes", as Mol and Law (2004) already stated, and practices of diabetes control are not confined to the enactment of clinical knowledge on bodies, but bodies also produce and contribute to diabetes knowledge practice.

In the practical engagement with knowledge and experiencing the instrumental property of knowledge, knowledge becomes more than something that is sought or rationed, or utilised to challenge power relations that hold knowledge.

Knowledge stemmed from social and embodied experience and was shaped and negotiated by such experience. In the following chapter, I will have a closer look at the most abstract element of diabetes knowledge and the most clinical side (and even site) of diabetes management, while Chapter 6 will explore the practical exercise of diabetes management. Chapter 5 will also take a closer look at the body. It should soon become clear, though, that one must move away from a dichotomy of abstract knowledge and practical lived experience. Abstract knowledge requires validation through practice, and abstraction gives meaning to experience.

## Chapter 5: Monitoring diabetes

This chapter is about numbers and technology. As much as diabetes control is based in the “low-tech” everyday, this is not to say that it is not profoundly rooted in the clinical. In this chapter, I aim to explore the most clinical, medicalised facet of living with diabetes. In order to manage diabetes, patients learn about the necessity to monitor it. The clinical gaze on diabetes is extended from doctors and nurses who check on bodily functions and complications, to laboratory tests that assess long-term blood-sugar levels, to the everyday scrutiny of the patients themselves. Ideally, they should not only keep track of various check-up appointments, subsequent consultations and possible treatment changes, but also regularly measure their blood-sugar (and blood pressure) levels at home, keep detailed diaries that list these figures in neat categories of date, time and contributing social context, and finally observe their overall well-being, the subtle hints their bodies send out to communicate that something is not quite well.

I will particularly focus on the importance of numbers in the patients’ lives. I argue that numbers are important as diabetes control is arbitrary, based on self-observation and experimentation, and numbers can help with this. Diabetes patients experience the importance of knowing about blood-glucose levels, blood pressure levels, cholesterol levels, and enter a routine of rehearsing and recognising clinical parameters of “too low”, “average for healthy people”, “average for diabetic”, “too high”. Illness status and the ill body are turned into a number – various numbers in fact – along metric scales that are often as arbitrary and complex as the symptoms and expression of the illness itself but appear linear and simple and, one could argue, agreeably impersonal. Far from being mere abstract entities, however, numbers have practical utility and meaning to those who juggle with them in the everyday. Abstraction can not only support coping with often “too real” (sometimes painful, sometimes life-threatening, often irritating, always intrusive) illness experience but most crucially provides the necessary parameters to frame and organise this very elusive illness and steady their out-of-control bodies.

Intimately tied to this “number game” is the technology of blood glucose meters. While recent reviews on the evidence base of self-testing conclude that it has

no benefit for type 2 diabetics (IQWiG 2009), the German Diabetes Union guidelines that include self-testing in type 2 diabetes education programmes have not yet been revised (Herpertz et al. 2003). Two years prior to this IQWiG<sup>24</sup> review, at the time of the fieldwork, both family doctors and the self-help group encouraged my research participants to measure their glucose levels on a regular basis. All patients I have met owned a meter and enthusiastically used it despite the fact that monitoring is quite a costly exercise (each test strip costs EUR 1) that is rarely covered by health insurance. I suggest that meters are more than technological artefacts introduced by health professionals to survey (or discipline) their patients – although that is, of course, a reason why they are handed out (and can today be connected to computers to read and document weekly and monthly results). I would argue that patients use such meters to their own ends. Diabetic bodies are out of control and unpredictable. Blood glucose meters help patients to visualise such unpredictabilities as poor diabetes control is only physically experienced at already very dangerous levels (close to hypo- or hyperglycaemia which leads to coma). Meters can reduce anxieties, and are daily companions that support the often very illusive practice of controlling diabetes.

## 5.1 Quantifying diabetes

Any first time attendee of Berlin’s Turkish diabetes self-help group was confronted with – and admittedly often put off by – a certain focus on a rather abstract way of understanding diabetes. Every session contained the inevitable moment when the group’s leader Yılmaz drew a series of numbers on the blackboard. The most common table I copied time and again into my little field note book (e.g. field notes 21.04.2007) was:

<i>Açlık kan şekeri</i> : [lit. hungry, i.e. fasting blood sugar]
70 – 99 ml <sup>25</sup>
100 – 126 ml

<sup>24</sup> IQWiG, the Institute for Quality and Efficiency in Health Care, is the German equivalent of NICE, UK’s National Institute of Clinical Excellence.

<sup>25</sup> In fact, “ml” is the wrong unit here. It should read “mg/dl” (milligram per decilitre) or “mg%”.

126 < ml
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<i>Tokluk kan şekeri</i> : [lit. full blood sugar, (two hours) after eating]
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90 – 140 ml
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140 – 199 ml
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200 < ml
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As abstract and inert as such tables appear to the newcomer, these numbers contain complex meaning. They are numeric explanations of the illness diabetes itself, the difference between healthy and diabetic, “good” and “bad” diabetes control, parameters of risk and danger and reference points of current illness status. These numbers appeared every week, sternly rehearsed by the sometimes eager, often anxious, crowd that was invited to correctly dictate each figure to Yılmaz. However, far from being a mere theoretical exercise, the self-help group members were dealing with these numbers on a daily basis in their very practical experiences of living with diabetes. They measured their blood sugar levels every day, comparing the results with the tables, adjusting medication dosage, food intake or exercise levels accordingly, recording the numbers in their diabetes diaries, understanding their current health in this way, sharing such information with the other self-help group members, health professionals and also family. “You were up to 300 once, Mama”, Sevim’s 10-year-old daughter announced when I visited them after their summer holiday in Turkey and inquired on how the diabetes management had been going there (field notes 17.07.2007). This subchapter is about numbers, figures, rates, levels, in short the numeric diabetes control.

#### *Blood glucose, pressure and cholesterol in numbers*

There are various forms of numbers a diabetes patient is confronted with. The above case is the most important set of figures: the table of blood-sugar levels or rather of the cut off points that determine clinical standards of glucose concentration in your blood. The first set of numbers of fasting blood glucose represents the levels before having eaten:

<i>Açlık kan şekeri</i> [lit. hungry, i.e. fasting blood sugar]	
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70 – 99 mg/dl	good (also average non-diabetic levels)
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100 – 126 mg/dl	average
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126 < mg/dl	high
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Levels until 100 are considered very good (and also represent non-diabetic glucose levels), between 100 and 126 are average levels, whereas anything above 126 is too high. Many diabetics' levels before eating, often in the morning, can be that elevated if their diabetes is not controlled very well and/or as the liver also produces glucose that a diabetic pancreas might not handle over night. The second set of numbers is measured two hours after eating (or two hours after having administered a sugary drink in order to diagnose diabetes in a so-called oral glucose tolerance test):

<i>Tokluk kan şekeri</i> [lit. full blood sugar, (two hours) after eating]	
90 – 140 mg/dl	good (also average non-diabetic levels)
140 – 199 mg/dl	average
200 < mg/dl	high

The table shows in a nutshell what diabetes is. While non-diabetic people's blood sugar levels are quickly controlled with a boost of insulin discretion of their pancreas, diabetics' blood levels shoot up and stay up after a meal unless adequate medication supports the insulin production to contain the high concentration. Determining the "two-hour" glucose levels can therefore diagnose diabetes, check the efficacy of medication and, in general, monitor diabetes control. Conversely, people who inject insulin – commonly 30 minutes before having a meal – test the fasting glucose levels at that time and might adjust the insulin dose accordingly. The glucose table also shows the complexity of diabetes. Depending on the time of the day (or rather the time of the last meal), "normal" blood-sugar concentration varies greatly. What is normal at one time can at other times be high or low. "Too high" or "too low" should not be understood as a mere clinical disciplinary notion but can mean being dangerously close to diabetic coma, and death – or at least to organ damage.

Other numbers are not quite as urgent yet not necessarily much less complex. The common table for hypertension scribbled every now and then on the self-help group's black board surely rivals the blood glucose one:

<i>Tansiyon</i>	
< 120/ 80	<i>ideal tansiyon</i>
130 - 139/ 90 - 95	<i>yüksek tansiyon</i> [high blood pressure]
121 - 129/ 81 - 89	<i>normal tansiyon</i>
> 140/ 96	<i>super yüksek tansiyon</i> [very high blood pressure]

Each set of numbers, e.g. 120/80, is read in the following way. The first number represents the ‘systolic’ pressure in the arteries when the heart contracts, whereas the second number behind the “/” is the ‘diastolic’ pressure of the heart at rest. According to this table, normal blood pressure would be e.g. 120/85 mmHg (millimetres of mercury), 135/92 would be considered high blood pressure or “mild hypertension”, whereas 150/100 would be very high blood pressure or hypertension. You can also just have a systolic hypertension, e.g. of 170/70, or just a diastolic hypertension e.g. of 120/100. Checking on hypertension, this added clinically gaze on the diabetes patient’s blood, is considered a vital secondary preventative measure. Up to half of diabetics suffer from high blood pressure and as hypertension is an independent illness that can lead to organ damage of kidneys, eyes and cardiovascular complications, it aggravates the health danger posed by diabetes.

The same goes for cholesterol levels that can be affected by insulin resistance but also add a separate health risk to diabetes. Yet unlike blood glucose and blood pressure, cholesterol is a fairly straight-forward number game, once you understood that there is something like good cholesterol, of which you cannot seem to have enough, and bad cholesterol, of which you should have as little as possible in your blood (as mentioned in chapter 4.2):

<i>Kolestrol</i>	
LDL <i>kötü</i> [bad]	< 100
HDL <i>iyi</i> [healthy or good]	> 45

In short, diabetes patients deal with a serious of numbers that “read” from their blood. They indicate blood pressure and cholesterol levels, fasting and non-fasting glucose levels. There is also the long-term blood-glucose HbA1c that has been mentioned before, which is the best indicator for diabetes control as it is robust against daily variation. HbA1c is not quite an immediate number as the short-term glucose measure as it needs to be determined in a laboratory (so is cholesterol, while blood glucose and blood pressure tests are now mainly done at home) and is recommended to be tested for every three months. Nonetheless it seems to be the most important reference point of communicating one’s diabetes status and progress (or setbacks) in diabetes control. Haemoglobin (Hb) is the molecule in red blood cells that carries oxygen. Glucose has the tendency to stick to this molecule and glycosylated (“sweetened”) haemoglobin is called HbA1c. As haemoglobin has a

“lifecycle” of about twelve weeks, checking for this measure of stored glucose about every three months can give a good indication of how high the blood glucose concentration was on average within this time. Non-diabetics have an HbA1c of 3.5 - 6.5 %, the target value for good diabetes control is 6.5 %; over 7.5 % indicates bad diabetes control and elevated risk of secondary complications. These HbA1c levels are taken from patient education sessions where I first learned about them.<sup>26</sup>

The cut-off points of HbA1c taught in the self-help group vary slightly. Yılmaz began the session with writing on the blackboard: 3.8 – 6.1, 6.1 – 7.0. People were confused, asking “*O ne?*” [“What’s this?”] and “*Anlamıdım!*” [“I don’t understand.”], so Yılmaz launched into a detailed explanation. HbA1c was a measure of three monthly blood glucose levels; that it was the doctor who has to do these check-ups as the necessary machine would cost EUR 2000. Hb stood for “*Hemoglobin Alyurvaiok*” [lit. haemoglobin blood], as he scribbled on the board, and A1c were a “*kot*” [code]. I struggled to understand his explanations – as I was sure the others did, too. But we got his emphasis on the importance of keeping these levels down and that high HbA1c levels indicated risk for co-morbidities in eyes, kidneys, or erection problems. (Field notes 10.03.2007)

Although HbA1c remained an elusive term to many that was produced in laboratories and revealed some information which your blood somehow stores, self-help group members knew of its importance within the clinical realm. Knowing that it is the long-term measure, knowing which figures are “good” or “bad”, last but not least being able to swiftly say “H B A 1 C” was understood as the indicator of a “good” diabetes patient (as already mentioned in 4.1). HbA1c were considered valuable to communicate with health professionals, health insurance companies or social workers. Even more so, being able to share each other’s HbA1c levels among patients would inform about current illness status, create and reinforce commonality, but also entail a certain moral connotation of success (or failure) of diabetes control.

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<sup>26</sup> All clinical numbers on blood levels regarding glucose, cholesterol or hypertension mentioned in this chapter are taken from information given by research participants or material they shared. As the next paragraph shows, these numbers were not always consistent. I checked the numbers with medical text books and some differ, although not substantially. Figures also differ between different text books (and internationally). Also see Mol (2008: 44ff) on the arbitrariness of clinical cut-off points in diabetes care. “Clinical standards” are in fact quite arbitrary and show a certain leeway (e.g. see Bowker and Star 2000).

During self-help group meetings, good levels were announced proudly in public and people would include their current HbA1c in the long formalities of Turkish greetings. Bad levels, on the other hand, were more commonly shared with concern among friends, often during the group meeting's break. Having said this, worse HbA1c levels were also starting points for discussions about concerns. Gizem, for example, had just received her latest HbA1c results after her holiday in Turkey. While she perceived her holiday to have had a positive effect on her health, her much worse HbA1c levels worried her. Yılmaz explained about the rapid effects that lax lifestyles during the holidays could have and how worse HbA1c readings after the months in Turkey were common in the people he advised (from field notes 16.06.2007). This social, political and moral economy of HbA1c also applies to other numbers such as the short-term blood glucose levels as well as blood pressure and hypertension, as not only diabetics but probably most people from a certain age experience in our time of preventative medicine.

#### *The clinical language of numbers*

In sum, even though biochemical and biomedical function and workings were often not clearly understood by self-help group members, they embraced the fact that they were able to read test results, relate them to their own bodies and health and knew that they could detect risky bodily states that might require attention. The self-help group's appreciation of numbers surely does not mean that all patients would adopt such clinical number games with the same enthusiasm. Given that most Turkish-language patient education sessions were very restricted in time and resources and focused much more on basics rather than elaborate clinical knowledge, their attendees would not even get in contact with numeric expressions of glucose, cholesterol or hypertension. On the other hand, the diabetes consultant that had a large middle-class German clientele replied to my queries about "my" self-help group's near obsession with numbers, for example expressing daily well-being in terms of glucose levels, with amused recognition. "It's a horrible term", she apologised, but you would call them "professional diabetics" (*Berufsdiaabetiker*). She went on explaining that some patients "really overdo it" but that it would hardly be

their fault because they were encouraged to perceive, express and present themselves in this way (from interview transcripts 26.06.2007, p.9).

Indeed these patients were taught and took on board that numbers represent clinical “objective” knowledge on illness status (Porter 1995). Diabetes is a chronic illness that can present itself in many different statuses and complications, and is lived, experienced and managed in private homes and disorderly individual and communal social lives. From a clinical perspective numbers are an escape from the messiness of personal illness experience, idiosyncratic self-management and patient-led therapy. Numbers represent abstraction away from the particular and personal but create “objective”, “universal” reference points (Porter 1995; Zaloom 2004). In the same way as medical students are initiated in the language of modern medicine to separate them from the lay everyday (Sinclair 1997: 141ff), “expert patients” of chronic illness enter the same apprenticeship of expressing their illness in such “scientific” terms (Nettleton 1995: 96, on self-help groups). Medical scientific language – mostly in form of Latin and Ancient Greek – replaces emotional, lived experience of illness by dispassionate clinical representation (Sinclair 1997: 141). Bowker and Star (2000: 170) explain the medical objective insofar as the “body is constantly in motion and varies by individual, so the ideal measurement is always a projection from a moving picture onto a timeless chart”. Here, they speak of turning bodies into static images – x-rays. Yet clinical numbers are the quintessential measure, recording moving bodies and illness in chronological graphs. Numbers aim to generalise, objectify and quantify individual experiences and make these experiences comparable, assessable and (e)valuable. In doing so, one could argue, it separates the diabetic blood and the person through which this blood is running, according to modern medicine’s convention of the Cartesian body-mind division (see e.g. Csordas 1990, 1994; Illich 1976: 156; Lupton 1994: 30ff; Turner 1992: 32).

#### *Playing the number game: embracing the abstract*

The above explorations of the clinical objective seem important to understand the purpose of clinical tests and numbers. And yet these accounts fail to consider that patients might be more than mere inert occupiers of “docile bodies” that are quantified, recorded, assessed and disciplined (1991a [1975]), in that they can be

entrepreneurs of such activities. I would argue that my research participants had a similar interest in numbers and using them to their own ends. Instead of being objectified, their bodies and/or their experience, by clinical terminology, they seem to embrace such “tactics” themselves. When sharing experiences with each other and me numbers were used as an introduction, summary and/or assessment of certain events. In order to tell me how Rana was getting on with her new medication, all she had to do was to say: “Last night I was 240” (field notes 13.03.2007). This was a quick way for Rana to explain that her diabetes was as controlled as she had wished for. Uttered among “experts” one could also empathise with her anxiety or frustration without Rana having to mention it specifically, while outsiders would have missed the significance of “being 240”. With the help of numbers, in accordance to the clinical intention, they render their experience of illness into something impersonal and abstract.

Just as the clinical realm is challenged by the messiness of patient-led illness management, the patients struggle with the messiness of experiencing such a fluent, inconsistent and often intangible illness. Bowker and Star (2000: 170) add to their account on “moving bodies” that patients’ experiences are equally in motion. They refer, though, merely to patients’ relation with health professionals, changes in social surroundings and the effect this has on the illness progress. I would argue that patients have the same motivation as clinicians to capture moving experience. Invoking “neat numbers” and “hard facts” can be a welcome coping strategy; in Foucault’s terms, it can be a “technology of the self” rather than a “technology of power” (Foucault 1997). By doing so, some “professional diabetics” might reify numbers to replace their illness experience altogether. Experiences emotions, health, well-being and suffering become abstract numbers, but these numbers gain concrete social lives themselves, with the agency of rendering a day “good” or “bad” both on the paper (or display) of a test result and in lived experience.

That in mind, the “number game” is no oppositional project. As much as patients are not necessarily unwillingly objectified as a number that can be compared with parameters of clinical tables, health professionals are not categorically encouraging such faith in numbers, such a reification of numbers. The above mentioned diabetes consultant encouraged those patients she would call

“professional diabetics” who overly expressed their well-being in terms of glucose levels to explore what lied behind the numbers and to understand the social context and events that might influence diabetes control. She was worried that her patients could get defeated by the “failure” of numbers if those were disconnected from plausible – and in a way “excusable”– circumstances. Her patients were encouraged to acknowledge that “having had a really nice day” could explain, and should never be denigrated by, a “bad” blood-sugar count. Her advice took into account that even though numbers could be perceived as objective, definite facts that could “confine” illness and therefore reassure, they can also very much create anxiety. Numbers can be ambiguous entities that are ascribed different meanings and interpreted in flexible ways, as for example Zaloom’s (2004: 259) ethnographic study on trade technologies of financial markets explored.

I believe that my research participants at the self-help group, however, perceived numbers as eminently generalised forms of expressing their illness, appreciating the impersonal nature of numbers. These experts – “professional diabetics” – shared an understanding of what these numbers meant, including an understanding of the emotions that came with various degrees of diabetes control. The self-help group meetings were never very intimate conversation and some elderly group members interacted very formally with each other. Nonetheless, their habit of sharing each other’s current blood glucose levels during greetings or telling the group recent episodes of defeat or success in terms of blood levels, as Gizem and Rana did, made it possible to exchange very personal experiences without having to disclose too much detail.

In *Trust in Numbers* (1995), the historian Ted Porter explored the appeal of objectivity and quantification in sciences and public life. He described numbers as seemingly formal, impersonal and public means of communication that correspond “beyond boundaries of locality and community” (ibid. viii). Porter mainly envisioned researchers, statisticians, journalists enchanted by (and ultimately shaping) numbers, yet can my research participants’ (lay) intentions be understood accordingly. Adopting a language of clinical numbers rendered their personal experiences into a “universal” form of expression. In other words, private suffering becomes “fit for the public”, be it the clinical practice and consultations with health professionals, or

financial negotiations with social workers or health insurances, or exchange in the self-help group.

Having said this, Porter saw numbers intrinsically linked to their local and social identity. So far, this chapter has not mentioned the specific situation or perspective of Turkish Berliners with diabetes. Indeed “monitoring diabetes” is a practice that I would suggest is close to many diabetes patients’ experience. Following Porter’s observation, however, my research participants’ striving for a means of communication becomes even more significant – or at least more obvious – in its local and social significance, as they struggled with the language of their healthcare system irrespective of the discrepancies between lay and expert jargon. In any Turkish-German communication that might be lost in translation, numbers can alleviate such barriers. Numbers do not require language proficiency or rather a different kind of language proficiency that is at least less complex than the elaborate words that exist in each language in order to express well-being, illness or suffering. An abstraction of illness experience can therefore also be seen as a simplification of complex lived experience. Inasmuch as diabetes is an elusive illness of blurred states of health and sickness, experiencing it would be hard to put in words (in any language), and reducing them to a numeric concept is an easy way around this communication problem. Communication here can of course also mean towards themselves, giving meaning to their experience in clear, unemotional and manageable terms.

#### *Abstract numbers in practice*

Therefore, “management by numbers” is more than the clinical strategy of diabetes care but can be part of individual day-to-day practices of diabetes control. Numbers are thus more than abstract entities but can be actually very practical. In fact, a dichotomy of the abstract and the practical, numbers and lived experience, would not serve us well to understand why the self-help group members use abstraction as an everyday practice. Numbers that refer to levels of blood glucose and diabetes control are not only ways of communicating or grasping their illness experience but numbers provide the necessary parameters against which they can measure their day-to-day practices of diabetes control. As much easier as it was to my research participants to

communicate “how their diabetes was doing” in a simple number (“my HbA1c is 7.2”), they could also keep control over their progress of diabetes management, if a new diet reaped the desired outcome or if an indulgent weekend was a set-back.

The self-help group would recount a number of success stories of group members that transformed from ignorant to “expert diabetic”, a transformation that was expressed in HbA1c levels. I could witness one such story myself. I joined the group in January at about the same time when Ahmet, a forty-three year old mechanic, became a member together with his wife Banu. Ahmet had been living with diabetes for four years when Banu read a leaflet advertising the group at the local job centre and got in contact with Yılmaz. She was worried that Ahmet’s diabetes control was not going well – mostly as he was not taking his medication regularly. Yılmaz inquired about her husband’s blood glucose and cholesterol levels to get an idea of the “gravity” of his diabetes, gave initial advice on diet and exercise and insisted that they should come and attend his group seminars. It had taken months of persuasion by Banu but finally the two joined the group and quickly became regulars who also helped actively organising group events. I was first invited to their home in March when Ahmet was telling me about his strict vegetarian diet his wife had put him on. His glucose levels, however, were still on the higher end of the scale with an HbA1c of 13, as he told me with slight embarrassment. (From field notes 28.03.2007) What was striking to me was that both Ahmet and Banu had already understood and adopted the significance of (expressing themselves in terms of) HbA1c. Only four months later in early July, during the self-help group’s last session before their summer break, I shared the back row of the lecture hall with Ahmet. Like me he had become a regular attendee of the group meetings and that day he leaned over to tell me proudly: “Guess what, my HbA1c is 6.1!” (Field notes 07.07.2007) His astounding achievement (any diabetologist would agree, I am certain) was later discussed in the group, and also retold to me (“Have you heard about Ahmet’s latest HbA1c?”) during many visits of group members during the following months.

These tactical practices will be further explored in Chapter 6. Of interest here is the practical utility of clinical measures. Moreover, numbers may be abstract but they are far from being neutral but enable normative comparison. Numbers can thus

have arbitrary and moral connotations and create conflict, as another incident during my fieldwork, which I will briefly describe, will demonstrate (from field notes 23.05.2007). I went to see my friend Rana before she was off to Turkey for the rest of the summer. She had not been attending the self-help group sessions for quite a while and I was wondering what was keeping her. Her grandson had been ill but she would usually try to make herself available for Saturday afternoons. To my surprise she told me that she decided not to attend the self-help group anymore. She was about to leave Berlin for a couple of months anyway for her yearly stay in Turkey and she would see after that. I was curious to find out what had happened and she admitted that it was about the group leader Yılmaz. She explained that she felt bullied by him – admitting that she was quite a vocal person who might have rubbed him the wrong way. She recalled several occasions when she had shared her experience with the group when such advice seemed to have been not quite as much appreciated by Yılmaz. The greatest dispute was about the pricy test strips for the blood glucose meters. She got hers prescribed and covered by her state health insurance after she had attended a patient education module with her diabetologist. Yılmaz, however, insisted that she must be wrong and that only patients on insulin would get the test strips for free. (Incidentally, the self-help group sold test strips themselves – announcing the latest monthly bargain on the blackboard before the session began.) I must admit that I was also told by many doctors and diabetes assistants that test strips are only covered by health insurances if prescribed to insulin injectors, but there seemed to be a clear conflict of interests fuelling the row between Yılmaz and Rana. Rana went on telling me that he was bullying her by having repeatedly publicly announced her HbA1c as 8 rather than her actual 6.something. These public announcements of HbA1c levels were usually an opportunity to praise somebody's great achievement and poor levels were only mentioned in connection to their succeeding remarkable improvement. Rana was so hurt by Yılmaz's constant misrepresentation that she was turning her back to the group – at least for now, as she was heading to her holiday home at the Aegean coast.

In conclusion, my research participants learned that diabetes patients need to know blood-glucose levels, blood pressure and cholesterol levels. Being able to read the

clinical numeric expressions of their blood tests, they could identify how their diabetes “was doing” in comparison to standard tables. Far from being an impractical exercise, I would argue that my research participants embraced such number games for various reasons and intentions. Turning the – often bothersome – experience of illness into a number can be a form of coping and distancing. Rendering a deeply intimate and elusive experience into an impersonal abstraction, enables, furthermore, to communicate it safely in public without exposing too vulnerable sentiments.

This numeric form of communication seemed to be also a way of entering clinical consultations on a much more equal basis. Rana, for example, did not only make negative experiences with number such as the above mentioned quarrel with Yılmaz. Her knowledge of clinical parameters fostered a very good relationship with her doctor. While I did not accompany her on consultation she would tell me afterwards how it had gone. One day she told me how they had assessed her recent diabetes control together – looking at her readings that she had documented in her diabetes pass – and decided to reduce her medication to one tablet a day (from field notes 12.03.2007). I did not doubt that Rana would embrace this challenge of getting her diet and exercise in line with this reduced drug therapy, but I was surprised by the collaborative consultations between the German doctor and Rana with her usually shy and reluctant German. In the case of the Turkish Berliners in the self-help group, their knowledge in clinical parameters seemed to help bypassing communication difficulties that might arise from language barriers.

This shows that seemingly abstract entities can have very “local”, concrete implications. Numbers, that might represent universality, objectivity and abstraction, can thus be local but also moral and create conflict. This is as making experience comparable allows for normative comparison. Numbers are certainly practical. Diabetes is not only difficult to express but often difficult to experience as variations in blood glucose levels can go unnoticed to the patient. They can serve as points of reference to evaluate both practices of diabetes control and the diabetes itself. This “making visible” of diabetes will be further explored in the next subchapter. Here was discussed that the numbers in the lives of diabetes patients can be abstract, distancing, quantifying and communicative, as well as localised, moralising, individual and practical exercises.

## 5.2 Watching diabetes

The most frequent and personal involvement with numbers is the daily self-monitoring of blood glucose levels with meters. Self-testing is taught in diabetes patient educations as it is encouraged in the German Diabetes Union's evidence-based guidelines (Herpertz et al. 2003). All diabetes patients I spoke to owned meters, and all my research participants used them with great enthusiasm. Meters are usually handed out for free by doctors who are – as they told me – swamped by these gadgets by drug companies. Blood glucose meters are a big industry and money is made by selling the expensive test-strips (that are only covered by the health insurance for insulin users). The more people test, the more money is made.

While I am writing this chapter, news headlines report “Diabetes self-tests ‘no benefit’”, following the publication of a study that also suggested that self-monitoring might even lead to more anxieties and depression in patients (BBC News 2008). That self-monitoring is not necessarily a reassuring exercise I witnessed at the following late lunch with Feyza (from field notes 27.08.2007). While we were waiting for a chicken to be done, which was slowly roasting in the oven, Feyza checked her blood glucose levels. She brought two small bags that held her glucose meter and her insulin pen. First she opened the kit with the glucose meter (the make they hand out for free at the self-help group), the little cylindrical box with test strips and the lancet to prick her finger. After inserting a test strip into the meter, she pricked her finger at the side of the fingertip. “The finger-pricking is the worst about it”, she commented while I was watching her. “That really hurts. The insulin injection itself is fine. Don't feel a thing.” She squeezed her finger and held it to the test strip which sucked in the blood drop that had gathered at her fingertip. We waited a couple of seconds and both read the result at the same time. To our amazement, the reading was 178, a very high meter reading just before eating. Feyza had only eaten breakfast hours ago and had only eaten an apple for lunch, as she assured me. She should feel dizzy from low blood sugar levels. Marvelling why the reading would be so high, I tentatively suggested that her finger might not be clean. Feyza went off to wash her hands again, then repeated the procedure, pricking the

same finger again, using a new test strip, and waiting for the result. The new meter reading was even higher: 185. We both struggled to find an explanation for the miraculous increase in blood glucose over these couple of minutes of measuring and started wondering if the test strips might be faulty. Aside from the odd test variation, we could not explain why it would be that high in the first place, considering the quite modest diet Feyza had had that day. Feyza suggested that the explanation could be stress, as a friend had once told her that stress can cause and worsen high blood glucose levels. We both agreed that she certainly had a stressful day today but were not convinced or satisfied with our speculations. As the general advice is to stay to one's usual dosage of insulin, Feyza simply got her insulin pen ready with the usual dosage. In the other black bag was her quite stylish looking red insulin pen and she twisted the middle of the pen to the right dose of insulin. Holding her T-shirt up she took a skin fold of her large belly and very slowly injected the pen.

In the above case, the test results were unsettling, and without professional advice at hand it can be a daunting decision as to what to do next. Feyza's problem illustrates the tension between the out-of-control diabetic body and the attempt (with technological help) to conquer this unpredictability. Unfortunately, a test result, despite producing a static visual image, can sometimes merely visualise such unpredictability.

### *Blood glucose self-testing*

Blood glucose meters are small devices a little bigger than mobile phones. There are various brands and each (drug) company sports its own product range. The simplest devices provide only the basic function. A test strip is inserted at the bottom of the gadget, a drop of blood is produced with the finger pricking device and lancet and is applied on the strip. Seconds later the usually large and easy to read display shows the reading. Differences between makes or brands seem to be often a mere design choice; however, some store meter readings, others even can be connected to a computer to transfer these readings into medical files. Older meters need to be calibrated or coded to each batch of test strips.

In the case of most of my research participants, preference to make or brand was mainly determined by supply (although meters are very cheap now with prices

starting around EUR 10). The self-help group was well supplied through the drug rep (of a major drug company) that sponsored community events and helped out at group meetings. The distribution of free glucose meters have always been part of the self-help group's recruitment strategy. At the big community information events they were giving out vouchers for meters that can be collected if attending one of the small self-help group gatherings and signing up as a new member. The vouchers always proved to be extremely popular and self-help group meetings after such events burst at the seams because of all the new arrivals. (And the drug rep's booth at each community event that offered free glucose testing was clearly the most popular and crowded attraction.) I also discovered that the group regulars had a whole bunch of these meters at home, often sitting untouched on shelves while some were brought to family and friends in Turkey. Some of my research participants simply continued using their old meters that had been given to them by their doctor or that they had initially bought themselves. They preferred them to the brand given by the group because they were used to them, or because their display was considered easier to read. Drug companies seem to be very interested in untangling these consumer choices, and I had the offer of one company to get part of my research funded if I were to investigate how Turkish migrant diabetics liked especially (or especially liked) their products (cf. Mol 2008, on glucose meters and consumer choice).

Blood glucose meters are relatively easy to use. The self-help group followed each handing out of free meters with a little "how-to"-session that would explain the fairly straight forward procedure. (The challenge is to be able to read and understand the result as the last subchapter explored.) However, many of the patients I talked to described glucose testing as a very painful practice, pricking your sensitive finger tips often several times a day. As with injecting insulin (a procedure that is often perceived as much less painful), injection or pricking sites should be rotated to allow for healing yet this also spread the number of sore areas. Still, the self-help group members seemed to self-test religiously, even if many were not insulin users and therefore there was no medical indication to self-test daily (and consequently no health insurance coverage for the pricy test strips). Even if daily self-testing was not directly indicated from a clinical point of view, patients were nonetheless animated to keep a close watch on their diabetes, monitor its progress and ups and downs.

Glucose meters seem to be the easiest and most instant way of achieving this. As mentioned in the previous subchapter, patients are encouraged to experience their illness in clinical terms. Frequent check-ups, not only on blood glucose, hypertension and cholesterol but also on eye and vascular health, kidney and heart function, are additional – and more professional-led – forms of testing. To add another example to the previously discussed ones, intraocular (eye) pressure (measured in mmHg like hypertension) becomes the indicator for the likelihood of future sight loss and blindness. Health or sickness status is assessed, converted and articulated as laboratory concept.

### *The clinical gaze at home*

Insofar as tests and their numeric expression of cholesterol, blood pressure and blood glucose levels aim to control for such complications, blood glucose self-monitoring can be understood as the easiest method to achieve this. Making the hidden illness diabetes (and high cholesterol and hypertension) visible becomes part of discipline of diabetes control. As diabetes control is not only fairly free of visible signs and symptoms but also not confinable to clinical spaces and therefore undertaken by the patients themselves in their private homes, medicine has an interest in surveying these individual illness managements and standardise such personal experience to fit standardised medical knowledge. Laboratories produce letters that state latest test results; family doctors' patient files hold such records to be retrieved for each consultation; and patients are encouraged to habitually record their blood levels in their "diabetes diaries" (DDG 2008). Blood glucose self-monitoring could thus be explored as an extended clinical reach into private homes.

This close laboratorial gaze, not even on the patients themselves but on their selected organs and in particular their blood, invites reference to Illich (1976: 47 and 129) who suggested (among others) that medical science and practice increasingly redefines aspects of social life in need of medical attention and reconstitutes every person as "a patient in some respect". Illich (1976: 97) observed that ordinary people had increasingly become subjects of "maintenance" practices, and that this "medicalization of prevention" was quite an international phenomenon as the word

‘check-ups’ entered various non-English dictionaries<sup>27</sup>. Screening and clinical tests increasingly aimed to detect signs for hidden illness and ultimately control or even prevent future complications, disease and early death (Lupton 1994: 106ff). People living with diabetes indeed expressed their feelings of being medicalised to me, that their bodies had become sites of constant investigation that report about overall health within a framework of risk and danger. Every meal becomes a clinical encounter – not with a health professional but with a clinical technology, the glucose meter (and the insulin pen).

Illich wrote in the aftermath of Foucault’s *Birth of the Clinic* (1986) in which the historic development of such modern “clinical gaze” on the human body was first described. Modern medicine and its technologies strives to “gaze into the sick body” in order to experience and thus understand and master sickness (ibid. 137). Foucault’s (1991a [1975]) later work on surveillance echoed this idea of an institutionalised interest in illuminating, objectifying and disciplining ordinary persons and their bodies. Extending this surveillance into the private homes of diabetics, just as Foucault (1991a [1975]) suggests that the power of discipline is internalised by the disciplined, blurs boundaries of the clinical and private.

However, blood glucose self-testing does not necessarily represent clinical interests as it may be suggested here, and the notion of the “clinical gaze” may not help understanding what is going on. While guidelines still contain self-testing as a recommendation (Herpertz et al. 2003; IDF 2005), recent reviews of the evidence base found no benefit of regular self-testing (e.g. IQWiG 2009). There is resistance to such findings, though, as the German Diabetes Union quickly issued a statement in response to IQWiG’s discouragement of self-testing (DDG 2009). In their response they highlighted that even the Global Guidelines (IDF 2005) still recommend regular self-testing for its benefits for all people with diabetes to assess their lifestyle-based self-management efforts. This may explain why my research participants were still encouraged to self-test by doctors and the self-help group. This controversy may, of course, be fuelled by multiple motives. Chapter 8.2 will look into what may lie

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<sup>27</sup> In the German dictionary ‘*Check-up*’ is explained as a ‘thorough medical examination’. In the Turkish dictionary I found it under the letter ç where ‘*çekap*’ (same pronunciation) refers to a ‘general health examination’.

beneath this, as there are obvious economic interests within the big business that is self-testing.

However, some of my research participants indeed experienced their self-testing efforts as Foucault's clinical gaze (from field notes 16.07.2007). I met Feyza after she returned from her stay in Turkey. Showing me her diabetes insulin diary, I could see that, during her weeks in Turkey, she had only measured her glucose levels in the morning – compared to the three-times-a-day figures in the rest of the diary. She was worried that her doctor would not approve of her lax monitoring, and guessed that her levels were much worse. She had not only stopped measuring regularly (“Because I couldn't be bothered, was fed up with it”), but had also eaten far more than usual (“Eating too much fruit. Apricots, plums – as big as fists, imagine! Not genetically modified! Cherries, whole buckets full of.”) and food cooked by other people. Feyza was clearly worried about what her doctor would say, more so than wondering about her diabetes and personal well-being. In Foucault's (1991a [1975]) terms, is blood sugar self-testing thus merely the internalised aspiration to monitor and control one's body according to clinical guidelines?

*Appropriating the clinical gaze: visualising uncertainty*

I propose to shift attention from the institutional clinical intentions to the individual motivation and perception of the patient, following Foucault's shift from “docile bodies” (1991a [1975]) to “caring selves” (1990 [1984]). Instead of understanding glucose self-testing in terms of bringing the clinical gaze into the private – in particular, as recommendations given to the patients may have less to do with clinical evidence base than financial viability – I am much more interested in as to why my research participants adopted self-testing so extensively. I have argued in the previous subchapter on numbers that it might be, in fact, a kind of coping strategy to turn the personal experience with illness outside the private and emotional realm into a meter reading that can be recorded and filed away. Here, it is important to note that diabetic bodies are out of control and unpredictable, and such uncertainties are fluent and invisible. Mol and Law (2004: 56) describe vividly what “plagues the body living with diabetes: the tension between control and capriciousness”:

However many calculations one makes, one's blood sugar level will still behave erratically. However successfully one's life may be under control it

still throws up distressing surprises. Modern diabetes treatment demands that patients consistently keep count of verifying about their bodies, even if it appears in the process that those bodies cannot be counted on.

I argue that a meter reading can be the attempt to turn diabetes into a visual and for the moment static entity. From a clinical perspective, this visualisation is an assessment exercise, checking on the treatment efficacy or disease progress. Patients seem to have another motivation, that of making their illness experience more predictable, and being more aware of the illness's status. The glucose meter is the required gadget to do so, the necessary technology that produces static numbers and renders experience more tangible and predictable.

Returning to my lunch with Feyza, she told me about an episode that happened in Turkey, when she was glad that she did after all measure her blood sugar levels every now and then (from field notes 16.07.2007). She had measured her glucose levels one morning before injecting insulin and was frightened to see how high it was, considering that it should be quite low morning levels. Struggling to know how to react and what to do she called Yılmaz in Germany. Yılmaz immediately guessed that she must have been eating a little bit too much lately – which apparently is quite common during holidays. She admitted that she was not watching her diet quite as closely as she does in Germany and Yılmaz recommended adjusting her insulin dosage to her changed diet. He urged her to be very careful but to raise the insulin dosage one unit. Feyza took the advice on board and got her diabetes under control again. (Field notes 27.08.2007)

Feyza's experience with blood glucose testing was clearly ambivalent. Perhaps her sentiment towards self-testing is best expressed as a necessary evil. She was on insulin and should ideally self-test before each insulin injection. On the one hand, she did not feel very positive about glucose monitoring but experienced it as a painful annoyance. Although disciplining herself quite routinely in the (German) everyday, she felt hassled to keep up the monitoring during her summer months in Turkey. Not only did she ease up on the frequency of testing there but also relax her otherwise quite closely watched diet. Most of my research participants with diabetes shared similar narratives with me. On the other hand, Feyza appreciated that self-testing could tell her how her body was doing. While knowing very well that her

lifestyle in Turkey upset her usual diabetes control, she nonetheless struggled to feel such changes herself. She anticipated worse diabetes control (as she told me earlier that she feared her doctor would tell her off), and still got worried to see bad test results. When I asked what she was most anxious about she explained that it was the fact that she could not “feel the diabetes”, elevated or low blood sugar, until it reached dangerous level. Testing made her aware of her failure to detect danger, but testing (on time) also helped avoiding or at least managing these risky states. Feyza’s main fear was a hypo<sup>28</sup>. The times she experienced a hypo, she felt dreadful and Yılmaz’ warning rang in her ears: “with too high sugar levels you might lose an organ, with too low blood sugar, it’s all over.” She told me about a phone call from her friend from the self-help group who had just told her that she had a hypo the other night. The family had eaten late in the afternoon and that happened to be the last meal of the day. She went to bed without having any extra food and woke up in the middle of the night shaking. She measured her blood glucose levels which were below 60. She quickly had some juice and recovered. Feyza was terrified to hear about this story and asked me: “Just imagine she wouldn’t have woken up.” (Field notes 16.07.2007)

Here, the glucose testing alleviated distress and evaded a dangerous situation. In other cases, of course, it is the meter reading that causes the worry, as Feyza’s experience in Turkey showed. In that case, she had to call her self-help group to manage the circumstances that she was made aware of by her meter and her anxiety. Both cases demonstrate the conflicts that arise because diabetes management is done at home and patients are largely left alone to handle it. While the “clinical gaze” might be often perceived as intrusive, it might at other times be welcomed inasmuch it can offer “technical support” with a fairly lonely, often daunting and sometimes scary experience.

Michael Power (1997) explored our *Audit Society*’s affinity to practices of monitoring, checking and accountability. He traced how “methods of checking and

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<sup>28</sup> “Hypo” is the colloquial term for hypoglycaemia when blood glucose levels drop too low (for what body cells require). With a hypo patients can feel dizzy, sleepy, faint, have blurred vision, headaches or sweat. If untreated, i.e. without a sugar boost, e.g. a glass of coke, hypos can lead to coma and death. In any case a hypo is a very unpleasant experience that takes a long time to recover from and was much feared by all my research participants.

verification” occur in situations of doubt and danger (Power 1997: 1). In his view, monitoring is a form of risk management and often perceived as a “risk reduction practice” (ibid. 5). Given that audits, practices of checking, however, are to a great extent formalised, they are often merely “cosmetic practices” which hide real risk (ibid. 123). Accordingly, risk management for my research participants might not necessarily mean avoiding risk but rather that the practice itself appeases anxieties over lurking risks. While the Foucauldian idea of surveillance is concerned with the clinical intention of accountability and discipline, the patients’ experience could be better understood in these terms of surveillance as risk management. Yet risk is, of course, an institutionalised concept with public health being a forerunner that enthusiastically embraces the notion of risk (Gabe 1995; Lupton 1994). Epidemiology lists, predicts, estimates, factors in or controls for a whole range of risks to our health. One group of identified risks are inaccessible, environmental risks such as air pollution or biological risks such as family history and genetic susceptibility (Lupton 1994: 35). Public health interventions and biomedical prevention models often focus on those risks that can be known and avoided, “risks of self-destruction” such as lifestyle choices of smoking, unsafe sex and unhealthy diets that can be abstained from (Lane 1995: 54). However, risk is clearly not only an institutional, political concept but also an individual sentiment (Beck 1992; Gabe 1995), one that was at times very immediately experienced by my research participants, for example when managing hyper or hypo blood sugar. Power (1997: 139) pointed out that while risk management is socially constructed, risks “are real and affect individuals in tangible ways”. Here it might help to distinguish risk and danger, with risk merely alluding to the possibility of danger. Carter (1995: 135) considered danger as a definite state of peril, whereas “the idea of risk is multifaceted, or Janus-faced, because it simultaneously points toward to the possibilities of security and insecurity”. This describes, in our case, also very well the ambivalence my research participants expressed towards their self-testing. Living with diabetes means to live with uncertainty, bodies that are out of control and cannot simply be fixed but need to be managed in some way. On the one hand, glucose self-monitoring is a tool to avoid and manage the danger these ill bodies can

cause and calculate risk; on the other hand, self-testing can itself create anxieties and uncertain situations that were otherwise undetected.

Meters are therefore more than an artefact, more than the mere technology to check on diabetes and support the “number game”. Meters are sometimes trusted companions that provided such securities and sometimes loathed reminders of chronic, continuous illness. It could be argued that these objects of clinical testing are also subjects that possess agency to shape the experience with diabetes. The agency of objects is, for example, recognised in Latour’s (1987) Actor Network Theory approach to exploring complex networks by including objects (technologies, products) as actors for a more complete understanding of social relations and lives. Meters define and negotiate the social spaces of danger and risk created by low or high blood sugar levels. They provide both security and insecurity. On another level they become incentives to attend information events or to become members of the self-help group. For many, being handed a glucose meter is the first tangible feature of diabetes self-management and the only remainder of “professional” support once home from patient education session, nutrition classes or self-help group meetings.

Summing up, my research participants were all encouraged by both health professionals and the self-help group to frequently measure their blood sugar levels. Meters were handed to them by the group, their doctors or were purchased by themselves as one of their first active engagement with their illness. Although self-testing is only fully covered by health insurances and recommended to those who were taking insulin, it was common practice of all my patient informants. Glucose meters were often considered a painful nuisance and could be understood in Foucault’s (1986, 1991a [1975]) ideas of the “clinical gaze” intruding people’s personal illness management practices as a form of “discipline” or “surveillance”. However, I would argue that patients are actively engaging with this exercise, adopting their own clinical gaze in order to make diabetes visible. Here, Foucault’s “technologies of the self” (1990 [1984], 1997) might serve better to understand such active engagement that serves a purpose independent of clinical (institutional) interests. “Docile bodies”, here are clearly replaced by engaged selves that try to challenge uncertainty. Yet I would propose that their motivation of self-care lied foremost in the lived experience of diabetes, emotional anxieties and embodied pains

rather than a moral economy of diabetes control. Meters helped my research participants to make sense of their diabetes, and as poor diabetes control was only physically experienced at already very dangerous levels (close to hypo- or hyperglycaemia), meters could negotiate risk and reduce anxieties. They were daily companions who supported the often very illusive practice of controlling diabetes. Making diabetes visible and tangible, however, was perceived as both comforting and distressing at times. Finally, insofar as patients assert their own agency on self-testing, one could equally presume agency to the technology itself. The simple testing gadget is an integral subject in the encounter with diabetes that transforms diabetes into a more concrete, visible experience. In any case, blood glucose self-monitoring makes diabetes “manoeuvrable”.

### *Conclusion*

This chapter on monitoring diabetes tried to untangle some of the clinical aspects of living with diabetes. As diabetes self-management is confined to the idiosyncratic private spaces and practices of patients, clinical measures and their numeric expressions of blood glucose testing (as well as blood pressure testing and to some extent cholesterol measures and other check-ups) are means to extend the medical reach. This might be a complex story that has less to do with authority over clinical surveillance and more perhaps economic motives. My focus in this chapter, however, was not so much on the underlying mechanisms of encouraging self-testing but on the patients’ motivation and involvement. I regard this not as a matter of “black boxing” biomedicine, the efficacy of such procedures or the political agenda behind interventions. Rather, in my opinion it is not as interesting to investigate clinical intentions as it is to explore the individual, personal motivations of patients to adopt such practices and gadgets. After all such technologies could be resisted (as it is often done in the case of drugs that are unchallenged prescribed but dumped instead of taken)<sup>29</sup>. Also, I am not discarding Foucault’s notion of a discipline of surveying and monitoring diabetes status and progress, but using them to look at patients’

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<sup>29</sup> Several of my research participants admitted to have frequently not taken medication they got prescribed. Common concerns were unwanted side-effects that they read about or experienced (e.g. Rana and hair loss with cholesterol medication, field notes 03.02.2007).

agency and objectives in such practices. I show that a clinical practice can be appropriated by those whose bodies are gazed at. I suggest that this follows two motivations. First, objectifying their diabetic bodies with abstract numbers is a tactic to make their illness experience more tangible or sharable. Second, watching and monitoring through blood sugar self-testing aims to make their diabetic bodies more predictable. On a final note, in this chapter, it is more fruitful to give up on trying separating the clinical from private, the professional from expert, or the abstract from the practical. Tests and numbers can be regarded as the link of knowledge and practice, as this chapter can link the previous one on the importance of “knowing diabetes” to the following chapter on “manoeuvring diabetes” with everyday practices of diabetes control.

## Chapter 6: Manoeuvring diabetes

This chapter is about the day-to-day practices of diabetes control that are led and shaped by the knowledge and skills my research participants have acquired about diabetes, and that are assisted by and controlled for through regular monitoring. As in the case of “learning diabetes” and “monitoring diabetes”, the focus should be on the practical engagement with their diabetes control that is not merely an enactment of learnt and internalised biomedical “healthy living”-strategies but that follows individual motivations and experience. As I see such practices as ways of making experience and expectations (of managing one’s diabetes) habitable, I borrow de Certeau’s (1984) notion of everyday practices of ordinary people as “tactics”, as opposed to institutionally structured and dominating “strategies”.

In order to explore such tactics, this chapter will examine “fasting and feasting”, tracing how (mostly female) patients negotiate their diets, implement health recommendations into their and sometimes their families’ diets, elaborately amend recipes, and deal with the sociality of food and food practices. This chapter will also look more generally at how diabetes control is a decisive yet only partial aspect in their social lives, but how these complex social lives can be negotiated through diabetes control. Finally, this chapter should discuss my research participants’ motivation for handling their diabetes the way they do and their perception of a “good life”. I suggest that not only are their views on what constitutes a “good life” challenged by their experience of living with diabetes, but that our preconceptions of what could be considered a “good life” might require a different perspective. (Quite uncritical) assumptions in critical medical anthropology that public health’s “healthy living” stands in automatic opposition to what we might regard as “good life” has only little relevance to my research participants’ lives. “Good” might in fact be the same as “healthy”, or rather “indulgence” might take a back seat in handling major complications of a serious illness (cf. Mol 2008).

## 6.1 Fasting and feasting

While numbers and their prevalence in the everyday speech of my research participants were surely a peculiarity for me, another much more ordinary practice of diabetes control dominated my ethnographic exploration. Central to the social lives of diabetes is food.

### *Diabetes and diet*

Diabetes is a metabolic illness that is intrinsically linked to food consumption and digestion. Eating is the reason for digressing health, and it is the most effective way of controlling diabetes. Insulin and oral medication have never replaced nutrition as the main therapy of diabetes, while a strict diet can sometimes substitute any form of clinical intervention. Although type 2 diabetes is strongly linked to genetic causation, it is nutrition that can trigger, delay or altogether prevent the onset of diabetes. For many patients diet represented the epiphany of “suffering” from diabetes (with the diagnosis expressed as a life sentence of no more puddings). Both in German and Turkish, diabetes is colloquially known as “sugar” (German: *Zucker*, Turkish: *şeker*). A diabetes consultant explained to me that along with the notion that people “have sugar” come “lay beliefs” that diabetes is caused by eating too much sugar and that the diagnosis of diabetes means the end to all sweets and puddings. Therefore any new patient must learn about the glucose cycle, pancreas and insulin and how its malfunction causes diabetes. Key is that people learn about the benefits of sugar in their blood, that it is about the balance of glucose in their blood stream not the absence and that the body needs to adequately process sugar in order to aid rather than harm their organs.

Dietary advice thus occupies centre stage in patient education sessions, self-help group meetings, TV health programmes and community events. The importance of diet is even more significant as for many people – and this certainly applies to my research participants – food has always been a very important part of their daily lives. Food can be comfort, connect to a distant home or bring families together at one table that might lead otherwise separate lives. Food is also the social glue and vehicle between friends, neighbours, a “community” or group. Social events are

marked with certain foods and food practices. Food and diet means cooking, offering and eating, as much as creating, sharing and sensing.

Therefore, an illness that fundamentally alters the experience of food and food consumption equally exerts its authority on social life in general. Diabetes becomes an ever-occurring state that cannot be forgotten, especially not in circumstances when people tend to get a break from such affliction, as in the company of family or friends, at joyful occasions or in the routine of everyday monotony. With diabetes every meal and snack gains significance and negotiating the “adequate” diet is truly in the hands of the patient. I could follow the members of the self-help group as they were changing their Turkish meals along standards that turned them into somewhat oddly more German diets, substituting feta cheese with cottage cheese, white pita bread with brown whole-grain bread (much liked in Germany). That said, there was much emphasis placed on the so-called Mediterranean diet (lots of fresh fruit and vegetables, olive oil), often aimed to highlight the positive and conducive elements of “migrant diets” instead of the ever-cited healthcare challenges such as illiteracy, smoking or obesity rates. I learned fairly quickly at the self-help group, however, that a Mediterranean diet did not necessarily equal as a “Turkish diet”, as the vast country boasts various cooking traditions, with East Anatolian cuisine using much more butterfat than olive oil, stews and sauces in contrast to the grilled dishes and fresh vegetables of the Aegean coast.

Experienced self-help group members had detailed knowledge of diet and the effect of particular foods on their blood glucose, cholesterol and blood pressure levels. They knew that a special diabetic diet is not recommended anymore but people living with diabetes should make a conscious effort to eat healthily and in moderation, avoiding fatty and salty food and choosing high-fibre carbohydrates<sup>30</sup>. They learned that there are three major nutrients: carbohydrates (which should account for 60 to 65 per cent of the daily diet), fats (10 to 15 per cent) and proteins (20 to 25 per cent). People with diabetes have to pay particular attention to

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<sup>30</sup> Information given in this section on nutrition is taken from my field notes and other material I was given during my participant observation with the self-help group, patient education sessions and other patient information events.

carbohydrates and fats, and learning about various foods and their properties is a central feature of both self-help group sessions and patient education modules. Carbohydrates such as fruit and vegetables, starchy foods such as pasta, rice and bread and dairy products are the most important components of a healthy diet as they are the major energy resource for our cells. Carbohydrates are responsible for elevating blood glucose levels and diabetes patients with insulin resistance or defective insulin production – the hormone that is essential to transport the glucose into the cells – are taught that there are slow and fast energy-releasing carbohydrates. Rather than avoiding carbohydrates it is important to know which carbohydrates release glucose slowly, e.g. fibre-rich starchy foods such as brown rice and al-dente pasta, and whole-meal bread (so the insulin can keep up with its ‘processing’), and which carbohydrates elevate glucose levels fast, such as sugar and white bread, rice etc. A general rule of thumb is to favour high-fibre carbohydrates in daily diet.

Having said this, the self-help group (and family doctors’ patient education sessions I sat in) taught a closer monitoring of carbohydrate consumption: how to count bread units (*ekmek einheiten*<sup>31</sup>). The concept is a bit outdated – instead recommending a balanced diet rather than meticulously watching each gram of bread or pasta – but bread units are still taught in Germany and often considered a useful part of a diabetes conscious diet especially for those injecting insulin. The regular members had a weekly routine of identifying that one bread unit amounts to 30 grams of whole-meal bread (*volkorn ekme*<sup>32</sup>) but only 25 grams of white bread (*beyaz ekme*). Yılmaz would usually accompany this routine with the drawing of two graphs on the blackboard, showing how blood glucose levels shoot up to an immediate high peak when eating white bread whereas the curve of slow-energy releasing high-fibre brown bread only raises slowly and levels quickly and low. As dietary advice is so central to each self-help group session it was quite repetitive but this repetitiveness constituted an important part of learning.

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<sup>31</sup> This commonly used term is a combination of the Turkish word for ‘bread’, *ekmek*, and the German for ‘units’, *Einheiten*. Berliners’ Turkish knows many such hybrid words; see also the next footnote.

<sup>32</sup> *Beyaz* is Turkish for ‘white’, *volkorn* is derived from the German *Vollkorn* for ‘whole-meal’ as Turkish bread is usually white wheat pita bread.

### *Eating at home: varied diet disciplines*

The way the self-help group was placing emphasis on the rigour in which nutrition should be approached as a person with diabetes, it seemed compelling to explore how this translated into everyday practices. The following paragraphs will specifically look at the relevance of the amount of food, type of food and patterns of everyday eating for my research participants. Comparing “what is said” and “what is done”, as a prime anthropological interest, proved an apparent exercise as food was both central in the teaching and learning process of diabetes management and the social lives of these students of diabetes control. Meeting my diabetic research participants in their homes always involved food, being offered snacks – mostly a selection of fruit, nuts, biscuits and crisps with Turkish tea or coffee, later followed by lunch or dinner depending on the hour and length of my visit. I learned that the amount of food is not only crucial in a diabetic diet but also in Turkish eating. Food was always offered in abundance, and second, third or fourth helpings were common and often inescapable. This generosity seemed often in stark contrast to the limited portion sizes that my diabetic hosts would allow themselves. They all seemed to follow the same tactic of clearing their plate to the kitchen as soon as they had finished their meal. This shows the tension between their diabetes control practices and the value of hospitality (*konukseverlik, misafirperverlik*) in their social lives.

One evening having dinner at Hilal’s, the patient consultant, this paradox became even more apparent to me. We were chatting about Turkish hospitality which she considered both a virtue and a strain. She explained to me that for her hospitality was not only the duty of a “good” Turkish host but placed similar obligation on the guest as a “good” guest should be grateful and accepting what is on offer. She thus regarded hospitality to be very burdensome at times and a recurring site of conflict with her mother in Turkey. During her frequent visits to her parents in Turkey, Hilal very much enjoyed her birth place’s warm reception, sociality, and not the least the lavish and manifold food. Yet time and again, she got irritated when she was forced by her mother into eating too much; “literally forced upon second helpings”, she would say, “as if I’m not grown up enough to know when I’m full”. I agreed with her that eating can become quite an unpleasant experience when pushed to overeat. And while agreeing with her, I could not help noticing that as soon as a plate of Turkish

pancakes, a bowl of salad, beans or olives became empty during our conversation she had discreetly refilled it. Despite discussing this very issue I felt too uncomfortable to turn down yet another helping. (Field notes 07.07.2007)

Similarly, the women of the self-help group grappled with such expectations towards both host and guest while reproducing such situations for others. Nonetheless they were very conscious of such contradictions while dishing out another helping. They would often voice their self-reflection by apologising for the difference in portion size between them and their guests that they after all “were not allowed to eat more” and that I “as a non-diabetic could eat more”. Most striking for me was Yılmaz’s frequent mission to address such tensions and to make his group challenge some of these social values they had grown up with, especially in regards to Turkish norms of hospitality. While it was difficult to turn down second helpings, even in a “diabetic” household, even worse was to enquire before arriving if, what kind of, and most crucially at what time food will be served. Insulin-injecting diabetics, especially, ideally need to know this information but even the “pros” of the group found it excruciating to have to telephone and ask, as Yılmaz suggested.

Aside from the amount of food, the type of food differed depending on setting, occasion and company. While some women would only amend their own diet, for example choosing whole-meal bread while serving the rest of the family *pide*<sup>33</sup> bread, other women would make a point that they were amending the whole family’s diet (sometimes as they felt several family members were a bit chubby and could do with a change in diet if diabetes ran in the family, or as other family members also had diabetes). During the months I was attending the self-help group food had also become the main fundraising activity of the self-help group as some women started selling snacks and drinks at the community events, and at any self-help group meeting women brought along food to share with everyone. Snacks sold at these community events were purposely healthy: whole-meal rolls with low-fat and low-salt fillings of vegetable, salad and cottage cheese, water, and sweetener for tea and coffee. Although they knew that many people attending would not live with diabetes, the group decided against offering sugar, or more typical Turkish snacks such as *börek* (filled pasties).

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<sup>33</sup> *Pide* is the Turkish version of the Arabic *pita*, white flatbread.

The women of the self-help group had gathered a wealth of dietary advice to make such healthy choices. Their recently acquired knowledge stood not in abstract isolation but was met with their wealth of practical knowledge and skills of food and cooking. Rana was an experienced cook who enjoyed cooking and baking for her family and friends and trying out what she heard in group meetings. For example, she followed the group's latest craze: spelt flour. Someone had read about its great slow energy-releasing qualities that make it ideal for people with diabetes. After heated discussion during several group meetings (including that you can get the flour very cheaply at the discount supermarket *Penny* not only at expensive organic shops) and several tastings (when women brought in experimental test spelt cakes), many have changed to using spelt flour as their wholemeal flour for homemade breads and cakes. Enjoying one of Rana's cakes at her home, she explained to me that she had also made it with fructose. The apple cake looked like a very German cake and she explained that she used spelt flour. "I don't even like wheat flour anymore." Wondering if her family was fine by that and she answered that everyone ate what she had put on the table. Her grandchild complained though because she used to make Tiramisu for dessert. The dessert high in sugar and cholesterol was not made in her household anymore. (Field notes 23.05.2007)

Finally, there is the frequency or pattern of eating, that is important in a diabetes diet. The self-help group members not only abolished favourite dishes from their diet but also tried to keep meals and snacks very regular. This was often very contrary to their families' eating patterns insofar as they were eating small portions as breakfast, snack, lunch, snack, dinner, snack instead of the more Turkish way of a late breakfast and a large dinner as the two main meals of the day. At the self-help group meetings, people would take along fruit and everybody was equipped with a small bottle of water as they had learned the importance of regular snacks to steady glucose levels and to drink plenty of water. Someone had also always brought treats to share, often home-made cakes made from their latest recipe with substituted brown flour and fruit sugar, but also sweets such as diabetic chocolate which is not recommended as simply too expensive and not all that different to normal chocolate, but which is nonetheless liked by many in the group.

Having said this, healthy snacks had always been common in the Turkish households, though had to be amended to accommodate certain vigilance. For example, large fruit platters with bite-sized fruit pieces would grace many coffee tables and accompany friends' get-togethers or watching TV with family. People with diabetes, however, have to watch the amount of fruit they are eating as most fruit contain much sugar. Health professionals – and the self-help group – would therefore discourage such habits and recommend more accountable ways, in this case eating whole apples, oranges etc. Again, some of my research participants would take this fully on board and also offered guests whole pieces of fruit rather than an assortment of mouth-sized portions, while others decided to maintain the platters and resist the temptation of nibbling away alongside their family and guests.

All in all, the type of food, amount of food and pattern of eating raised tensions between the diabetic diet and the Turkish diet. Food and eating is an inherently social experience and practice and it is others, not necessarily individual motivation, that render a diabetes-conscious diet a challenging exercise. This exercise is nonetheless vigilantly pursued, following the recommendations of the self-help group.

In general, the self-help group did not represent a unified body of practices and opinions. Rana had changed her whole family's diet, although she pointed out that her husband had "perfect cholesterol levels, although he ate saturated fat wherever he could find it", and although she liked spoiling her beloved only grand-son. However, she chose not to observe her diet with too much rigour. Contrary to the self-help group's recommendation to count carbohydrates, she liked to trust her instinct and experience on how to balance her meals. Her group colleague Feyza took a similar relaxed approach on keeping track of carbohydrates, but she prepared slightly different meals for her husband and son than for herself. For example, she would serve *pide* bread to her family, while giving herself (and me as the German) whole-meal bread rolls.

Others, however, were very strict in their diet, for example 75-year-old Sadik who was famous for being very knowledgeable. He had digital scales to monitor his carbohydrates consumption (as advised by Yılmaz ) and he once brought them along

to accompany Yılmaz to one of his appearances on local Turkish-language TV and demonstrated to viewers how he would weigh his slices of bread or portions of rice. I was shown the footage of this TV programme but was never close enough to Sadık (nor most of the men of the group) to visit him at home and see if these scales were indeed part of his daily routines. He also seemed to be the only man in the group in charge of his own cooking as he lived alone as a widower.

Despite a certain liberty in what kind of food was eaten and with how much stringency, most self-help group members seemed disciplined in their food practices. That such discipline was not without dilemmas, for example in their social lives, and involved sacrifices, was often voiced. The following story particularly comes to mind. I was invited to meet a woman who was the neighbour of a self-help group member. She was not a member herself and her friend had told me that her diabetes was badly managed and that the poor suffered from severe complications. This had not always been the case, she told me when meeting her. She used to follow her husband's strict routines which he, a diabetic himself, had carefully devised in the last years of their marriage. However, after her husband had died she dropped his programme of diabetes control and told me she particularly enjoyed her lie-ins after being forced daily breakfasts at eight o'clock sharp for years. (Field notes 10.05.2007)

### *Theorising practices of discipline*

Previous research on diabetes such as Ferzacca's (2000: 28) study of compliance among diabetic patients in an U.S. Veteran clinic suggested that "diabetes management [...] focused on the cultivation of an ideal self whose 'technologies' and 'ethics of self-care' mimic a capitalist logic that links self discipline, productivity, and health". Ferzacca can be consigned to the ranks of social scientists who seek understanding of the workings of health politics, public health and healthcare practices – especially on such issues as obesity or healthy living – in "neo-liberalism". Indeed it seems seductive to focus on the hegemonic character of today's biomedicine that has partly abandoned its devoutness to medical technologies and magic bullets and shifted much emphasis to illness prevention, i.e. the population's responsibility of healthy lifestyles. Others seek explanation in Foucault's potent

concept of “bio-power” (1998 [1976]) and his later work on “self-care” (1990 [1984]) (cf. Peterson and Bunton 1997). Foucault conceptualised power as something coercive and persuasive, and suggested that medical authority exercised power over the patient through surveillance and emphasis on self-care and -discipline. Power is not purely exercised from above, the medical profession, but also reacted upon and internalised by the patient. Medical dominance thus exerts itself in everyday life (Foucault 1998 [1976]). His later work suggests a more moral economy of self-care (Foucault 1990 [1984]). Ferzacca (2000) indeed suggested that his data on diabetes management resonates only at first glance with the notion of bio-power. He explored how diabetic U.S. Veterans negotiated their self-care in quite conscious and individual idiosyncratic self-management practices – much like what I could observe during my own research. However, turning to an argument of neo-liberalism, he argued that such normative selves profoundly stemmed from an ideology of capitalist production that were shared by both clinicians and patients.

Yet, my research participants’ experience of handling of diabetes control seems to be only partially explained by notions such as Foucault’s sovereign “disciplines” (1991), bio-power (1998) or self-care (1990), or with capitalist efficiencies of neo-liberalism. I believe the story of my research participants – or rather of their day-to-day experiences – is not foremost a story of hegemony, dominance and oppression, or one of resistance, subversion or even (moral) conformism. True, the members of the diabetes self-help group absorbed medical knowledge on diabetes management (often quite uncritically) and effectively implemented it into their lives to achieve control over their illness. True, they were not “rebels” that resisted such prescriptions but devotedly baked spelt bread to replace their *pide* bread, substituted cottage cheese with feta. And yet I suggest that it would be a reductionist view to understand them as “victims” or “subordinates” who unconsciously buy into a medical hegemony that profoundly reshape their lives, replacing their ideas of “good lives” of *baklava*, *börek* and *kebab* with “healthy lives” of salads, brown bread and brisk daily walks.

They did they not blindly adopt recommendations but negotiated their utility in their daily lives. Every self-help group member found her own way of making sense and implementing recommendations into the everyday. While a lonely

widower who did not tend to cook his own meals for most of his life enjoyed the company and guidance of digital scales and formulated recipes, an experienced cook like Rana who had to negotiate the diet of partner, parents, children or grandchildren would handle nutritional advice in a very different way. Both practices, however, were following the same motivation of controlling diabetes and therefore improving well-being and using the experience of a certain diet's impact on their bodies as parameters to evaluate such practices.

This following story I was told in regard to exercise and diabetes control can illustrate such experiential tactics. Rana managed to lose lots of weight during the past two years – mainly through changing her diet – as I could see to my surprise when the lean petite woman showed me family photo albums that pictured a quite obese Rana over several decades of family outings and get-togethers. Although she used to like swimming and still walked quite a bit she was suffering from bad back pains when I first met her and she felt immobilised. Physical activity (*hareket*) is an important part of diabetes self-management. Exercising lowers blood glucose and cholesterol levels, helps losing weight, improves insulin resistance and blood circulation and generally less insulin is required. As many members of the self-help group share Rana's plight of skeletal complaints as well as a certain reluctance to take on sports, Yılmaz mainly recommends walking (*yürümek*). “*Yürümek, yürümek, yürümek!*”, was his mantra during each group session. Interestingly, Rana expressed her worries of losing even more weight, as she considered herself quite skinny now and she would at least like to keep her little pot belly not be all “skin and bones”. This aesthetic concern might add to her general unease with exercise and sports since she had developed back pains. Nonetheless she had experienced and routinely and effectively employed the immediate impact of physical exercise on her diabetes control. For example, some day she told me about the other night, when she had measured 240 mg/dl after dinner. She was really shocked and had reacted by exercising for an hour to get the blood glucose down, jumping around in the bedroom “like skipping rope, just without a rope, and my husband thought I'm crazy”, she giggled. But Rana's exercise had been very effective and levels were down to 130 after an hour. (Field notes 13.03. 2007)

Understanding Rana's motivation in terms of Ferzacca's moral economy of self-care seems hardly applicable. It would mean she was "buying into the capitalist health paradigm" of exercise as means to achieve disciplined and productive bodies, as for example suggested in Ritenbaugh's (1982) study on American middle class women's quest for slim bodies and her conclusion that obesity and its moral economy should be regarded a "culture-bound syndrome". Granted, far from appreciating the aesthetics of a slim body, Rana did nonetheless accept the therapeutic potential of exercise. Yet this appreciation followed the situational urgency and practicality of such exercise.

### *Bio-tactics of diabetes control*

In order to understand my research participants' ways of manoeuvring diabetes control, I borrow the term "tactics" from de Certeau's work on the *Everyday Practices of Life* (1984). De Certeau emphasised the agency of the ordinary person. For him consumption, for example, is not necessarily in opposition to production. Rather, the consumer, for example when reading a book, possesses as much creative agency by bringing it alive in his imagination as the person who wrote the book. De Certeau traced how ordinary people manoeuvre through ordinary situation of living, for example the work place or walking through urban spaces. He distinguished between "strategies" (here e.g. diabetes care plans), which are embedded in institution (e.g. the healthcare system), occupy fixed sites of operation (clinical spaces) and manifest themselves in products (information brochures, blood pressure and glucose meters), and "tactics" of the ordinary (patient) who make such strategies "habitable" to their lives (ibid. 34ff). In his approach, de Certeau clearly considers "tactics" as tools of the weak, as flexible and "unmapable" forms of subversion or resistance. I thus prefer de Certeau's concept to Foucault's moral self-care (1990 [1984]), as his idea of "technologies of the self" towards achieving freedom (Foucault 1997) seem to require a certain degree of being free. While Foucault's earlier ideas of bio-power (Foucault 1998 [1976]) feature the ill, the criminal, in short the marginal, self-care seems to apply to men, never servants or women. I regard tactics as a useful concept to understand how my research participants manoeuvred health advice and their ill bodies in a formal healthcare system that does

not provide adequate care or information. Resourcefully adapting clinical frameworks to their individual and communal life circumstances on their own terms, is what could be called “bio-tactics” as an alternative approach to bio-politics.

My supposition that Rana and her colleagues were using health recommendations to their own ends is, of course, neither a new nor a very radical idea. Literature on chronically ill patients often explores how they “are often creative in the way in which they react to their physical conditions (Nettleton 1995: 70). My research participants’ tactics can well be understood as a case of “coping strategies”, balancing health advice to maintain a certain degree of normality, hiding illness, or tolerating effects of illness (Nettleton 1995: 92ff). Indeed, all people, not only chronically ill or “expert patients”, manage their health with a certain agency, often seeking advice with family, friends, neighbours or media before seeing a doctor (“lay referral”, Freidson 1970; Hannay 1979), consulting several medical systems to meet specific needs (on complementary medicine, Sharma 1992), or negotiating health risks (e.g. Davison et al. 1992). Accordingly, the self-help group members learned to negotiate clinical encounters and exert their own influence, for example by tactically scheduling appointments, discussing and flagging side-effects of medication, or demanding to see a specialist.

However, diabetes self-management is primarily happening outside clinical settings and (unlike many other chronic illness and therefore unlike much what is explored as chronic illness coping strategies) focuses on lifestyle rather than medication as the centre of therapeutic efforts. Although most of us would certainly self-manage our everyday health and lifestyle in tactical ways, for example by indulging a bit one day, then eating healthily the next, this would not work to keep diabetes controlled. Diabetes self-management demands a highly structured and long-term practice that renders every room for manoeuvre a delicate and conscious matter. Insofar as everyday diabetes self-management is thus a much more complex and urgent exercise than the kind of health practices we all engage in at times, de Certeau’s (1984) notion of making (constrained) social lives habitable seems appropriate in understanding “agency” here in the sense of a purposeful and indispensable engagement rather than the mere negation of inertness.

I thus speak of tactics and manoeuvring, when Mol (2002), for example, would refer to “tinkering”. I suggest this language of military connotation, not necessarily because I consider practices of diabetes control as a battle (cf. Sontag 1991) but because these are indeed deliberate, purposeful and urgent practices to defend life, yet at the same time messy, risky, not without defeats, surrenders and threat to life. Successful tactics can achieve a better and longer life; in the background of such practices linger potential stroke, blindness, amputation or kidney failure.

Here, I also see the limitations of de Certeau’s notion of tactics, as I aim to avoid a simplistic understanding of tactics’ sole purpose in resistance. I believe the self-help group members’ motivation lies in their personal well-being, the rather complex and urgent exercise of preventing organ failure and early death, rather than reacting to some dominant ideological discourse or power. Telling their story as one of power and domination, or moral obligation, would flatten the account as there was something much more emotive and experiential that guided their practices. I believe it was the positive experience – feeling less tired and sluggish, improved eye sight or returning sensation in hands or feet – that resulted from enacting their new knowledge, not abstract authoritative advice from their doctors that guided their practices. Revisiting the field notes excerpts (03.02.2007) at the beginning of this section (p.88), Rana’s experience with cholesterol medication can illustrate this argument. As she told me, she had gained knowledge and confidence in the self-help group to challenge her doctor’s choice of cholesterol medication. The medication had caused her hair thinning and falling out, so, at first, she had simply stopped taking the pills. Later, with the self-help group, she learned how to actively engage in her healthcare by voicing her wish to change medication and adopting some physical exercise. While Rana’s story could be understood in terms of authoritative clinical advice that is challenged or tactically made habitable, Rana highlighted her remedied hair loss and improved cholesterol levels that will reduce her risk of diabetes complications. I suggest acknowledging such physical and emotional experience, in Rana’s case of a healthier body and of her proud achievement and improvement.

In conclusion, food and food practices occupied centre stage in the lives of my research participants who were living with diabetes. Dietary advice was intrinsically linked to therapeutic recommendations that were disseminated, shared and negotiated within the self-help group. This was not least significant as food was immensely important in their everyday social lives. Dietary recommendations were put into practice in individual and highly conscious ways. This meant that self-help group members made varied but deliberate decisions in their daily lives on what types of food might be amended, replaced, or kept, and if family or guests would be involved or nutritional changes confined to own diet choices. This was done with various degrees of rigour but always in view of advice and in line with a certain clinically shaped discipline. De Certeau's notion of "practices of everyday life" (1984) help to understand how common (lay) people use such tactics to make their structured worlds (or the expectation of structure) habitable through their own active engagement. Negotiating and amending diet, as I encountered it, was an idiosyncratic and powerful exercise. I do not understand it as a mere case of hegemonic domination or resistance but see it as intrinsically linked to a much more emotive, embodied and urgent motivation. By that I mean that their everyday lived experience of diabetes was shaped by the physical experience of feeling the impact of dietary changes of, for example, regaining eye sight and sensation in their extremities, and not by negotiations, challenges or constraints of power relations or moral commitment. In view of this physical and emotional basis of their practices, "tactics of diabetes control" have a very different quality to Foucault's (1997) "technologies of the self" as a personal moral economy of self-care that values the healthy body as the vital vessel of a healthy mind. The following chapter will have a closer look at such moral economies and why the notion of a "good life" might miss the point of understanding tactics of diabetes control.

## 6.2 Managing complexities

The above account of how food features in practices of diabetes control shows merely a snap-shot of the extensive and multifaceted regimes of illness self-

management that guided my research participants' lives. Learning about diabetes control and implementing this knowledge into their everyday lives changed, to pick the above example of diet, the types of food they were eating, how they prepared food, and when they consumed such food. As food is ultimately a social, not only an individual experience, these changes affected and were affected by social lives and relations in family life, friendships, community participation. Considering such altered socialities, one might be compelled to ask how lived experience of diabetes shapes personhood and selves. Literature on chronic illness debates such phenomenological investigation (of "suffering") and so far I have avoided to explore "being diabetic" in favour of what is significant about "doing diabetes". Incidentally, "diabetic" as a personal noun is (in international literature) considered an pejorative, labelling term, as it would reduce people to their illness when they would prefer to be identified as mothers, wives, friends, professionals, and so on. Although this is not a discussion my research participants ever had, the underlying argument fits their lives very well. Diabetes neither seemed to dominate their self-perception nor was it inevitably their only cause of "suffering". In this subchapter, I aim to explore the social lives of the Turkish migrants<sup>34</sup> with diabetes beyond their diabetes. These lives were perforated by many other concerns that were often more worrying, debilitating, or simply more current than diabetes. In fact, it seemed that practices of diabetes self-management provided them with viable tools of regaining control in such contested lives. Addressing finally the question if the highly scrutinised and structured lives devoted to diabetes control as explored above challenged notions of what a "good life" is supposed to be, I would argue that firstly, their perceptions of what constitutes a "good life" had been challenged long before the adoption of diabetes control routines. Secondly, resentments towards altered and limited lives through diabetes control were directly juxtaposed to the lives of others (neighbours, acquaintances or family members) whose un-controlled lives featured severe diabetes complications and bodily suffering (cf. Mol 2008).

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<sup>34</sup> "Migrant" can surely be considered as similarly pejorative as "diabetic", as it too reduces a person to a label that – at least – might not connote a particularly pleasant and proud experience compared to being a parent, partner or a skilled labourer.

### *Changing lives*

As mentioned above, the lives of those members of the self-help group who had started to apply and negotiate everyday practices of diabetes control had severely changed. Dietary practices involved for some of them home-baking, substituting butter with olive oil, or keeping track of each portion of fruit and slice of bread. Most were challenged to fit regular meals – which in their social worlds was a most irregular habit – into their daily lives without too much disruptions to themselves or others, and to plan bringing snacks whenever leaving the house. Then there were other lifestyle alterations that were not necessarily linked to food, which included physical exercise to compliment dietary changes – and meeting the self-help group, on Saturdays, which used to be for many the day of shopping and other chores. Finally, there was the actual medical aspect of monitoring glucose control and the often extensive medication regime (not only insulin or glucose-lowering drugs but also blood thinners, cholesterol and hypertension medication) which added another procedure of structure or rather disturbance. These severely planned lives were tolerated by many and even welcomed by some (as in the case of the widower Sadık). Others clearly suffered from this discipline such as the woman I mentioned earlier who immediately dropped her husband’s stringent diabetes practices after his death.

In light of such accounts one could conceptualise diabetes as an all-encompassing, defining and identity-shaping experience. Many studies explore chronic “illness narratives”, and there is an ever growing literature on illness and phenomenological subjectivity. Much of medical anthropological accounts understand personhood and self as shaped in lived, embodied experience of “suffering”, while seminal sociological works investigate the more temporal disjunctures caused by chronic illness. Bury (1982) framed the experience of being diagnosed with chronic illness as “biological disruption” that separate past lives from altered future imaginings. Charmaz (1983) considered the impact of altered social relations in disability on personhood as a “loss of self”. At first glance, my research participants’ “illness narratives” contained similar stories of bereavement and discontinuity. Diagnosis was narrated as a great shock, and often a stark reminder of

the loss of parents at a too young age due to same illness. Indeed, their lives had been greatly altered, and biographies truly changed. Yet I could not find evidence that their perceptions of self and personhood had been severely shaped by diabetes as a singular decisive experience. This might be largely due to my methodological choice of observing how they “performed” diabetes (practices) rather than how they phrased their diabetes experience. However, in doing so, it became quickly apparent that their lives did not revolve entirely around diabetes and that they were continuously challenged by various issues, not just diabetes.

### *Complications and complexities*

For most self-help group members, bad health did not only mean diabetes and its complications but included skeletal disorders from arthritis, osteoporosis to slipped discs as well as depression (cf. Lawton et al. 2006: 48). Each time I met my diabetic research participants we would exchange the typical array of polite greetings in Turkish. Once I knew some of them better, in the sheltered environment of self-help group or after having become a more frequent guest in their homes, I would get honest answers about their physical wellbeing. Rana would usually give me updates on her back pain, Feyza on her husband’s knee operations, while diabetes was rarely discussed in the sense of “how one was doing”. Hilal, the patient consultant, told me that chronic pain was a common problem within the Turkish community of Berlin. Many Turkish migrants of middle to older age were suffering from skeletal disorders, which were mainly due to the hard manual labour that had defined most of their working lives. Some looked back to bleak childhoods that involved labour from a young age in farming or the household. Such skeletal disorders were often leading to extended sick leaves, long-term unemployment or early retirement. As a result, people grappled with the loss of social roles of providing for the family or of being a valued community member. Hilal explained that her patients struggle with feeling lonely, bored and useless. Women have spent their whole lives looking after their children and often working full-time, too. Inevitably, their children leave home (several generations in one household is not common anymore and not feasible in cramped deprived housing), while sickness (and Berlin’s economic situation) forces unemployment or early retirement. Accordingly, men lose their roles as household

providers, either as their wives also work in fulltime employment due to low household incomes or (more often) due to the men's own unemployment or early retirement. Women, especially, also told me that they were still living in great home sickness and looked towards uncertain or often unwanted futures. Their husbands had promised to return to Turkey eventually, yet children and now grandchildren were born that make a return and retirement in Turkey impractical. Such challenges are identified as the psychosomatic causation for other chronic pains such as persistent headaches and stomach aches and considered the major cause for depression, a widespread illness which was often well hidden. Only by the end of my research did I realise that many of my research participants were suffering from depression and were in fact in medical care – and that included not only those research participants who were living with diabetes. Depression can also be a complication of diabetes or perhaps even cause diabetes (Mezuk et al. 2008). Obesity as an eating disorder in turn was also related by Turkish-origin doctors to these social challenges.

Such social problems of deprivation are, of course, not only significant in relation to health, and pressures of feeding your family, trying to get them into education and employment and negotiating other issues around welfare benefits, housing and crime in deprived areas pose challenges in their own rights not only as contributors to experiences of depression, obesity or diabetes. The self-help group leader lamented that people would not be able to afford the bus fare to get to the meetings and the immense success of handing out free glucose meters (see Chapter 5.2) was surely related to profound experiences of deprivation. The way severely challenging social lives are both departures and disruptions to diabetic lives is also explored in Schoenberg et al.'s (2005) article on “lay discourses on diabetes” and stress in multiethnic poor Americans. The main argument is that some patient groups' lives are more complicated than others and often unaccounted for. Participants of the study reported that severe poverty, crime, and therefore stress of bereavement, fear of losing one's livelihood or indeed life, and multiple day jobs to provide for the family hindered diabetes control and healthy diets, not simply “busy life schedules” as acknowledged in very middle-class centred healthcare provision.

Only the research participants who I got to know very well shared such “non-diabetes related” aspects of their lives with me. Here lies the strength of ethnographic participant observation that opens its lens to everyday lives. Lived experience of diabetes does not happen in a vacuum and only inquiring about experiences of diabetes would not represent their worlds very well. However, diabetes control was a constant in their varied, complex and often testing lives, and much talked about through the platform of the self-help group. Nonetheless, the complexities of social hardship and bad health tried to be accounted for within the self-help group, though not so much among (even Turkish-origin) doctors. The self-help group, for example, recommended types of physical exercise that would be compatible with the common skeletal complaints. It was pointed out that gentle exercise could in fact not only help preventing complications of diabetes but also alleviate pain conditions. Hilal told me that this was quite counterintuitive to many of her patients as the “Turkish way” of handling any time of illness was mainly to rest. People were advised to walk whenever possible in their daily lives and possibly to take up an exercise such as swimming that had a low impact on their, often arthritic, joints. Hilal and the self-help group also gave and shared advice on welfare services or low-cost shopping.

#### *Diabetes control as life management*

Diabetes, however, did not merely represent another challenge in such taxing lives but also an opportunity. By that I mean that diabetes control compromised an array of management tools that could provide structure and control in a fragmented and demanding social world. Diabetes was thus much talked about and paramount as it offered procedures of managing health and the everyday and a support network. Chronic pain had often passed any manageability; conditions such as depression seemed very problematic to communicate and advice difficult to seek. Social problems such as xenophobia and deprivation were even more debilitating as beyond the reach or chance of a solution. This stood in stark contrast to diabetes care and its rhetoric of taking therapy in your own hands. The self-help group was all about finding people with the same problems who could share experiences and fates and give support. Through the self-help group and their “outreach work” in community

information events, their members were even given the often novel opportunity to participate in community life (as will be addressed in more detail in the next section).

Above all, though, through diabetes self-management people could closely monitor their bodies, translate experience and suffering in communicable terms (as explored in Chapter 5.1), and apply regimes to their lives that had a real impact on their bodies. They could thus experience a powerful agency that was often taken from them in other regards. Such reasoning could be supported by having a closer look at those moments in my research participants' lives when they got a break from their deprived, unfriendly and cold surroundings. For many their summer months in Turkey were an escape from the problematic everyday. Many also admitted that they tended to drop their diabetes control practices that had been so carefully implemented in Berlin (like Feyza's sketchy glucose monitoring in Turkey as mentioned in Chapter 5.2).

The self-help group leader Yılmaz thus focused in the last sessions before the summer break on diabetes control during holiday in Turkey (field notes 16.06.2007). Many group members shared with each other that they would always feel much better in Turkey, but some were concerned that their HbA1c was much worse after the summer break. Yılmaz explained that people might live generally healthier lives "back home" in Turkey, eating lots of fresh vegetables and fruit and being more physically active, socialising, visiting friends and family, going to the beach, swimming etc. Having said this, they were also leading much more undisciplined lives. Many managed very structured lives in Berlin, timing their meals and medication intake and counting and limiting the amount and kinds of food eaten. During the summer months in Turkey, this discipline was given up, meals were eaten irregularly – often very late with family. Food was less divided in different meals throughout the day but often eaten as a big meal in the evening. Also, Yılmaz cautioned that fresh fruit may not actually be healthy but full of sugar and far too much fruit was eaten during holidays in Turkey and people forget to count how much is eaten. Yılmaz also held a community information event in early summer that featured the hidden sweet dangers of fruit, late evening eating, and feeling too relaxed to be vigilant (field notes 05.05.2007).

Yılmaz's concern was that people's blood glucose levels would rise in this time without being noticed. He thus urged people not to loosen diabetes control during their summer months in Turkey, and added that this is particularly important for those who plan to observe Ramadan in September. The reason for his concern was, of course, a positive one. Many people felt much better in Turkey – less stressed, happy about being reunited with family and friends, enjoying the nice climate – so they took less tablets or even failed to take any medication. Many perceived their trips to Turkey as a welcome getaway to a friendly and lush place of socialising and feasting that improved their health, although others were quite concerned about how this lifestyle challenged their diabetes control even if willing to keep up their regimes. Generally, the summer months require less managing – chronic pain and depression is eased in the company of family and sun, unemployment and financial problems are less pressing – or management responsibility (e.g. provision, food preparation) is altogether taken away during these trips as guest at family's or friends' homes. It is the taxing lives in Berlin that require life-management.

#### *A good life?*

Extending the gaze on their social lives at this point serves to address a commonly asked question I asked myself time and again and also heard from colleagues. The question is as to whether their disciplined, highly scrutinised lives are in fact considered “good” lives. Are my research participants' lives – so limited and often remote from their desired lives, as represented in their lifestyles during Turkish summer months – corruptions of their “old” food habits, their “cultural” heritage or social worlds (if that is a less contested term)? This question seems to epitomise an assumption that seems to be always lurking in critical accounts of the political and moral economies of biomedical ideologies. If one would follow the logic of the literature that considers body disciplines as rooted in neo-liberalism (e.g. Ritenbaugh 1982), a disciplined life seems to be capitalist and therefore surely “bad” or ascetic and undesirable. In other words, critical medical anthropology often presumes that the biomedical ideology equates a healthy life with a good life – alongside notions of the good patient. In doing so, such anthropological debates often take on an equally

normative and political viewpoint that regard “healthy living” agendas as the opposite of a “good life” in its more hedonistic, indulgent, unrepressed form. In contrast, Foucault’s (1990 [1984]) notion of self-care explored how historically moral economies of healthy living as a *raison d’être* have equated “good” and “healthy” long before the rise of a capitalist ethic of disciplined bodies.

I would argue that, although the question of a good life might be indeed linked to severely altered lives of diabetes control, I believe that experiences of unemployment, deprivation or depression have long foregone any notion, or at least contemplation, of good living. On another level, my research participants indeed connected notions of a good life to their own experience and even diabetes control, as their relatively healthy diabetic bodies stood in opposition to those in the community that suffered from loss of limbs, vision or organ function (or the memory of family members that had suffered a similar fate). In this context, members of the self-help group did indeed share a certain moral notion of “looking after oneself”. They could not understand that they met people during their information events who suffered from major diabetes complications and were offered the support of the self-help group yet declined their help. These people were often referred to as having themselves to blame to a certain degree but were also pitied for their suffering. Accordingly, many in the self-help group told me that they felt sorry for their parents’ generation that did not have the same information they had and that they should make sure their own children would not grow up in ignorance. Most important to the question of “good life” is the perspective. While a philosophical or political debate on the quality of life may be an interesting one, it seems hardly relevant to those who do not have the privilege of a mere theoretical discourse. As Mol (2008: 30) put it powerfully in her plea for “patientism” that acknowledges that patients have different concerns than citizens: “By definition, citizens are not troubled by their bodies. But patients are.” Facing life with a severe chronic illness that puts a constant strain on one’s body may indeed raise fundamental questions of what life should be like, but also determines the scope of possible answers, especially if prior challenges are already given.

### *Summary*

This chapter, in conclusion, explored the daily practices of diabetes control as it is significant for both the experience of illness and sociality. Exploring how food was negotiated, amended, rationed and enjoyed, I borrow from de Certeau (1984) who conceptualised everyday practices of ordinary people as tactics that make the social more habitable. In doing so, I propose to frame my research participants' idiosyncratic manoeuvring of self-management advice as "bio-tactics" of diabetes control. This is particularly important as my research participants' practices of diabetes control were not only a highly complex and delicate affair but as their social lives were challenged by complexities and concerns beyond diabetes. I also suggest to consider the notion of tactics, as unlike Foucault's notion of technologies of the self (1990 [1984], 1997) such practices cannot be (entirely) understood as a moral enterprise, but were much more immediate, flexible and un-structured. "Un-structured" here seems the wrong terminology in light of the rigour that is advised and adopted by some of the research participants, yet by that I mean that such practices were not unified or shared but individually and situationally negotiated. The members of the self-help group all had found their own way of handling their diabetes control.

Such individualised tactics were closely linked to their own social complexities that challenged diabetes control but could also be addressed through diabetes control in return. Other common health problems were skeletal and chronic pain disorders and depression. Adverse health added to and was influenced by social concerns such as deprivation, unemployment, challenged and changing social roles and xenophobia. These complex social worlds can, nonetheless, be seen through the lens of diabetes control. The self-help group addressed such challenges and gave specific advice, for example on physical exercise in regard to other pain disorders, or health management in the face of financial deprivation. On a broader level, the self-help group members learned about self-management as a tool to take problems into their own hands. This provided them with both a very practical social support system and with daily practices that enabled them to manoeuvre their often inhabitable social worlds with agency that could be experienced with their bodies. Such accounts of complex social lives are hardly surprising and only significant to my migrants

with diabetes. All our lives are in many ways complex and all of us manage such complexities with a certain agency. Yet my research participants' lives are certainly more testing than most of ours and diabetes management more complex, urgent and delicate than your everyday health manoeuvres. Within this context, the question if their highly managed lives were still perceived as "good lives" was not a concern of my research participants. However, their tactical skills were appreciated in contrast to the extreme diabetes complications of loss of limbs or vision or kidney failure other community members or family members had endured in the absence of such self-management. Also, practicing diabetes control allowed for participation in and renegotiation of lives that had been debilitated by many other challenges besides diabetes. The next section will have a closer look at such opportunities for social and communal participation.

## SECTION 3

### Politics of diabetes control: Beyond biosociality

The Turkish-German nursing day care centre I'm visiting today is in a poor area of Berlin. Stepping out of the *U-Bahn* station I pass a big Turkish supermarket. The day care centre is located within the grounds of an old hospital and I quickly find my way following the many signs directing me to the day care ward. The centre's owner and manager Ayşe, an attractive woman in her late thirties with short dark hair, trendy clothes, make-up and eye-catching jewellery, suggests giving me a little tour through the ward.

There is an "activity room" in which two young female occupational therapists are doing crafts with some elderly ladies. The next room is the busiest – a large room with a TV, showing a Turkish channel on its highest volume, several sofas and armchairs, Turkish carpets, plants etc. It's a comfy room and well used by many elderly people who sit together chatting, watching TV or reading Turkish newspapers. A nurse is serving up Turkish tea. The ward has also a "relaxation room" with four beds and more armchairs for their nap after lunch, and several toilettes. Ayşe comments: "Half of the ward is toilettes, it's ridiculous really but that's according to regulations." The bathroom has a big bathtub and Ayşe explains: "You must know the small and narrow bathrooms of Berlin's old buildings. There is no chance for family members – or nursing staff – to properly shower these elderly people. We can bathe them here once or twice a week." Then we reach the smoking room of the ward – where we find a very old lady wearing a long headscarf and a baggy dress hanging on her tiny, skinny body. She smiles at us as if we caught her doing something naughty and greets both of us with kisses on our cheeks. Ayşe tells me that the lady is in the last stages of Alzheimer's. Finally, Ayşe shows me the kitchen in which they prepare breakfast and lunch each day. Traditional Turkish food is cooked and all ingredients are bought at a local Turkish store. Lunch is about to be cooked and the counter is full with bags of food, tins, fresh vegetables, and meat. "We tried to offer our patients with diabetes different food but it wouldn't work out", Ayşe tells me. "There would be a huge row, 'but he got this...but why did she get this?' Patients would also trade food and we would have not much control over what they are eating. So we decided to cook the same food for everyone but low-caloric, low-fat, low-salt food. That's good for everyone."

Back in Ayşe's office we chat about the success of her nursing service. "Everybody told me not to do it. They thought that there is no demand, no market for this." She tells me about the "myth of the extended family", and how many people warned her that attempts of others to pull off such a service had failed. "I couldn't hear it anymore. I can tell them why they've failed. All these people who think it's enough to employ Turkish staff. As if it's enough to speak the language. You need qualified personnel!" She's been successful for eight years now and the appearance of more and more such services confirm her hunch that there is a market for "cultural-specific nursing care". I ask her how she recruits patients. "It's all through the home care service.

Without the home care service the day care centre wouldn't run." There is some word-of-mouth advertising but there is no help from family doctors. In fact, she complains that there is no co-operation at all with most doctors. She doubts that some of them actually have a special diabetes qualification. "Some just call themselves 'diabetes focussed practice'. Nobody really checks on them. I already had to report doctors for malpractice. These doctors think they know it all best but really it's about money. Patients are put on certain diabetes medication in the hospital and when they are back home their family doctor thinks he knows it all better and changes the medication. The worst is... Do you know Dr. X? I get angry just thinking of him. I have to deal with patients here who suffer from sever dementia and he thinks he can give them an insulin pen to handle themselves. They should hold the pen to their ear and listen to the clicking ...one, two, three, four. I mean, that's so delusional to think they could do that. I try to get doctors on the phone to speak to them but they wouldn't take a little bit of time to discuss these patients with me. I mean, I don't earn much money through prescription, but we have to do the care, we know the patients, see them regularly and know what they can handle." Apparently many doctors do ask her to do a daily blood sugar reading for them, which they then take and sign off as their own. I ask her if there is a difference between Turkish-origin and German family doctors. "They are all the same. It's all about money." I take the opportunity to hear her opinion on the special health insurance incentives for diabetic patients. "Has any patient ever received any extra care? I don't think patients profit from this system, just health insurances and the doctors."

When talking about how doctors don't provide patients with enough information she tells that she also does diabetes education sessions – and used to invite diabetologists. She stopped doing that though as these sessions seemed to be too difficult for her patients. They use all this jargon and explain everything in too complex ways. "This bread unit nonsense. Some nutritionists came up with this and cannot imagine that people without their training might struggle with these concepts." I tell her about the self-help group and say that people seem to like that they can learn about diabetes bit by bit – from other patients not doctors. To my surprise, Ayşe has equal resentments about the self-help group. "I have bad experience with this group. It's all about money and profit for them, too. They cooperate with certain nursing services because they get money for advertising them. I know these services. They advertise to provide free service and then charge the patients afterwards. And these other nursing services use un-qualified staff – as if it's enough to provide these patients with someone who speaks Turkish. Some of my nurses do not speak Turkish and the patients love them anyway, because they do a good job." [Field notes 12.02.2007]

While the chapters of the previous section were about the individual experience with diabetes – the patient side of practically engaging with the management of diabetes in the everyday – this next section aims to explore the community experience with diabetes. Here, "self-care" is investigated as a societal response of managing the

burden of diabetes in one's "community"<sup>35</sup>. In the previous section, self-care practices are, of course, also inherently social practices, but they focus on sick bodies. For example, dietary recommendations have to be implemented in family life or are challenged by social values of hospitality, yet their purpose is to maintain individual diabetic bodies. This section, then, is not about health, illness or sick bodies per se; more precisely, it is not about diabetes as a bodily or emotional experience. Rather, I will argue that diabetes is also collectively experienced by a population group and a starting point for social, political, economic and moral engagement.

Berlin, as I encountered it, with an increasingly growing, stratified, diverse and challenged but also increasingly confident and settled Turkish-origin population, turned out to be a site of multiple and diverse responses to diabetes. Chapter 7 sets out to address this communal experience of diabetes. There is a substantial number of Turkish-origin practising healthcare professionals who are organised in various professional groups and societies and show particular interest in diabetes among "their community". Recognising that diabetes is a burden to this population group led to the initiation of a self-help group that also organises community information events. Such collective, organised response can be understood as biosociality or bio-activism. Unlike Rabinow's original conceptualisation, however, biosociality is not born out of biotechnologies and their challenge to patient's biological identities (Rabinow 1996a); biosociality or bio-activism, here, has different motivations.

Adding to these social activities, further interactions and involvements around diabetes are local TV health programmes, events and programmes by local working groups, charities and NGOs and the above mentioned rather fast growing market of nursing care services. Chapter 8 will explore who is involved in this

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<sup>35</sup> The term "community" is a problematic one that a large body of literature discusses. There is, of course, not one coherent, bounded "community" of Turkish Berliners. Contrary to popular perception, they cannot be located in specific spaces, and they are stratified in generations and socio-economic classes. There is not even a more or less unified way of referring to their belonging or identity. While some doctors would highlight the expression "German Turks" or "Turkish German" (and feel strongly about respective terminology), the drug rep would talk about "my folks", while some NGO workers would frequently use the English word "community" (instead of the German *Gemeinde*) to refer to a population group or ethnic minority rather than an actual physical community. I tend to follow the latter example and write about "community" or "communal" in order to capture when my Turkish-origin research participants referred to a collective "us" that should refer to the Turkish migrant population in Berlin.

biosociality. There are not only patients-turned-activists but the politics of informal diabetes care add many social roles to people's lives. I will argue that this local field of informal diabetes care is a site of both opportunities, support and co-operation and "conflicts, tensions, resentments, competing interests and power imbalances" (Morley 1999: 4, on micro-politics). The following section will thus focus on junctures of social participation and "community self-care", profession and profit, co-operation and competition, as illustrated in the above field notes. The local social, political (civic) and economic response to the presence, burden, or even threat of diabetes is another important part of the story that this thesis sets out to tell; it situates the thesis in a wider body of "biosocial" literature and explores in what way diabetes challenges and reshapes communal experiences of Turkish Berliners.

## Chapter 7: The communal experience of diabetes

In many ways this thesis is an account of privileged patients. Most of the research participants diagnosed with diabetes were, of course, demographically speaking anything but privileged with their largely low socio-economic and educational status and marginal position as mostly elderly, unskilled migrants with limited German proficiency. And yet time and place offered a departure from such demographic disadvantage. Berlin, in its first decade of the new Millennium, is a vibrant place with a large Turkish-origin population that occupies by now not only the segment of society of low-paid, unskilled labour with poor housing but has entered academic, professional and political positions, initiates NGO, charity and social work, and shapes media and business. Furthermore, health and healthcare seems to have become the focus of much present-day political and public concern. The self-help group of Turkish-speaking diabetics is a poignant example for such local initiative and also illustrates that illness is, far from being a mere individual and private experience, also a communal encounter of suffering, coping and managing that instigates social participation and interaction.

In fact, as much as the diabetic body becomes a reason for sociality, such sociality is often quite separated from the embodied, physical experience of diabetes. By that I mean that collective action and interaction can have a therapeutic element for individuals and the communities in which they are living, but it can also be an opportunity for social participation beyond practices or concerns around health. The following chapter is about the communal participation around diabetes care. Diabetes had been, so to speak, diagnosed by the Turkish migrant population in Berlin as a communal problem that required control and self-management. On a more individual level then, and as alluded to earlier in Chapter 6, diabetes in its social form of self-help had become an opportunity to manage life and participate in life. Social interaction had become central and prominent in the lives of the self-help group members but such social interaction also involved many who did not share an immediate physical experience of diabetes; lived experiences of diabetes can be something else and might not only concern diabetes patients. Notably, my account departs from other literature on biosocialities in that the origin of social activity and

communality was not rooted in technological advances that shape society in new ways. This is an account of a “low-tech” sociality, a *new* social movement, nonetheless, that assumes communality stemming from a biological concern. However, this emerging sociality is not due to new techniques or technologies that redefine how people identify and organise themselves, for example as explored by Rabinow (1999). Both treatment and social activity is inherently low-tech, there are no fancy diagnostic tests one would advocate for, no genetic testing for susceptibility, and no virtual community of diabetics. This is the account of a biosociality beyond biotechnologies but emerging out of a specific social, political and economic context.

### 7.1 Local self-care: diagnosing and healing the community

In this subchapter I outline how diabetes had become a pressing issue in the Turkish migrant population of Berlin that sparked social, political and economic activity and involved individuals and groups, professionals and laypeople, old and young, the poor and middle classes – Turks and Germans. At the centre of my attention to such communal activities (not necessarily matching all activities happening in Berlin) lay the self-help group and those involved and allied with the group or challenged by it. Through the lens of this communal self-help activity I aim to acknowledge the collective social experience and local political economies around illness and healthcare. I argue that diabetes has been diagnosed as a social problem within Berlin’s Turkish population by local medics, politicians and (national) academics, and treatment has been sought in active engagement and self-management, by filling provisional gaps through informal care.

#### *Excursion: Why do Turkish Berliners have diabetes?*

Before I explore diabetes as a communal problem for Turkish Berliners, let me make a short excursion to a related research question that I did not ask but that always lingers in the background. A commonly asked question by most people I tell about my research is: so, why do Turkish Germans have so much diabetes? First of all, as mentioned before, this is not a proven statement. As a starting point to this research I

used the study of Laube et al. (2001) that states that Turks are almost twice as likely to have diabetes as Germans or Turks in Turkey. But I have also highlighted earlier that the research is considered a poor study with a convenient sample that required to be controlled for age and sex. However, much epidemiological research indicates that migrant and ethnic minority population groups indeed show more diabetes prevalence (Qiao 2004; Unwin and Zimmet 2009). So, could my 12-month-long research contribute to this research question? I did not set out to answer this question, and would lack the methodology and training to do so. Nonetheless, I spoke to many health professionals and patients, and their common agreement was that diabetes is perceived as a current and severe problem of this population group. Relying both on the scarce medical statistics, which had been – in turn – produced by mostly Turkish-origin academics, and their own personal experience of everyday diabetes prevalence among their patients, Turkish-origin doctors identified diabetes as a communal problem that needed addressing. Narratives varied but the concern was widely shared and backed with the ever-cited Laube (et al. 2001) study. Some doctors would also refer to a local council study on high obesity rates among Turkish-origin school children (Delekat 2005) in order to back their own observation and experiential knowledge with more “hard facts”. Cautioning me at all times that “this is only anecdotal evidence”, they explored the reasons for the indeed high occurrence of diabetes in their practices. That it is perceived as a burden might not necessarily reflect the relative or absolute numbers of diabetes but the challenges to provide healthcare and other support systems. The immense efforts of health insurance companies, I witnessed, to sign up Turkish-origin diabetes patients to their management programmes, and of drug companies to target this newly discovered consumer group with “ethno-marketing”, indicates that this patient group is increasingly moving into focus, irrespective of reliable prevalence data.

Could I then shed more light on the question as to why Turkish Germans might be vulnerable to developing diabetes? There are three hypotheses about diabetes risk to certain ethnic minorities: their lifestyles, their genes, or foetal/childhood deprivation (also see Mol 2008: 64ff). While, again, I did not set out to explore these issues, research participants did frequently comment on all three aspects. First, as frequently mentioned before, type 2 diabetes is associated with

unhealthy eating habits and sedentary lifestyles (Zimmet, Alberti and Shaw 2001). Some doctors I spoke to highlighted that Turkish diet, contrary to the myth of the Mediterranean diet, can be very fatty and sugary. Anatolian cooking, especially, many women also explained to me, uses a lot of butter fat instead of olive oil, and fried and baked stews are more common than grilled dishes.

Why then would their diet be worse in Germany than it used to be in Turkey? Some health professionals pointed out social deprivation. A doctor explained how people were altering their diet to save money (interview transcript 02.11.2006, p.2): “Everybody talks about the healthy Mediterranean diet. As if! They don’t use olive oil anymore. Butter is much cheaper. Turkish cooking is abused here, really.” Taking the environment into account he went on to complain that the streets of Berlin’s Turkish districts were lined with cheap Turkish fast-food eateries: “Just walk down *Hermannstraße* and you’ll see all these discount shops. Fantasy prices! It’s insane, really. You can eat so cheap nowadays that you wonder how they can still make a profit. These shops – huge Turkish supermarkets where you can buy anything – and these take-away places weren’t here ten years ago.” Indeed, while public health professionals would often point out that fast food is actually much more expensive than home-cooked food, Berlin’s extremely cheap Turkish fast food begs to differ. This cheap food at every street corner also helped to change eating habits. Talking to Turkish Berliners about childhood obesity, many parents shared their frustration with me that while Turkish-origin children still have sit-down meals with their families, they also snack on burgers, pizzas and kebabs on the way to the family meal. Doctors would also point the finger at the parents: “People living here in *Neukölln* are still very traditional. They still raise their children like decades ago. You’ve got to spoil your child.” (Interview transcript 02.11.2006, p.1). For these elderly Turks obesity would still be a sign of prosperity.

Several doctors also mentioned that stress was an important factor in diabetes – in terms of causation and management. Many older Turkish Berliners suffered from complex health problems; for example, my research participants with diabetes were almost always also chronic pain patients or suffered from mental health problems. Another frequently mentioned illness was eating disorders (especially over-eating) in connection to high depression rates, especially among women of all

ages. This, finally, leads to sedentary lifestyles as a behavioural cause of diabetes. Again social factors might play a role, for example a population group that suffers from high unemployment and early retirement is perhaps less likely to lead active lives. This is, as mentioned earlier, linked to high rates of skeletal illness that also restricts movement. The doctor that pointed out the plight of fast food venues also mentioned that Turkish Berliners can now enjoy an abundance of Turkish TV channels with their satellite receivers. He suggested that many people were less physically active after migrating to Germany. In recent years, he added, this problem had worsened, as tens of Turkish TV programmes were available in Turkish-speaking households in Berlin by then. Some decades ago people had to leave their houses to meet friends to socialise. Now, “they can sit on their sofa all day and be entertained” (interview transcript 02.11.2006, p.4).

The second possible explanation why Turkish Germans may be at risk of diabetes is biological: genes. As mentioned in Chapter 1, the so-called “thrifty gene hypothesis” says, that insulin resistance used to be a useful evolutionary trait for people that lived between periods of fasting and feasting (McDermott 1998). If food is scarce, the rare moments of feasting require a slow metabolism that would not process the energy source glucose too quickly. With industrialisation and increasing wealth, people (the implication is, in the Western world) slowly adapted to changing food availability and eating habits. People in the developing world (e.g. Asia, with increasingly high diabetes rates, Zimmet, Alberti and Shaw 2001), undergo such changes too rapidly for their metabolism to cope. Population groups that made this change even more abruptly, namely migrants, this thrifty gene effect is even more significant, especially when keeping above mentioned lifestyle and environmental factors in mind. Less controversial are other gene-related theories of illness causation. Scientists seem to agree that type 2 diabetes has a definite genetic element in its aetiology (Hedgecoe 2002). Genetic research suggests multiple gene defects at play and is currently focussed on unravelling these complex workings (Rock 2005).<sup>36</sup>

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<sup>36</sup> The anthropologist Melanie Rock (2005: 117) explores this recent genetic research on diabetes onset and quotes a genetisist who linked a Mexican-American population to a certain gene that “reduced the desire to exercise” in laboratory mice.

Third, Turkish Berliners might not only share habits, environment or genes, but similar childhoods. Research also points to a connection between risk of diabetes and deprivation during pregnancy and early childhood; in this theory, the environment can have an impact on biochemistry. Hales and Barker (1992) called this the “thrifty phenotype hypothesis”, in which (in accordance to the thrifty genotype hypothesis), deprivation is said to be able to alter the biochemistry of a foetus and baby, to prepare the young person for a life in poverty and scarce food supply. This is often explored in birth weights (Harding 2001). Although there is no data on the birth weights of my research participants with diabetes, some shared biographical stories of great poverty in early life with me. While labour migrants tend to have lived in relatively poor circumstances before making the brave move to try their luck in a wealthier environment that offers more opportunities, it has to be pointed out that patients’ childhood memories are subjective and are not appropriate as the basis of epidemiological evidence.

The above explorations of possible causes for diabetes are, of course, speculations that are fleshed out by observations, perceptions and experiences of my research participants. The only possible answer to the question why the Turkish Berliners may be at risk of diabetes is shared by most researchers in the field of diabetes. Diabetes causation is complex and research would have the task to disentangle the multifaceted factors of lifestyle, psychology, environment, genes and biochemistry (Zimmet, Alberti and Shaw 2001; Unwin and Zimmet 2009).

#### *Diagnosing a communal health problem: the medics’ society*

The above interview excerpts show that it was particularly Turkish-origin doctors who voiced their concerns about diabetes as a problem of “our community”, and much of Berlin’s activity around “Turkish diabetes” was instigated by them. Berlin with its large Turkish-origin population (around 200,000 of the 3.4 million inhabitants; Statistisches Landesamt Berlin 2006) has by now over a hundred Turkish-origin doctors whose practices mainly accommodate migrant patients who appreciate the offer of native language healthcare. The number of doctors of Turkish migrant backgrounds used to be much smaller and still is relatively small (compared to, for example, South-Asian origin doctors in the UK context, as many Turkish-

origin doctors would highlight). Social mobility is made difficult in German society and the for-profit, entrepreneurial system of medical practices is a financially risky and trying business. Doctors therefore organised themselves in medics' societies that functioned as both support and lobby networks. They also felt strongly about the politics involved in their patients' care. While the doctors in the above interview excerpts often expressed their evaluation of the roots of diabetes in personal choices and failings, they were also keen to point out environmental and social constraints, and structural and political disadvantages of their patients. For example, many felt that it was important to raise awareness among healthcare professionals and bureaucrats to have the necessary language skills to talk to migrant patients. "In some hospitals, they let the cleaning lady do the preoperative informed consent procedures," a doctor complained (interview transcript 02.11.2006, p.4).

I suggest understanding how these doctors identify the social and political dimension of diabetes in terms of symptoms, diagnosis and treatment of a communal problem. Drawing parallels to the clinical way of diagnosing the physical illness diabetes, the social problem of diabetes appears to be explored in similar ways. While the individual, physical experience of diabetes often begins with symptoms such as thirst and fatigue, these also metaphorically frame the local discourse of Berlin's migrant population group as deprived and drained. The diagnosis of diabetes, then, is clinically done with a glucose test in form of a blood test or sometimes, although outdated, urine test. Biomedicine narrows general problems and complaints down to a particular place or seat of illness. In accordance, this marginalised population is, in general terms, burdened by deprivation and marginalisation, while the medics' society aims to investigate more specifically the burden of this group, in particular diabetes (and high rates of obesity, sedentary lifestyles, unhealthy diets and depression as contributors to diabetes). While for national politics the problem of this marginalised population group is lack of societal "integration", activists and academics consider challenges in lacking acceptance and provision in terms of education, employment and social welfare. Local medics, of course, identify much more specific needs of their particular patient group, in particular obesity and chronic illnesses such as diabetes, but see such ill-health as closely linked to, shaped by and in turn shaping deprivation and marginality.

In short, diabetes could be regarded as a symptom of social hardship or social disadvantage and diagnosed by diabetes “activists”, here involved medics, as a social challenge, burden or demand. Such diagnosis of diabetes as an ultimately social problem remains largely undetected by national and local mainstream politics. Combining their own everyday experience of illness prevalence with more “scientific”, “factual” data of the scarce statistics produced by their (prominently Turkish-origin) academic colleagues in research, Turkish-origin doctors produced a certain political agenda. In their interviews the local medics positioned themselves in these “tales of diagnosis” at times as the scientist or professional who identifies someone else’s problem, bad habits and uncertain futures, and at times as members of the “community”, doing something for “your own”, threatened and burdened all the same by such illness, or at least acting as spokespersons. Similar to such shifting positions, their stories (of causation) were also variant, evoking both patients at fault of such bad practices and backward beliefs, and a population victim to structural disadvantages and economic market forces that determine bad eating habits and sedentary lifestyles.

*Community self-management: the self-help group*

Subsequent to the analytical device of symptoms and diagnosis, what follows is the question of treatment. Central to diabetes care is self-managed diabetes control. Again, self-management cannot only be a clinical therapy but also a political and social remedy. While the diagnosis was largely in medical hands, the treatment of diabetes as a social problem of a population group was diverted – like in the case of diabetes treatment itself – to the care of the patient, to the self-management of this problem by the members of the affected population group. Depending on the positioning of Turkish-origin doctors as such community members as opposed to observant or privileged outsiders, the doctors became themselves “patients” that needed to take the care into their own hands. “We had to do something for us”, would paraphrase their motivation. Such quasi “self-care” undertaken by local medics included individually offered patient education sessions in Turkish that accommodated Turkish foods and social lives in order to offer an education their patients would not be able to access otherwise. On a group level this meant the

establishment of a professional society that would, on the one hand, protect their own interests as professionals who were in some ways marginal to the mainstream system and by and large caring for a deprived and disadvantaged patient group without extra support. On the other hand, the society was a self-care response to offer adequate (including native-language) healthcare to this patient group in a more institutionalised, structured and therefore ubiquitous approach.

Independent of the positioning of local Turkish-origin medics and their imagined and lived experiences of diabetes as a communal burden, their initiation of a patient-led self-help group truly based self-management in the hands of the “community”. The diagnosis of the high prevalence of diabetes among the Turkish migrant population and Berlin’s inadequate formal healthcare response was followed by the fairly standard and perhaps unspectacular enlistment of self-help and voluntarism (Robinson and Henry 1977: 8). In other words, the “community” can be helped, if not healed, by filling such provision gaps through self-organised informal healthcare provision.

In the early 1990s, one of these medics’ societies earned a grant from the Berlin Senate to tackle the alleged threat of HIV/AIDS within the Turkish population of Berlin. The medics set up a walk-in clinic that offered both treatment for HIV-positive patients and counselling for their family members. Members of the society told me that they had enough funds to employ four fixed-term staff that also provided a general service of native-language healthcare. Many doctors affiliated to the society donated their time and energy; there was also a nutritionist, two practice nurses, a sexual health consultant and a regular parents’ consultant. Before long, a much more urgent health issue emerged that was not anticipated by the Berlin Senate: type 2 diabetes (and other obesity related chronic conditions). The medics reported a high prevalence of diabetes among their patients and saw a demand for information on this issue that affected and concerned so many people in their community. They decided to organise an awareness raising event and an affiliated pharmacist offered his large pharmacy to host the gathering. They soon realised that the space would not be big enough to accommodate the large audience that had turned up. Another meeting was planned, this time in a wedding hall that could hold

a hundred instead of twenty people, and these information events soon became institutionalised.

It was around this time, in the late 1990s, when funding by the broke city Berlin became scarce that the medics' society searched for alternative ways to provide care and support that would require less of their own resources and time. Patient-led self-help groups are a common response to such structural provision gaps (Robinson and Henry 1977), and the medics sought out a non-medic board member of their society – a local and well-connected businessman – who was himself living with diabetes to lead such a self-help group of Turkish-speaking diabetics. The group's leader Mr Yılmaz narrated that he was at first hesitant to take on such a role, “after all I was not a doctor, but Dr. S said that he was not born a doctor either” (field notes 15.03.2007). With the initial help of the medics and much immense personal investment of time and money Yılmaz underwent training by the German Diabetes Union in order to qualify as a diabetes consultant and later he took courses elsewhere, also in Turkey. Yet he was denied the official qualification certificate as he lacked the initial medical training in either nursing or nutrition that is usually requested for diabetes consultants. Doctors told me that this represented “typical local politics” of Berlin's branch of the diabetes union that did not like to see the conservative hierarchies challenged.

The bureaucratic journey to achieve official recognition as a group was equally problematic. The first three years the self-help group only operated as a loose group, with only a few interested people attending its first meetings. During the first year there were fourteen people actively involved, including four patients, a pharmacist, a lab assistant, Yılmaz and some doctors from the medics' society, and the first event was attended by forty people. The medics planned to register the group as a separate association but putting together the charter of the association proved difficult and registration failed. The two groups apparently fell out which might have had to do with the development that Berlin's bankrupt senate had by then ceased much of the funding it had invested in its better-off times, and it seemed that the two groups, the medics' society and the self-help group, had become competitors rather than partners in their provision of alternative diabetes care. Yılmaz then took it into his own hands to write the articles with the help of his (German-born and German

native speaking) daughter and got the association finally registered in 2003. With official recognition the group started to provide the community with their own information events and four years on, when I met the group, Yılmaz told me that thousands of members were registered.

The self-help group offered a forum to give advice, support and above all information and education that formal healthcare failed to deliver. This failure, incidentally, included many of the medics, as I mentioned in Chapter 4. These doctors might have shown enough initiative to draw up more adequate education plans, translating brochures and compiling Turkish slides and other educational material, yet often they could not actually deliver these efforts efficiently due to their own resource and time constraints and their patients were left to their own devices. The self-help group stepped in to offer personalised, detailed and more compassionate education. Moreover, they disseminated information and raised awareness in the wider community by taking over most of the community information events that the medics' society used to host in wedding halls. Yılmaz also often replaced the medics' society as a regular appearance on local Turkish-language TV and radio to inform about diabetes, its care and their service.

This is not to say that the medics were not involved anymore in this kind of communal response. In fact, a range of actors and groups showed an interest in locally managing diabetes care in activities that could all be subsumed as informal healthcare provision. Involved in this kind of informal network of diabetes care were furthermore nurses who were trained as diabetes or patient consultants, some of whom were members of a special migrant working group of the German Diabetes Union. Other doctors were part of this group rather than the medics' society but surely most people involved more or less knew each other or of each other. These included people from health insurances and drug companies as the Turkish migrant population is regarded as a big market – rather cynically due to their high illness rates. This is not to say that those individuals who represented insurers or drug companies did not genuinely care for these patients who they regarded – being Turkish-origin themselves – as part of “their community”.

### *Collective illness burden and biosociality*

Summing up, diabetes is not only an experience of illness, sick bodies that require health practices and bodily maintenance. I argued that diabetes is also collectively experienced as a communal problem (cf. Mol 2008: 57ff). Diabetes is communally both suffered and tackled and such social experience could be understood in medical analogies. Diabetes was diagnosed by local Turkish-origin medics (alongside some scarce epidemiological statistics) as a problem common in their specific Turkish-origin patient group, and causation was identified in both personal failings of beliefs and practices of this population group, namely contemporary unhealthy lifestyles, and structural adversities of deprivation and marginality. The medics positioned themselves fluently as both “outside” health professionals and observers and “inside” members of the very community that is burdened by such ill-health and inadequate healthcare provision. Treatment of this communal problem is, then, sought in informal solutions to address such gaps in provision and manage this challenge. Just as diabetes is treated in terms of self-managed diabetes control, the “community” is treated, if not healed, with a similar self-care approach. The Turkish-language self-help group follows its self-evident principal of helping each other and helping oneself, and offers education, information and support to a population group that is inadequately accounted for by the formal healthcare service.

The recognition of diabetes as a collective problem invites reference to Rabinow (1996a: 102) who envisioned “groups whose members meet to share their experiences, lobby for their disease, educate their children”, and “[...]have medical specialists, laboratories, narratives, traditions, and a heavy panoply of pastoral keepers to help them experience, share, intervene, and ‘understand’ their fate”. Rabinow’s notion of biosociality describes well some of the motivations of the self-help group. A social group formed based on the collective vulnerability to diabetes. What makes Rabinow’s biosociality stand out is that sociality is not just founded on the basis of an illness but how this illness is (re)imagined. For him, it is the innovative and challenging character of biotechnologies, the “life in the making”, that re-imagines biologies (Rabinow 1996b: 2). Rabinow imagined such groups to be formed around chromosomes and genetic markers; Rabinow’s biosociality stems from biotechnological intervention that puts our conceptions of our identities and

bodies in question. Social movement then is both guided by technology – for example in Internet chat-rooms as virtual support groups – and its aim is about mastering such technology, lobbying for access to diagnostic tools or treatment or raising funds for further research. Rabinow’s legacy therefore explores further biotech avenues. Gibbons (2008), for example, described how molecular research into genetic breast cancer markers invigorated and redefined patient activism of “BRCA carriers”.

Lock (2008), accordingly, aimed to investigate such changing identities of “APOE carriers” with genetic Alzheimer’s susceptibility. However, she concluded that such self-perceptions might not be inevitably shaped, and she cautioned against assuming that socialities would be inevitably formed (Lock 2008). In this chapter I argue that while Rabinow’s concept may not be readily applied to any sociality forming around health and illness issues, “low-tech” biologies, for example an emerging diabetic identity, can create sociality similarly innovatively without any biotechnological involvement.

In the case of Berlin’s Turkish diabetics, there are no technologies at work, no re-crafted and re-invented cyber-biologies. Previous discussion on the genetics of diabetes causation may indicate a very strong bio-tech component. However, this was not discussed by any of my research participants, neither patients nor health professionals, and not relevant to their self-perception or collective belonging and activities. Nonetheless, biologies are at stake, are managed and shaped, and sociality is emerging that is situated in a certain time and place that offered the right momentum. I suggest that a complex of societal, political, economic and personal elements contribute to such momentum. First, society is – foreseen in Foucault’s bio-power (1998) – fine-tuned to public discourse of healthy living, consumer responsibility and chronic illness problems of obesity and diabetes. Second, the Turkish migrant inhabitants of Berlin are a large and increasingly economically stratified community that is politically organised, socially active and represented in local media. An increasing number of Turkish-origin health professionals place the health needs of “their own” population group at the centre of attention and action. Third, albeit increasingly stratified, the Turkish population in Berlin is still socially and politically marginal and is burdened by social inequality and deprivation, which

sparks increasing political organisation and activism. Deprivation created the problem of diabetes in the first place, as many believe, but the current strained economic situation, for example, also initiates communal support and social action, as the Senate's dried-up funds required alternative provision in a self-help group. I thus also argue against biosocial ethnographies that suggest that marginality and deprivation would not allow for biosociality such as Bharadwaj's (2008) and Sunder Rajan's (2008) ethnographies that consider India's deprived and marginal people as, at the most, bio-available, never bio-active.

In sum, rather than criticising the notion of biosociality here, my aim is to use his concept in order to understand the Turkish-speaking self-help group and other such local diabetes-related engagements as something more than mere self-help and voluntarism as understood by Robinson and Henry (1977: 8). Rather I consider their sociality significant in their time and place that reshaped how these Turkish-origin Berliners living with diabetes have identified and organised themselves. Several colliding aspects, a certain social, political and economic environment and the initiative of certain individuals and groups, allowed for the emergence of an interest in Turkish diabetes care in Berlin and created social spaces such as the self-help group.

## 7.2 Diabetes care as social participation

Recognising diabetes as a communal problem of and by Turkish Berliners provided the opportunity for communal participation. The self-help group cannot only be understood as representing and providing self-managed local Turkish-language diabetes care, but the group offered diverse opportunities that enabled more generally participation and sociality. Biosociality may have been created by diabetes but has not always diabetes at heart. This subchapter will explore how the self-help group as a "biosociality" provided the occasion for social gathering, new social relations and frequent social interaction. Such social activity was often experienced as separate from their illness encounter insofar as group interests such as fund raising had gained significance independent from personal interests of acquiring diabetes control

practices. This is not to say, finally, that social participation had no impact on the lived experience of diabetes and its individual management. The group made successful personal diabetes control possible – as explored in Section 2 – but it could also have a negative effect on such individual illness experience when the group created conflict or tensions. Members also learned to demand what care they were entitled to, and to occupy a visible communal role. Rather than being involved in lobbying for patient rights or innovative diagnostic tools, however, their bio-activism concerned everyday needs of care.

### *Seeking sociality*

Here, I trace in greater detail how Turkish migrant diabetes care is a communal experience that offers the opportunity for social participation. Needless to say, any group belonging enables people to “get out of the house”, meet socially with like-minded people, share time and space, maybe memory and experience. Contrary to common views of the Turkish family as a household of several generations that grant each other compassion, company, material provision and child and elderly care, such experience seems to be indeed a “myth of the extended family” (“*Mythos Großfamilie*”), as it is often called in social care circles, and was not shared by any of my research participants. Cramped housing space would not allow for such sociality, and many young adults preferred to leave their parents’ households anyway to lead their own lives. Changing family structures and function – at least compared to how (temporally and spatially) distant family lives and traditions were envisioned – had become such a prominent concern that it sparked similar communal self-management responses than the diabetes self-help group. Turkish-speaking elderly care services had started to spring up as a new niche within the self-employed sector of local Turkish-origin businesses and were already in great competition at the time of my research.

Furthermore, some elderly migrants indeed succeeded in returning to their home country in retirement. Literature usually speaks of a mere “myth of return” (Anwar 1979) that alludes to an imagined, unrealistic future in the past homeland, but return is nonetheless realised at least by some. The members of the self-help group shared stories with me of lost friends and neighbours that had recently returned

to Turkey in retirement and left empty social spaces. Social and healthcare workers also highlighted how the women's roles as mothers become obsolete when their children leave home. This often coincided with retirement due to age or chronic illness, as mentioned before, and the loss of social interaction with colleagues or customers. Such stories varied, between those who experienced them and those who identified them as experiences of others; they were sometimes tales of abandonment or loneliness, lost tradition, values and companionship, sometimes stories of liberation, embracing lives after tiring housewife's duties and double shifts at minimum wage, or after controlling spouses and demanding children. In any case, meeting the self-help group had offered the chance for new social interaction; for some it meant the desperately missed support in illness but for many it also simply presented the space for a chat and some company.

#### *The social life of self-help*

The self-help group's invested interest thus went beyond providing an alternative health education for diabetes management and a coping and support network. Core members of the group were not only engaged with the maintenance of their diabetic bodies but also with the maintenance of the group. During my field work, the group was not only keeping busy with weekly meetings and personal everyday practices of diabetes control but increasingly with their club life. The members were concerned with matters that related to the social life of the group, its activities, events, membership and finance.

Berlin's competitive market of ambitious Turkish-origin businesspeople took its toll on the self-help group when their sponsors pulled out of previous arrangement. The group, for example, ran adverts for their big community information events in form of informative health programmes on local radio and TV. The leader Yılmaz had known the responsible partners there for years and had arranged free "air-space". Early during my research, Yılmaz showed me a letter from the radio station that would, from that moment, cease their sponsorship and charge the group for their time on air. Adding to this challenging new situation, their other media partner, the local Turkish-language TV station, found out about this and proceeded to demand payment themselves. Yılmaz reported this problem to his

group and they devised a fundraising project in order to be able to pay for such events, advertisement and speakers. They decided to sell coffee, tea and sandwiches at the monthly big community events. Prior to such events the group then started to use some time of their gatherings for organisational purposes and debated in long discussions how and what kind of drinks and food should be sold, who would buy what kind of products, and who would be in charge of food preparation and sales. An important point of discussion was also how much group members would be able and willing to contribute towards the purchase of these products. Members were concerned that they, themselves, did not have much money but Yılmaz suggested getting everything at the discount supermarket and to my surprise most people in the group pledged a quite substantial amount of money for each fundraising. There were less pressing and yet similarly long debates on whether to sell cups of water or small bottles of water, brown or white plastic cups (the solid brown ones were better for coffee, the white ones cheaper and good enough for water), what kind of bread and sandwich fillings, and so on and so forth. I was always pencilled down for some task without much asking and in general every member of the group was expected to contribute in some way.

At the actual community events many members were more involved in these fundraising activities of selling food and drink, or organisational matters of preparing the venue or registering attendance, than actually attending the talks given on that day. At the first community information event at which the group engaged in fundraising the group members had gathered almost two hours prior to the event (field notes 31.03.2007). The two had put up two large banners, one in German, one in Turkish, saying: Turkish speaking self-help group Berlin. The women were sitting in a little alcove at the entrance of the main auditorium next to big commercial coffee machines and sandwich fillings of cheese, veggies and salads. Bread, coffee and tea were still missing and eagerly awaited. Yılmaz strolled outside for a cigarette while Defne and Sadık put up more posters – unfortunately of last month's event, but those were left over – at the front door of town hall and lecture room. Yılmaz's assistant began laying out leaflets for May's event and the attendance lists in the little anteroom of the huge meeting room. Finally, Nare arrived – forty-five minutes late, to add to everybody's nervousness – with the missing bread and Ahmet pulled up

with his brand new estate car and his three daughters helped us carrying pallets of little water bottles, a big Turkish teapot and a huge thermos of coffee to the town hall. Back at the meeting room everybody was busy preparing food and drinks, a price list (water and sandwiches: 70 Cents, tea and coffee: 50 Cents) was put up and Yılmaz's assistant was setting up tables and chairs for registration. Two teenage girls, the daughters of Yılmaz's assistant, sat down at one table, and I made myself comfortable next to Ahmet's wife Banu at the other table. At around 12.15 pm, people from the community started arriving. We welcomed them in and asked them to take a seat at our little table and give us their details for our attendance sheets. In the end, around seventy people had gathered – and Yılmaz was disappointed by the meagre turnout considering our fundraising efforts. “Must be the gorgeous weather”, we both marvelled.

All seemed to enjoy these events very much, working together, pulling off huge events, and raising some money for the group. Interestingly, not every self-help group member had diabetes themselves. Some were family members like Banu and her daughters, or Yılmaz's assistant and her daughters. Others just enjoyed the social aspect of the group but were met with suspicion at some occasions. Some people appeared to have become very involved, planning new events well ahead, and spending much of their spare time on organisation. Many, it seemed to me, jumped at the opportunity to engage in such a social life, enjoying both company and accomplishment. The programme of such events then became a minor matter. Granted, most of these talks were of a fairly basic introductory content with which most of the regular members were familiar anyway. Therefore some of the women preferred guarding their food stands with many cups of tea and chats, and focused their interest on talks on more seasonal or specialist topics, or on service changes due to the current health reform.

### *The burden of sociality*

Sociality, however, is not inevitably a positive experience. The group offered an environment for social engagement, company and support and was, thus, a positive experience for its members independent of their illness. At the same time, it had a direct and positive influence on their health as it provided the ideal assistance for

individual diabetes management. Sadly, however, the social engagement with the group could also backfire. Some husbands showed a growing suspicion about the group and some women had to leave the group and therefore the support for their diabetes control. Group belonging and social interaction could create tensions and conflict and therefore challenge the social lives outside this group context and ultimately inhibit diabetes management, as Sevim's story will illustrate (field notes 17.08.2007).

I visited Sevim late in summer to catch up with her after her long stay in Turkey. Chatting away, she added matter-of-factly that, quite possibly, she would not attend the self-help group meetings anymore. Her husband had told her not to go anymore and she was arguing with him quite a lot lately anyway. Sevim explained to me that he had become jealous about her involvement in the group. She enjoyed not only taking part in the meetings on a regular basis but had been quite active in their latest fundraising efforts of selling tea, coffee and sandwiches at the big community information events. She worked in catering and enjoyed selling coffee and providing the group with the huge coffee makers from work. She had also helped Yılmaz to buy water and other provisions before and her husband got angry that she would be alone with Yılmaz in a car, and spent so much time with him and the group. Her husband kept on asking her why she was going there, and she had also once got in trouble when introducing a friend to the group who also suffered from diabetes. Their husbands talked about this, and the friend's husband got equally upset about the situation. Subsequently, both women were in trouble and were told not to visit the group anymore. Sevim looked upset when she told me the news but also tried to explain: "Our husbands are different, you know", she tried to shed light on the situation. "They don't want their women to meet with other men – as if we would be approached by every man we know – and as if we were interested or couldn't tell them off."

Sevim also added that her decision against the self-help group was only partly due to her husband. She also felt that attending the group, and actively helping with raising money, cost a lot of energy. Sevim had told me before that she was suffering from depression – which was not only related to her marital problems but many concerns such as her two unemployed teenage children. Feeling depressed, tired and

sluggish made it hard to make it to the group on a regular basis. But really she seemed to like attending the group and felt sad about that new development. I asked her why her husband would not be interested in her diabetes at all and why he could not attend the meetings together with her but Sevim quickly shrugged off this idea. “He would never come along. He is not interested.”

Here, the group had become a burden for Sevim. Her engagement with the group added to her conflictual relationship with her husband, and the attendance itself had become difficult in her current life circumstances. Her group membership was not necessarily a positive experience and as she became *too* social with the group’s activities, it challenged her existing social relations. As these tensions could not be negotiated, Sevim decided to leave the group and therefore gave up both her social engagement and ties but also the practical and emotional support for her diabetes management. The social life of self-help group and the way it has to be negotiated with other social engagements could thus even have a negative effect on health and well-being and not necessarily always provide a positive supporting function.

#### *Civil participation and everyday bio-activism*

The way in which the core members of the self-help group became increasingly involved in activities of the association, acted as confident representatives at self-organised community events or public diabetes conferences and took on administrative roles, might suggest something more than mere social participation but societal involvement. By that I mean that the self-help group membership enabled civil participation in the organisation and representation of a civil grouping that most of the involved had not experienced before. Women such as Rana, Sevim and Feyza might have applied how they privately negotiated and managed their family and work lives to such event planning, yet the club life of organising public events and representing one’s group to the public was new to them and took some out of their comfort zones.

Becoming increasingly confident in such activities, the women also started to adopt a more active civil role. Through the group they learned how to assert their civil entitlements in formal healthcare. They learned about the kind of services

chronically-ill and socially deprived patients are entitled to in the state health insurance, they learned what kind of provision one can demand and how and where to demand it. As a result, they were confident to request patient education and specialist care when they felt inadequately treated by their family doctors. Probably the most telling example of such patient right's claim involved the so-called DMPs, Disease Management Programmes (in English, not a German let alone Turkish translation) for chronic illness patients.

These DMPs were devised as part of the recent healthcare reform and involved the state health insurances signing up their patients who suffered from particular chronic illnesses such as diabetes for a structured care plan that should ensure standardised quality care with regular, monitored check-ups. Patient lobbies such as the self-help group welcomed the DMPs as tools that would ensure that doctors adhered to good practice care and that supported patients financially by covering most out-of-pocket expenses. Many doctors, on the other hand, saw the DMPs as a major bureaucratic effort that cost time and resources rather than ensuring better quality care and they, no doubt, did not appreciate being controlled from the outside. The self-help group would frequently advise current and new members to request the DMP from their doctors, knowing that many doctors did not like to sign too many patients to the programme, at least not "problem patients". Some doctors indeed told me that they were reluctant to enrol their migrant patients to the DMP and explained that these patients tended to miss appointments due to their frequent travels to Turkey and such failure to attend would fall back on the doctor's quality of care. Some – doctors, patients or other healthcare workers – would also comment that DMPs were merely another business venture for health insurers that made the insurer more money than saved the patient costs, and the insurers' quite aggressive campaign to get Turkish-origin patients on board made me reach a similar cynical assessment. Attending that year's World Diabetes Day conference in Berlin, for example, I saw how the biggest local insurer had staffed their booths with largely Turkish-speaking promoters. The frequent Turkish-language advertisement letters sent to their Turkish-origin clients told a similar story. This, however, also made clear, that most chronically ill German patients were aware of DMPs and that it was illiterate or non-German speaking migrant patients who needed targeting as they

were unaware and missed out on this government induced scheme. The frequent members of the self-help group all took part at the DMP and also supported each other in correspondence with the health insurance and how to negotiate mandatory check-ups with summer stays in Turkey.

I would argue then, that the women, in particular, seemed to have replaced their fairly inert marginal position in society with an active role in club life and maybe even more strikingly with an active and confident patient role that negotiated healthcare provision and funding. Such notion of civil participation might invite reference to Petryna's intriguing ethnography on Ukrainian assertion of "biological citizenship" (2002). She explored how, in the backdrop of post-socialism, "the damaged biology of a population has become the grounds for social membership and the basis for staking citizenship claims" (ibid. 5). She traced Ukrainian citizens from being Soviet subjects that were not fully informed about the dangers of the Chernobyl reactor explosion to being democratised radiation damaged victims that can claim compensation for suffering. Such injured biological selves were thus evoked in order to negotiate state provision and citizen right. The concept is also formulated by Rose (2007: 132) "to encompass all those citizenship projects that have linked their conceptions of citizens to beliefs about the biological existence of human beings, as individuals, as men and women, as families and lineages, as communities, as populations and races, and as species". A similar concept is that of pharmaceutical citizenship, that Ecks (2005) uses to describe how people with depression in India are deemed marginal, while antidepressants promise integration in middle-class mainstream society.

Is "biological citizenship" or "pharmaceutical citizenship" thus applicable to my research participants and would it be useful to understand their experience as a social practice of negotiating citizenship on the basis of their diabetic bodies or their success control of them? At first sight, the members of the self-help group indeed repositioned themselves as no longer marginal, but as citizens with rights to certain healthcare provision and assumed such a position within a healthcare system that did not encourage much participation. They did this quite late in their lives in German society – often thirty years after settling down in Berlin – as diagnosed diabetics.

Such uptake of the citizen's role that is entitled to rights happened due to their diabetes but perhaps more significantly due to their subsequent encounter with the self-help group that brought out such citizen awareness. But was their engagement in the management of their group and their illness about being citizens, or perhaps patients, and was their "biological belonging" based on being Turkish migrants or diabetics? Such ascriptions seem incidental. Indeed, the group and their social participation enabled many to challenge their marginal societal position. My research participants, though, did not consciously evoke civic rights or participation, and rather learned to assert a mainstream (as opposed to marginal) patient position within the German healthcare system. Insofar as the state was represented in DMPs and bureaucratic rules about association statutes, it could be argued that the group was engaged with the state and its healthcare system. Yet they did so in search for appropriate care and not so much for citizenship and state acknowledgement. Likewise, the state did not seem to acknowledge their "expert patientism" that contradicts the public image of challenged, marginal migrant patients. Their experience could be thus better understood as some sort of "bio-activism" as a more fluent, situational and haphazard social practice. It was not about being citizens but about being patients, not demanding rights or recognition as much as good care (cf. Mol 2008: 31, on citizenship vs. "patientism", see also Chapter 6.2).

Above all, I suggest understanding the self-help group's biosociality or bio-activism as a mundane everyday practice that is motivated by everyday concerns. As I argued that this biosociality was not born out of biotechnological innovation, it also does not involve lobbying for access to such high technology. Diabetes diagnosis is not dependent on sophisticated and exclusive biotechnology but is today offered at any large supermarket's pharmacy section. While there is some medical research into pancreatic transplantation and genetically modified insulin analogues, the most effective treatment remains to this day nutrition. Political lobby work is therefore often focused on guaranteeing adequate patient education. More so, people learn to "lobby" for everyday access to care, how to request specialist care or discuss their medication with their doctor. Finally, social organisation is not happening on virtual platforms, but the self-help group and most health professionals involved in Turkish diabetes care in Berlin operate on a very low-tech level, using phones not emails,

flyers not websites, town halls not virtual chat-rooms. Nonetheless, an information network has developed in recent years, though a rather more personal one than virtual talk-boards. All in all, this is a “low-tech” bio-activism, but has concerns and demands for better diabetes care at its heart.

### *Conclusion*

In this chapter I argued that diabetes was identified as a communal problem that required a communal response. While this “diagnosis” was initially done by those closest to the problem, Turkish-origin doctors, the response also involved patients – organised in a self-help group – and other interested community members. The self-help group provided its members with the opportunity for social and perhaps civil participation. While this sociality could be quite separate from the illness experience itself and invested interests went beyond health concerns and included group organisation and representation, the social experience of diabetes was at the same time linked to individual, lived and embodied experiences of diabetes, as explored in Section 2. For the members of the self-help group, their diabetes provided them with the chance of socialising, getting out of the house and meeting like-minded people. Many of these (mostly elderly) people suffered from some loneliness, had lost partners and friends, their children had left the house, and they were retired or unemployed. With their diabetes they gained another opportunity to meet new people and start new activities. Many embraced the challenge of raising money for the group, and for example became very involved in planning what kind of food and drink could be sold at information events. In fact, especially some of the women had not previously had such an opportunity of social involvement, campaigning for something, or being part of a larger group (without their husbands present). The group’s effort to ensure formal healthcare provision for themselves, understanding the system, asserting a position as mainstream rather than marginal patients, and claiming patient entitlements, for example for specialist care and education, means that diabetes also provides the opportunity for civil participation in what might be referred to as “biological citizenship” or, omitting the state, as “bio-activism” or “biosociality”. Rabinow’s (1996a) biosociality seems indeed fitting; a group formed around their diabetic bodies, forming a mutual support network, a place for

identification and representation, and a place to assert better care. Yet unlike Rabinow's biosociality, Turkish Berliner's bioactivism does not focus on lobbying for patient rights or diagnostic tools but largely involves giving support, information and confidence to assert and achieve better everyday care, or simply social company. Indeed, unlike Rabinow's conceptualisation, social engagement here is not born out of technological innovation and imagined biotech futures that shape present understanding. Nonetheless it is an innovative sociality that emerged in a specific time and place. Contrary to biosocial accounts that argue that poverty excludes biosociality, social momentum here is generated from marginality and deprivation, social inequality, and local politics. But it also gains momentum from personal experiences of social isolation as well as the appreciation of sharing diabetes knowledge.

## Chapter 8: Positions and politics in diabetes care

This chapter sets out to disentangle what lies beneath communal activities within and through local diabetes care. If diabetes among Turkish Berliners can be understood as a kind of biosociality, what does it look like? This biosociality involves individuals and groups, various settings and events. Berlin was an active field for migrant health initiatives, both formal, for example represented by Turkish-origin doctors, and informal in form of the self-help group and community information events. Initiatives were sometimes generally framed as “health in the community” issues, but often addressed as specific problems such as diabetes – which, incidentally, served as a test case or telling example for wider concerns such as obesity or consumerism. The participants of such activities and initiatives presented themselves as a sort of network of involved individuals and groups (“one knows one another”), however, as a network that was often perceived as “dysfunctional” (characterised by mistrust and competition) or sometimes – more paradoxically – as “non-existing” (meaning it lacks co-operation). They considered this network flawed with conflicts, while my own conceptualisation of a local network faltered due to the complexities of positions and roles within these encounters. While anthropologists have acknowledged in recent years that our investigation should expand from a focus on doctors and patients to activist groups, policy makers and industry, they have failed to recognise that such positions and sites and their interactions with one another are more complex than often described. In this chapter I look at Berlin’s field of informal diabetes care, its participants, their varied roles in varied settings and events. While biosocial literature imagines the patient-cum-activist as well as scientists, therapists, businesspeople, I will suggest that a patient can be a lay person and an expert at the same time, a student and a teacher, an activist and a businessperson, and position herself fluently in different engagements and encounters. I argue that as positions and places are flexible and complex, this creates much space for solidarity and conflict, co-operation and competition in a local political economy of market, hierarchies, power tensions and ethics.

As in the previous chapter, this is not so much about health or the ill body but about those people and places that form around diabetes care. By that I mean, this

chapter is not about politics on the diabetic body (e.g. as in Foucault's biopolitics) but about politics because of diabetic bodies. It thus includes a wide range of people, not only those living with diabetes or health professionals in diabetes care.

### 8.1 Berlin's field of informal diabetes care

My ethnographic investigation of Berlin's Turkish diabetes biosociality proved a diverse and eventful endeavour. I not only encountered doctors and their patients, clinical settings and private homes but active interest groups like the self-help group and the medics' society and the enigmatic personalities that led such groups, shaped activities, interactions and avenues of involvement. People would describe this interaction as a network of informal diabetes care. Trying to disentangle these relations and structures analytically, I deliberately use the organic metaphor *field*. Neither the locally used "network", nor more recent technologically framed concepts of "assemblages" or "biocrossings" can account for the complex and fluent involvements and interactions that I encountered but imply deliberate structure, organisation or construction. After deciding to describe this activity and sociality around diabetes care as a field, I explore the kind of people who occupy this field, the varied roles that belong to this field and the varied settings and events as such roles are taken up.

#### *Diabetes as a network*

During my fieldwork participants frequently evoked the imagery of network (in German *Netzwerk*). They referred to themselves as networkers in healthcare and regarded diabetes as an ultimate "network illness". They explained that diabetes affects a whole network of organs that are connected and compromised in their function by the sweet blood of the diabetic body. Glucose-rich blood clogs arteries and strains the kidneys; it damages the nerves of eyes, hands and feet. Diabetes care, therefore, requires the attention of a network of health professionals: the family doctor, the diabetologist, the nutritionists, the podiatrist, the ophthalmologist (eye specialist), the cardiologists, the nephrologist, the social worker and so on and so forth. These health professionals should ideally work together and form a therapeutic

network in the interests of the patient. While this “network ideal” was shared by many involved, tensions between participants of this evoked network resulted in a general frustration and cynicism that it was, in fact, a dysfunctional network which was more guided by financial competition and personal feuds than genuine professional concern for the patient.

My own conceptualisation of above relations, collaboration and dissonance was, halfway through my fieldwork, also readily framed as a local, informal network of diabetes care. This invites reference to Riles’ (2001: *The network inside out*) consideration that in some of our contemporary research projects our analytical tools have already been appropriated by the research participants. “Network” is a concept widely used in healthcare, public health and health NGO circles<sup>37</sup>. Yet social network analysis is also an established analytical and methodological approach in (mainly quantitative) social sciences. Scott (2000: 2) describes social network analysis as *the* analytical tool for relational data, i.e. the data of contacts, ties and connections, group attachments and meetings which relate one agent to another – as opposed to attribute data of attitudes, opinions and behaviours of agents (which requires variable analysis, i.e. the analysis of variables such as income, occupation, education etc.). I attempted a social network analysis during my fieldwork, when I realised that the diabetes patients I met at the self-help group shared the demographics of poor, uneducated, first generation migrants, yet showed confident diabetes knowledge and control. The difference was, of course, their belonging to the group, and their social relations that made access to knowledge and support possible.

Social network analysis was developed in order to investigate social structure rather than function, and as sociologists saw networks in particular as a (new) way of capturing social structure. Some (e.g. Mitchell in Scott 2000: 32) insist on a further distinction of *networks* of interpersonal relations and *structures* of institutional relations, thus distancing themselves from general structuralists. The earliest, most formative social network analysis are Lee’s (1969) study on how information on (illegal) abortionists is acquired by women, and Granovetter’s *Getting a Job* (1974),

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<sup>37</sup> On networks of care, e.g. see Horden and Smith (1998); on the impact of social networks on health, e.g. on stress and mental health, see Haines and Hurlbert (1992); on sexual networks and HIV transmission, Parker (2006); on religious social networks, which try to fill gaps of governmental social welfare, see Clark (2004); Cooke and Lawrence (2005).

in which he famously discovered that it is in fact weak, not strong, social links through which vital and new information is acquired. Both studies were interested in knowledge networks, that means how knowledge is transported through social networks and how these networks are maintained.

Later developments of social network analysis moved increasingly away from a pure methodological approach and saw “network analysis as basis of a relational sociology”, replacing “approaches that have stressed culture and meaning” (Scott 2000: 37). This, however, assumes that it is the structure that is interesting about networks not which meaning actors attribute to these structures. Social network analysis analyses connections and their density and direction. This fails to account for what makes such connections meaningful, for example to explore the basis of such ties as a joint endeavour to provide informal healthcare and to share, for example knowledge, and what kind of knowledge is shared, negotiated, or withheld. Moreover, social network analysis does not provide a framework to map hierarchies and dominations, sympathies and antipathies, solidarity and tension.

Nonetheless, some anthropologists have valued the analytical qualities of social network theory. The urban anthropologist Boissevain (1979: 392) saw it as a “tool which enables [...] to deal with the relation between face-to-face interaction and institutions in an extremely complex social field. [...] Network analysis asks questions about who is linked to whom, the content of the linkages, the pattern they form, the relation between the pattern and behaviour, and the relation between the pattern and other societal factors.” Boissevain, however, queried the overemphasis on technique and data, the reliance on mathematics and methodology rather than “human life” and wondered if a purely quantitative focus on network structures produces trivial (descriptive) results rather than helping to understand these structures. Wellman (1983: 165) agrees with seeing a value in social network analysis as previous studies tended to lump people, for example white, female, Protestant, American, voting Democrat, as one group neglecting social structures and the relations among individuals. As much as he can see merits in the development of mathematical tools he also commends new approaches of using fieldwork and archival methods to study network structures (Roberts 1973; Bodemann 1980). He suggests: “The essence of the network approach remains not in the method used but

in posing questions and searching for answers in terms of structured connectivity.” (Wellman 1983: 171/172)

My own attempt of an anthropological social network analysis helped to place emphasis on a network of diabetes care, the local interactions and transactions that alluded to more than commonalities of Turkishness or diabetes, of being a patient or doctor, and identified sites of relevance, for example town and wedding halls, that were not anticipated. Yet I soon realised that an ethnographic exploration struggles to come up with the neat structures, connections, nodes and focal points that a social network analysis requires (just as my research participants struggled to map the neat network ideal on their lived experience of “networking”). Law and Mol (2002) argue that such structural approaches aim and fail to simplify and order “complexities”. Accounting for complexities, they argue that networks cannot be neatly traced, “they add up and do not add up” at the same time, are both “functional” and “dysfunctional”, and there are multiplicities of networks. My research participants formed indeed connections in what they perceived as diabetes networks but the network idea could not – neither as a method, nor a metaphor – capture that interactions were fairly unstructured and messy, some ties broken or disrupted by conflict. Most importantly, it could not portray that individuals could occupy various positions and roles within these interactions, be patient, client, activist and expert at the same and different sites and time.

#### *Assemblages, biocrossings and fields*

The notion of networks implies ordered structure, a certain completeness that neither my ethnographic methods could fulfil nor one that seems particular fitting to describe what is going on in multiple layers, positions and sites. Indeed it is commonly suggested to refrain from using the same terminology as research participants, in order to step back analytically. Commonly used in recent years is the idea of “assemblages” as the concept that tries to capture loose and partial connections (Strathern 2004a), changing scapes, formations and procedures, involving bodies, technologies, ethics and political economies (see e.g. contributions in the edited volume of Ong and Collier 2005). Gibbon and Novas (2008: 1) thus describe Rabinow's concept of biosociality as “biologies and socialities that are being

assembled by a range of practitioners and social actors across a variety of interconnected sites such as laboratories, biotechnology companies, patients' organisations, medical clinics, biomedical charities and state institutions". While this concept of assemblages captures well the complexities of involvements across domains while, unlike the notion of network, also suggesting certain unpredictabilities (Bharadwaj 2008), I fear the rather mechanic assemblage metaphor nonetheless alludes too much to a technical construction.

Bharadwaj (2008) proposes the notion of biocrossings in his exploration of IVF and embryonic stem cell technology. His scope ranges from cells, tissues and bodies to the state, science and capital, and understands biocrossings as "transfers between biology and machine and across geo-political, commercial, ethical and moral borders" (ibid. 102). Moreover, with his idea of biocrossings he expands "bio" from human biology to "biologically based biography, be it individual (e.g. an illness narrative or cultural/'ethno' conception of human body) or institutional (bio-science/medicine/technology etc.)" (ibid. 102). Such "bios" are altered through "multiple crossings across various borders and thresholds [...] imploding boundaries between nature, culture, biology and society" (ibid. 103). Again, however, such conceptualisation implies technologies, new futures that are bio-transformed and transforming the bio.

As I argued in the previous chapter, in the case of diabetes-related biosociality, despite all postmodern complexities of fluent positions across domains of social, political and moral economies, I suggest that something much more mundane is going on, nothing radically "cyborg", no changed futures of biologies or lives (cf. Haraway 1991). This is not to say that technologies do not take up spaces and roles in such interactions; clinical number and glucose meters, for example, influence how both individuals make sense of their experience as well as how interactions and transactions between groups and individuals are shaped. Nonetheless, there are no new media and communications involved.

Searching for an appropriate concept to understand such connected sociality around diabetes care in Berlin, I propose the, perhaps old-fashioned, term "field". Field, in my opinion, does not imply a network structure of specific focal points, nodes and linear connections, nor does it allude to the technical or "cyborg"

constructions that assemblages connote. Field is a less “high-tech” metaphor, more organic. It allows for, but does not delineate, connections, assumes participants but without static positions. Note that I am duly omitting the idea of a “level playing field” in my conceptualisation, as “my field” is riddled with trenches and fences, with hierarchical structures, power inequalities, discordances and encumbrances.

### *Positions and roles*

What does this field of Berlin’s Turkish diabetes care, then, look like, and why does it require an organic metaphor for description? Involved was a variety of individuals, groups, places and domains. My particular focus was on the self-help group and their awkwardly opposing organisation, the medics’ society. Certain colourful personalities such as Yılmaz and doctors like his friend Dr. S seemed to dominate such groups and their representation, yet equally influential seemed quieter individuals such as the patient consultant Hilal, the drug rep Sedat, or self-help group members such as Rana, Sevim and Feyza. I paid less attention to – in my opinion – more marginally influential activities of certain NGOs and working groups, and the business of private nursing care. Yet all these individuals, groups and organisations shared their involvement in local diabetes provision; that is why I tried to organise them in some sort of informal network of diabetes care. The notion of network became a problematic one as any attempt to ascribe roles and settings – and events – to certain people and groups in some sort of graphic mapping failed. A mapping failed because people held multiple roles and positions. Unlike other biosocial literature, I met not only the patient, the scientist, the drug representative. While such literature imagines the patient-cum-activist, I encountered the patient-cum-activist-cum-businessman-cum-manager. I began to list typologies of those involved in healthcare:

People involved held roles as: patient, lay person, consumer, client, community member, doctor, nurse, specialist, academic, researcher, expert, consultant, teacher, businessman, drug representative, manager, leader, politician, activist, NGO/charity worker, nutritionist, podiatrist, diabetologist, nephrologist, cardiologist, eye specialist, optician, diabetes consultant/assistant/nurse, patient consultant, diabetes union working group member, self-help group member/leader,

medics' society member. They moved and interacted in various sites: the family doctor practice, various other specialists' practices, clinics, town halls, wedding halls, lecture halls, private homes, university, TV studio. These sites were private or public spaces, clinical or non-clinical, civic or commercial. Finally, people met at these places for various events that required respective roles, events such as: consultations, check-ups, group meetings, community events, talks, TV and radio programmes.

While it is easy to compile such lists, trying to ascribe research participants neatly to such roles or particular settings is a more difficult exercise. Yılmaz was the self-help group leader, a management and administrative position he occupied confidently after years of self-employment. When he was approached by the medics' society to take on this role of the leader, however, he was insecure as he considered himself a layperson, a non-medically trained person that could not possibly inform anyone else. "But I'm not a doctor!" he exclaimed when first asked to step up to the challenge. He was, indeed, a patient, someone living with diabetes and therefore ideally suited for a leading role in a self-help group. Yet had he not acquired any special knowledge about his illness. Accepting the task he turned into a committed student, undertaking numerous training courses that turned him into an expert of his illness, albeit being denied formal qualification in form of a certificate that would only be given to someone with a nursing or nutrition background. In his leading role in the self-help group he used this expertise and passed on his knowledge as a teacher and a consultant for both outsiders and members of the group. Campaigning for his group made him become a media presence, regularly appearing on local TV and radio, and leading community events both as an expert speaker and as an organiser of talks by medical and social law specialists. As an activist, he strove to both expand the reach of his group and to raise awareness about diabetes in his community. As a well-known community member, he was successful at this endeavour, being an outspoken and sociable person that had already known many Turkish migrant families in Berlin through his door-to-door sales job. His background as a businessperson also became handy in his administrative role for the self-help group as this charitable organisation nonetheless had to engage in extensive fundraising to cover event costs for speakers and venues as well as running costs through the year.

In short, Yılmaz was a layperson, diabetic patient, student, teacher, expert, consultant, activist, manager, organiser, leader and businessperson – depending on settings, how he positioned and represented himself and was regarded by others. Such positioning happened fluently and situationally, occupying roles sometimes at once and inseparably, or purposely and deliberately selectively.

I understand that this is not a new insight into how people take on social roles in their everyday lives; I can be a PhD student, activist, friend, wife, musician – at the same time, or depending on situations, sites or domains. Yılmaz, for example, is of course also a father in his private life, a salesman in his work life, and so on. What I am suggesting here is that diabetes adds equally plentiful social roles. Within this domain of health/illness most anthropological exploration would ascribe him solely the role as a patient, or alternatively as a self-help group leader and perhaps activist. I suggest to widen the scope and, as described above, add that the administrative side of the self-help group required Yılmaz to adopt the roles of manager and businessman, and that the importance of information to the self-help group demanded from Yılmaz to be a teacher and consultant (and as a prerequisite a student of such medical knowledge).

Moving on from Yılmaz's example, such varied and fluent positioning in social roles applied to most of my research participants. The doctors seemed to occupy equally plentiful and often seemingly paradoxical roles. Their roles as family doctors were a complex job description in itself, being carers, healers and consultants for their patients, as well as businesspeople, managers and trainers in their high-profit practices with often extensive staff. Some were researchers for their academic career, conducting studies in their own surgeries, writing papers and giving talks. Many of the Turkish-origin doctors were active in their medics' societies, as members, bookkeepers, secretaries or board members. Belonging to groups could be political, some doctors were actively engaged in minority groups such as the Alevi community. Some doctors were, then, prominent public figures, assuming roles of local politicians or frequently appearing in local media to inform and comment on health issues but also general community concerns.

There is also the drug-representative Sedat. At first sight he represented “big pharmaceutical industry” to me that had a strong presence at the big information

community events which the self-help group frequently organised. There were often various drug companies present at these events but Sedat's booth had always a central position. His company was mentioned as the main sponsor during introductory speeches, and Sedat's brochures, pens and free testing were always very alluring to every attendee. The self-help group also got free meters for its members and used the meters to recruit new members. Vouchers were handed out that event attendees could redeem at one of the small group meetings if signing up as a new member. Sedat talked much about the high prevalence of diabetes among this migrant population group and what a great market of potential clients Berlin was. Having said this, Sedat did not only consider himself a businessman. He also represented himself as a member of this population group and felt quite strongly about "doing something for his folks". Sedat donated much of his private time and tended to help and stand in when Yılmaz could not hold group sessions. He was a devoted teacher and consultant much liked by the members of the self-help group, giving members information about diabetes, insulin and drugs (not surprisingly) but also everyday life issues. During a session in early summer Sedat ran the group through the scenario of a wedding in Turkey. We had to come up with all the issues to which a person with diabetes would have to pay attention. Much food, for example plentiful sweet fruit and sweets, and the stress of heat or, for example, being the concerned bride's mother, would elevate blood glucose levels quite significantly. On the other hand, he made us tease out that much dancing, sweating and alcohol could also lower blood glucose levels during the course of this wedding party. Sedat also used to assist Yılmaz with teaching material, for example clinical numbers and risk diagrams, and helped the group with administrative issues and fund raising. I met the drug-rep Sedat, therefore, not only as a businessman, but also as a community member, a teacher, consultant and confidant to the group, and thus in a way, even as an activist for the group. In any case, he was more than simply a representative of the pharmaceutical industry.

To pick a last example of complex roles and positions, there were the nurses. Here I not only struggled because I found many roles within the category of nurse, but also that being a nurse meant various job categories in Berlin's Turkish migrant diabetes care. There were those nurses who held positions as practice nurses, a badly

paid and low-qualified job in Germany that is often done by young women with low school education who often leave after several years to change career to better paid jobs or for marriage. Yet the nurses I got to know had made an effort to gain extra qualification, being trained as diabetes nurses and often took pride in offering education sessions in their patients' language that took their patients' needs into account. They were carers, experts, teachers and consultants. These nurses held difficult positions within the hierarchies of the surgery; they were young, low-skilled women who, albeit being experts of diabetes, were ranked well below the older, male doctors. Indeed I always first heard from doctors, during an interview or a public lecture, about their efforts of Turkish-language education sessions. Visiting these sessions then, these doctors were absent while their nursing staff practised what their bosses had preached. On the other side of the spectrum was, for example, Hilal, my good acquaintance and informant, the patient consultant. She was trained as a clinical nurse (ranked much higher in the German healthcare system than practice nurses) and held an extra Master's degree. Such university qualification is unusual for nurses in Germany and she aimed for an academic career, preparing her PhD proposal at the time when we met. She was another kind of expert than the diabetes nurses, and in her role as a patient consultant she worked fairly self-organised within her non-governmental organisation, and donated much of her time to establish co-operation between interest groups, lobbying for better migrant health provision and giving public talks. While being a nurse, consultant and activist, she was also a confidant and support to the self-help group, helped organising community events and helped out at the small member group meetings. Finally, there were the entrepreneurial nurses who started "culturally-sensitive" nursing services. These services seemed to be founded and headed by determined women who started out with the low qualification of nursing and used their business drive to employ Turkish-speaking staff and provide "culturally-appropriate" care and food for elderly migrants. Within a few years a thriving market of such Turkish care services had developed as well as a fierce competition between these providers.

Certain roles would also not confine to certain sites and events, and sites would not necessarily match their purposes. The self-help group met weekly, quite appropriately in a clinical and academic space, the small lecture hall of a private

hospital. This space, however, was made available by a doctor outside the medics' society but who was active in a non-governmental working group for migrant diabetes care. Although he worked at the hospital, the arrangement was not entirely official, not formally accepted but tolerated by hospital administration, and therefore for free. Community events did not take place in a clinical but a civic space, the town hall, yet had to be hired commercially for a hefty fee. At the event, then, Sedat was indeed the drug-rep behind his booth, but he could be a consultant at the same time, giving some tips about diet to a self-help group member who stopped by to greet him. A doctor could be the event's speaker but viewed by others as a businessman who not only requested a fee for his appearance but was also suspected to merely attend in order to advertise his practice. This example also reiterates that sites and roles might be taken on purpose, others by chance or unconsciously, or positioned differently by others. The doctor might represent himself as a philanthropist but be suspiciously viewed as an entrepreneur.

As confusing as above attempts to outline the complexities of roles and sites and their positioning and relations might seem, this is exactly what I aim to convey here. That it is a challenging endeavour to map these interactions, spaces and participants in coherent structures or orders. They are inherently linked to each other – after all, social roles are what we present or perform to others or how others perceive us (Goffman 1959) – but the question is how to describe such sociality. My aim was to expand the scope of many biosocial accounts that only ascribed limited roles to participants of biosociality.

## 8.2 Ties and tensions in diabetes care: economics, politics and ethics at stake

If the field of Berlin's Turkish diabetes care can be characterised by diverse participants who represent multiple roles and occupy fluent and complex positions in interactions and transactions both as individuals and groups, why is it significant to alert to such complexities? What is at stake for a patient/expert/activist/entrepreneur? An immediate answer would be that this lively field of Turkish diabetes care was not

a harmonious one, nor one guided solely by diabetes provision. Those involved knew each other, and many actively co-operated with each other, in which case each new encounter during my fieldwork often automatically yielded further contacts. On the other hand, interactions between participants and groups could be tainted by distrust and conflict, and my own connections with some would prove suspicious to others.

Rabinow (1996a: 102) imagined his biosocial groups to “have medical specialists, laboratories, narratives, traditions, and a heavy panoply of pastoral keepers to help them experience, share, intervene, and ‘understand’ their fate”. He argued that science and technology are increasingly and inherently connected to industry and venture capital and such transform and create future patient selves and socialities. I agree that we have to expand our scope to acknowledge and understand the influence of politics and economics. Diabetes experience always also involves those who are not ill with diabetes. There are those involved in the provision and organisation, patients and health professionals, but also those involved in politics, policies and business. Therefore, local political, and always also economic, arenas inherently influence how diabetes care is delivered and achieved. I am arguing here that in the field of Turkish diabetes care in Berlin such influences and interrelations played out in the everyday experience and practice of participants. This is largely unexplored in biosocial literature. Social interactions of Turkish diabetes care were deeply embedded in a local political economy and in turn provided a platform for political and economic engagement. There were not patients, health professionals, scientists and drug representatives on opposing or distant sides. I will explore how economics, politics, power and hierarchies, and moral economies affected *and* motivated all those involved in this field, and shaped their fluent roles within care and capital, co-operation and conflict, solidarity and competition. I borrow from feminist literature that uses micro-politics as “the ways in which power is relayed in everyday practices” and how “conflicts, tensions, resentments, competing interests and power imbalances influence everyday transactions”, networks and coalitions (Morley 1999: 4). In order to understand everyday communal, social experiences with diabetes, I suggest understanding the local field of informal diabetes care (in the form of the self-help group, community events, medics’ society, local media health programmes) as a social, political and economic space that every participant

occupies, shapes and challenges. In accordance with contemporary accounts of political economy, I will explore how finances, authority and ethics were at stake in this local field of diabetes care.

*Care and capital: obvious economies*

Diabetes in Berlin was big business and for many the involvement in both formal and informal diabetes care was also, albeit not always foremost, a financial opportunity, a commodity – or a financial strain. In any conversation with participants of this local diabetes care about other individuals, groups or organisations, most people's actions were evaluated in light of their strong economic, material component, in other words the chance to recruit members, patients and customers, or the costs of doing so, and I came to a similar conclusion about the significance of the local economics of diabetes care.

The self-help group was my first insight into the underlying material aspect of their activities. Despite being a non-profit organisation, they had to deal with the running costs of their group activities. The community events, in particular, offered the platform to reach a large group of people and potential members; but they also cost a lot of money. The self-help group's leader and manager Yılmaz painfully experienced the financial strain of running elaborate events and weekly group meetings and it was common knowledge that his involvement with the group had made him bankrupt. He, himself, was keen to tell me about his immense private financial contribution and sacrifice towards the group, especially during the first years of the group when he had not found sponsorships for their activities. No doubt it was his experience as a self-employed businessman and the good contacts he had among Berlin's Turkish population that he found financial aid from local entrepreneurs, media and branches of health insurances and drug companies. Due to his efforts they also got their weekly meeting room in a local hospital for free (provided by a German doctor), but the group had to hire the town hall for community events and also had to pay for the speakers. I was amazed to hear that the Turkish-origin doctors, who represented themselves as very active in local diabetes care provision, would request a fee. The group's most important partner to cover these costs was a drug company that gave yearly contributions, offered free glucose

tests during community events and provided the group with free glucose meters. The drug-rep Sedat explained to me that drug companies never really make money with these meters but that the real profit lied in the selling of test strips. He also offered these test strips to the group, however not for free but for a “special price”.

One might be cynical about the involvement of the drug company in this group, yet freebies like the glucose meters proved good PR tools for both parties. Moreover, the drug-rep Sedat who organised this partnership was devoted to helping the group meetings on the rare occasions that Yılmaz could not attend. But not all co-operations worked that smoothly. During my time with the self-help group their biggest concern was their problem with the local Turkish TV and radio stations. As mentioned before, the sudden request to pay for the air-time that the group used regularly to advertise their community events, kick-started a new endeavour of fund raising to cover these new costs. Alongside the groups’ effort to sell refreshments at the events, the drug company’s booth started to charge EUR 1 for each glucose testing, so did the optician booth that offered eye exams. The money raised by these sponsors went directly towards the group’s earning. This alludes to the often blurred boundaries of for-profit and non-profit, business and charity, and market and social interests.

The self-help group also held a rather tense relationship with its founding association, the medics’ society, at the time of my fieldwork. This was not an overt feud over public funding, and there was no open or straight-forward rupture between the groups. It took me a long time to even pick up on this quarrel and the self-help group kept alliances to certain doctors who would still help out at community events, while other doctors would openly boycott such events by scheduling competing events at the same date and time. One of the few times someone gave me a frank assessment of these local quarrels, was when a (German) doctor voiced his frustration (interview transcript 04.08.2007). I asked Dr. W about his perspective on the self-help group’s tension with the medics’ society. He explained that Yılmaz was once on the board of the medics’ society and that they had parted with a big fight. I told him that I had heard a lot of rumours about the fight but never really heard what was happening. Dr. W told me that he only knew that they had an argument and that some of the doctors had started boycotting the self-help group’s events. Dr. W

explained that Yılmaz had invested lots of money in these events and was clearly disgruntled that the medics' society suddenly happened to host such events at the very same time. Dr. W said that Yılmaz was financially ruined now and the doctors did not feel the slightest remorse for their strange feud. At least that was Dr. W's impression. "There are a few doctors one can work with", he added – Dr. S for example, was a very nice man who seemed to be a good partner to work with. Dr. S also seemed to be the only doctor Yılmaz still trusted and liked to work with.

Dr. W seemed to see the root of most conflicts in this local Turkish diabetes field in financial competition between the participants. He went on bemoaning how economically driven all the Turkish-origin doctors of Berlin were. They take on far too many patients and so many of them called themselves diabetes specialists despite lacking any kind of special training, let alone the capacity or time to take care of such high maintenance patients.

There is this doctor in *Kreuzberg* who has just moved to a much bigger surgery although it is puzzling how he can take care of his already quite large patient contingent. [...] He isn't that bad – in fact, he is probably a good diabetes doctor – but he is simply taking on too many patients. [Interview transcript 04.08.2007, p.3]

His anger softened though and he explained that it was not only the Turkish doctors' "fault". He mentioned the name of a German doctor who has famously enlarged her surgery more and more and was finally charged for fraud. "It's the German structures too, that allow for such abuse." As cynical and possibly unjust this view on the motivation of some of the family doctors was, the Turkish-origin family doctors indeed had a reputation among many participants of Berlin's diabetes care field to use diabetes and their offer of specialist care in their native language to attract patients. The German healthcare system structurally condones – or even requires – such entrepreneurship in family doctors as the (often clinical) doctors who criticised such conduct would admit. The more patients a practice holds (and there seem to be no limits) the more money this practice earns.

I could not help but notice the sometimes fierce competition between doctors, and that conflicts did not only happen between groups such as the self-help group and the medics' society but also within groups. The medics' society did not practice such co-operation in their everyday work, albeit always keen to talk about both their

relaxed relationship with the self-help group – who they had to “let go” in order to be truly patient-led – and also the great solidarity within their own society. Hardly explicitly mentioned but often implicitly shaping professional relations, work would not simply be shared with one another. I realised this when a doctor of the society had invited me to his practice for one of his Turkish-language diabetes education sessions (field notes 27.06.2007). He showed me the little room that was equipped with a corner sofa, a personal computer with a big flat screen to show slides and various education materials such as plastic foods. Running me through the many Turkish-language slides of educational information he had made himself, he was keen to tell me how important it was to tailor the education sessions towards this specific audience. I commented that his colleagues at the society must be very grateful that he put this Turkish-language material together, assuming rather naively that members of the society would share their efforts in their quest to provide better diabetes care, an endeavour that they so keenly pointed out during interviews. Instead he quickly told me that he would never share any of this, “after all we are all not only colleagues but also competitors, and I spent a lot of time making these slides”. I would experience many times later that over such competition for patients, doctors would refrain from sharing education material or from referring patients to colleagues in case they cannot meet the education demand due to time constraints.

#### *Hierarchies and authorities: knowledge politics*

The self-help group’s rupture with the medics’ society, however, cannot merely be explained by the economics of funding competition. Perhaps much more significant was the fact that the self-help group increasingly undermined the authority of these medics. Most prominently they would recommend any newcomer to question their family doctor’s expertise and seek specialist care instead. This, incidentally, undermined not only the authority of the society’s mostly family doctors but in fact also the formal healthcare system’s politics of allocating general diabetes care as the family doctor’s responsibility and referring only critical cases to a specialist.

Such knowledge politics (Foucault 1980), as discussed in more detail in Chapter 4, were indeed a common cause of conflict within Berlin’s Turkish diabetes care field. I was often surprised how health professionals would dismiss the merit of

the self-help group, although admitting that the migrant patients would need all the native-language support they could get. Despite the fact that the self-help group occupied the function of self-care in its proper sense as patient-, “lay”-led activity, it nonetheless held a more challenging position in relation to other actors in Berlin’s field of informal diabetes care. The self-help group and its advice and experience was awkwardly placed in between formal and informal healthcare, expert and lay knowledge, and patients and doctors. The group’s activity – perhaps as an organisation that represented a marginalised population group and challenged formal bureaucracies, institutions and authorities – was often scrutinised and sometimes questioned. Yılmaz had a speech ready with all his training qualifications, place and time, the kind of institution and for how many training hours. His first training was organised by Dr S and the medics’ society, then he attended various other courses which he could recount in great detail. In 2001 he received training from Berlin’s university hospital Charité (30 hours with Prof. Dr. H; 30 hours with another consultant, Yılmaz would list). He then completed a course with the German Diabetes Union and a state health insurance and he attended a course at the University of Heidelberg. In the previous year he undertook a diabetes management course at the University of Izmir (he itemised: 160 hours, both theory at school and practical training at the hospital; from field notes 15.03.2007).

While I understood that some doctors would not inform their patients about the group due to above mentioned quarrel, I was surprised that many nurses shared a similar attitude. During a long conversation with a nurse that worked as a diabetes consultant she first questioned her boss’s devotion to his patients. This family doctor would give talks about the vulnerability of his patients yet only had little time for them in his practice. I commented that at least there was support by the self-help group but the nurse quickly doubted the self-help group’s merit for their patients. She knew that he had undergone the same training to qualify as a diabetes consultant but she alerted me to the fact that the formal certificate was denied on the grounds of Yılmaz’s missing medical background. These nurses found themselves, of course, in their own delicate position as diabetes experts that had undertaken extensive training that did not show much in their salaries or in the respect paid by their high-earning bosses. In such a diverse response by a diverse population group, some of these

participants had more recognised and mainstream credentials, as medics or formal members of the diabetes union, but even among health professionals the hierarchy was clear. As young women on the lowest ranks of the (rather male dominated) medical realm, their positions were constantly challenged and I can see how they had to defend their official qualification against those who did not own that paper (as in the case of the layperson-, patient-led self-help group).

All those who got actively engaged in such local diabetes care found themselves in a very politically charged arena between individual, communal and market interests. The medics' society was formed as a structural and political support forum to represent a marginal group of professionals and only later entered Berlin's diabetes care field. The Turkish-speaking diabetes self-help group was founded as a community response to provide informal healthcare for a vulnerable minority population, but the group itself soon found itself in a delicate position of competing for material resources, namely space and funding, and authority over the kind of knowledge and advice they were providing. In teaching to by-pass family doctors, the self-help group has become more than a competing organisation for funding grants but also became a threat to the recruitment of patients for the individual doctors and their (for-profit) practices. Nurses see their expertise and educational services – offered in very limited time and space – challenged by the weekly, more informal, education provision of the self-help group. These might not be surprising tensions in a field with stark hierarchical structures, and fluent positions of experts and lay people, health professionals and patients, business people, politicians or volunteers.

Such knowledge politics even created conflict within the self-help group. To pick an example of such tensions, I am revisiting Rana's dispute with Yılmaz (see Chapter 5). She told me how she felt bullied by Yılmaz about her blood glucose levels and guessed that he was behaving in such unjustly manner as she, every now and then, tended to challenge of some of the information he gave the group. Most prominently Rana shared with the group that, contrary to what Yılmaz said, she had found out that even non-insulin dependent patients can get glucose test strips for free from the diabetologist. For one, her information contradicted that of Yılmaz who generally monopolised the educational aspect of the self-help group. It also

challenged the group's extra income who sold test strips to a bargain price thanks to their drug company sponsor. Finally, and probably most importantly, Rana questioned the moral standing of the group to pursue only the best interest of its members to correct information and best deals. The group, indeed, needed to rely on such integrity and reacted sensitively to any kind of offence, as I also experienced at another incident. I, myself, had a bit of a rough patch with Yılmaz at the time of Rana's dispute as it transpired that Yılmaz would not give me access to the group's membership database. He voiced his mistrust that I would handle the data confidentially and after I worried about what caused his doubts in my integrity I began to suspect that such a formal database simply did not exist. In any case there was a general tension within the group – mainly triggered after it transpired that a member had stolen from the group – and my own unease with Yılmaz was finally resolved silently. He brought me two CDs of photos of the groups events and activities, as an alternative to the membership database.

*Moral economies: ethical performances*

The above examples show that there was more at stake than political economies of financial competition, hierarchies and authority over knowledge. A moral economy that highlighted solidarity and integrity seemed paramount to many participants in the field of Berlin's Turkish diabetes care. Speaking to the doctors, nurses, active patients, drug representatives and nursing home managers involved, the main interest they voiced as individuals or organised in groups was, perhaps unsurprisingly, an altruistic one. It might seem somewhat naïve to take such statements at face value, yet the incentive to help people, raise awareness of health risks, available healthcare and support systems and alleviate the community from some suffering was certainly the most public and not necessarily a less genuine motivation of most people's involvement. It seems often forgotten (by critical medical anthropologists), that doctors indeed do their job to help their patients (for a similar discussion, see Good 1994 and Lupton 1997), and similarly I would argue that the drug-rep Sedat who invests his private time to come to community events or help out with self-help group meetings does so to support "his folks", and that the self-help group recruits people foremost to share their success with those in need of support rather than

banking on more membership fees. Nonetheless this, of course, alludes to a whole range of and not necessarily complimentary motivations.

Albeit being a keen businessman himself, Yılmaz was frustrated about the money-driven attitude of so many people. He told me about the patients who hoped to get their bus fare to the group meetings covered by the group as the weekly expense would strain their social benefit budget. He mentioned the TV station that requested a hefty fee from a non-profit group that is committed to a good cause. And finally, he condemned the doctors who were only keen to expand their patient base without ensuring quality of care. In fact everybody seemed to accuse everybody else to be solely financially motivated and the frequent “money, money, money” lament was as often heard as the usual “Allah, Allah, Allah” to express worry or the educational appeal to “walk, walk, walk” for more physically active lifestyles. Although all involved were very deliberately aware and demonstratively knowledgeable about local politics and material interests, they would nonetheless express their distaste and distrust for too financially or politically motivated participation in what should really be a moral engagement in health issues concerning a vulnerable patient group. The German doctor who frankly talked about the quarrel between the self-help group and the medics’ society questioned the medics’ society’s agenda as mainly market-driven and thus flawed and questionable. Such moral scrutiny in regard to financial interests was commonly and frequently expressed by most of the participants. The self-help group was accused to be just after more members, or of giving particular doctors or care providers a “PR” platform at their events. The doctors were accused of only showing an interest in a current concern like diabetes to stock up their practices with more profitable patients. They abused these patients’ greater vulnerability and need for care while failing to be able to provide them with the necessary time and resources only a practice with few such “high-maintenance” patients can offer. Such an accusation of unethical behaviour was in a way a recurrent performance – one, that never seemed to have any consequences except for some gossip over a glass of tea and the release of some frustration and tension in the plaintiff. It was also always a demonstration of one’s own integrity and reaffirming one’s own altruistic, caring and – emotionally and financially – costly personal contribution to the cause.

*The micro-political economy of diabetes care*

The above ethnography shows that interactions in Berlin's field of Turkish diabetes care were often tense, and money seemed a prevailing and sore issue, even in regard to authority struggles and at the centre of ethical concerns. Karl Marx (1932 [1867]) conceptualised political economy as the constant impact of capital and production on politics, and economic structures always embedded in social formations and political decisions. Here, I follow more contemporary explorations of political economies that broadened the lens to include such issues as gender, ethnicity and ethics (cf. Mutari et al. 1997), by alluding to the complex interplay of economics, politics and ethics.

There is a plethora of literature on political economies of health and healthcare that investigates the influence of political and economic structures and interdependencies on the health of certain social groups, populations and individuals (Singer and Baer 1995). They explore how such structures cause illness (e.g. Doyal 1995: *What Makes Women Sick*) or how market developments and national political decision-making influence healthcare provision (as done in much of the HIV/AIDS industry literature, e.g. Poku and Whiteside 2004; or on genomics and drug development, Sunder Rajan 2006).

Some of this literature aims to omit earlier attempts to distinguish macro (e.g. state system, capitalist markets and globalisation) and micro (e.g. local suffering of health inequalities) and challenges such dichotomies by taking a "micro" look into the science laboratories of the "macro" biotech industry (Rabinow 1999; Sunder Rajan 2006). In the case of diabetes care provision for Turkish migrants in Berlin, it was the provision gap of a strained healthcare system, which failed to accommodate chronic illness that occurred increasingly in marginalised population groups, that prompted such a localised community response. A response that is very much in accordance with (bio-)political and economic strategies to divert care responsibilities to "health-conscious" citizens or civic groups, or customers. Having said this, here I am much more interested in the specifically "micro": the political economy in its local, situational, everyday form. And this is where I depart from literature on biosociality that largely limit their investigations to the influences of capital markets

that involve biotechnology companies, biomedical charities and state institutions (Gibbon and Novas 2008: 1).

I argue that the daily Turkish migrant experience with diabetes was less one of “Political Economy” than “political economy”. By that I mean, it was not about great political encounters with the state and its market economy but about local involvements. Here, I follow the accounts of micro-politics that explore the everyday practices of power, interests, empathies and antipathies, co-operations and conflicts that guide social engagements (cf. Morley 1999). While some individuals, NGOs and working groups were indeed involved in political debates and actions as voiced in conferences and other more political arenas, most actors such as the self-help group and the medics’ society were engaged in another kind of political activity. They did not actually exert explicit political pressure in local politics to improve healthcare provision, but they practised politics of achieving adequate local diabetes care provision by filling gaps with informal “self-help”, and teaching and learning how to gain the most out of the formal healthcare system. Such local political economies of diabetes care included not only the negotiation of informal healthcare alongside the formal system, but also the negotiation of such informal provision within local structures of authority, networks of co-operation and competition, and financial opportunities and constraints. For them it was then not so much about big healthcare politics and their inherent healthcare economics of pharmaceuticals and care finances. Instead it was about everyday struggles for group funding and sponsorships, competition over clients but also over knowledge and authority, fighting for their place in a formal diabetes care provision in a specific market under specific constraints.

### *Concluding*

In conclusion, Berlin’s participants of Turkish diabetes care provision interacted in a field that provided social, political, economic and moral scapes, positions and roles. Unlike the usual medical anthropological focus on patients and doctors, clinical and private spheres, I explore the varied places and roles that such informal social healthcare response creates. While at first sight such co-operations and solidarities could be understood as an informal network of diabetes care, the complexities of

roles and positions taken on, allude more to less organised assemblages, or fields as I would suggest a less technical conceptualisation. Asking who is involved in such social responses to diabetes and what is their motivation, alludes to a political and moral economy of diabetes care. Market competition and contestations of authority and hierarchy shape interests, types, commonalities and disjunctures of groups and involved individuals and engender and warrant moral scrutiny and request solidarity.

## CONCLUSION

### *Ethnographic summary*

This thesis explored Turkish Berliners' experiences with type 2 diabetes. This involved both everyday practices of those living with diabetes to manage their chronic illness and the social, political and economic communal responses to diabetes in the organisation of groups, activities and events around diabetes care. While I formally separate practices and politics of Turkish diabetes experience in Berlin in this thesis, categories of individual, social, collective and communal, as well as practices and politics, are not clear-cut. The following summary of this thesis aims to address such conceptual ambivalence.

I refer to individual *practices of diabetes control* as they are individually negotiated by respective research participants. While diabetes education may convey general clinical information, patients take this advice into their everyday lives that are messier and more complex than an education manual can acknowledge. The story is already more complicated for my research participants as such educational materials are largely not in their native language and contain information that does not apply to their lifestyles and food practices. This provision gap is recognised by other Turkish Berliners who, as health professionals, strive to bridge this gap locally. The result of such collective effort is a self-help group. Such communal response to diabetes will be summarised further on; you already see that a separation of categories of individual, social or communal is merely a structural device. Acquiring *knowledge* on how to manage diabetes is a collective effort; learning and rehearsing knowledge in the group is a social activity. Having said this, such knowledge is not readily accepted as useful. Only in taking it out of this social group context into their homes, knowledge is recognised and appreciated by the self-help group members. By implementing knowledge in the everyday, their individual lives with diabetes are gradually changed. Thus, in order to be practical, knowledge must be specific and relevant to their everyday lives, and here we are back to the social. The acknowledgement of shared Turkish types of food, habits of eating and cooking make knowledge useful. On the other hand, being a skilful cook, having

knowledgeable bodies that recognise too high or low blood glucose levels, constitutes one's personal knowledge that assists or hinders individual practices of diabetes control.

Diabetes is messy, invisible and often unpredictable and creates much uncertainty. Controlling this messiness is largely in the hands of the patient; aside from education on lifestyle adjustments, all clinical care can offer to help with this home-based treatment is the provision of self-testing gadgets and skills. *Monitoring* blood glucose levels at home is another individual and social practice my research participants with diabetes engage in. Clinical numbers are learned and rehearsed in the group, glucose meters are provided by the group; self-testing, then, happens at home. Clinical numbers of blood glucose, blood pressure and cholesterol may seem abstract entities, but research participants embrace them for their perceived neutrality. They enable them to communicate personal and emotive experiences in seemingly neutral and objective terms. Such a universal communication tool is particularly useful in language-problematic consultations. These numbers, however, can also be arbitrary and normative; let alone from a clinical assessment perspective, within the self-help group, sharing one's blood values (sic!) may be a social exercise of support but can also be the basis of comparison and judgment. Self-testing can also cause anxieties as it can visualise the messiness of diabetes and make patients feel observed and controlled. Many research participants, though, appreciate this tool of control in order to gain some sort of tangible hold over their diabetes control. Blood glucose monitors help to visualise not so much the messiness than lurking risk and thus manage uncertainties that they face (individually, without the support of the group at all times present).

Practices of diabetes control need to fit individual experiences, and are therefore idiosyncratically negotiated. How this negotiation is done, nonetheless, is more determined by social lives rather than individual motivation. The example of diet as the most important means to self-manage diabetes can illustrate this challenge. Food practices and habits do not exist in a social vacuum. While public health may often evoke the notion of personal choice in healthy nutrition campaigns (Mol 2008: 58), it does recognise that the problem is often structural and environmental; fresh fruit and vegetable has to be available and affordable (e.g.

Shepherd et al. 2006). Turkish Berliners with diabetes encounter different problems. While my research participants enjoyed the access to the many and affordable Turkish supermarkets and fruit and vegetable stores, and embraced home-cooking and family meals, this inherently social aspect to food challenged their individual practices of making their diet diabetes-appropriate (cf. Lawton et al. 2006). Nutrition as a social practice requires to adjust dietary advice to their family lives and the family's acceptance to changes and to negotiate cultural norms of hospitality. I call this idiosyncratic strategic implementation and use of recommendations *bio-tactics* of diabetes control. These tactics are not only useful to manage diabetes. Research participants with diabetes also tend to live with other complex health problems as well as social challenges of poverty, unemployment or social isolation. The sociality of the self-help group can serve as support for problems such as depression that are not socially communicable and for which help is not sought. Also, learning how to take control over one's diabetic body and experiencing positive effects can give a sense of empowerment that deprivation and depression may have taken away. Highly structured and disciplined lives with diabetes, therefore, are not necessarily undesirable.

The other major focus of the thesis is on the *politics of diabetes care*. Diabetes has sparked lively communal activity among the Turkish-origin population. Here, the collective or communal experience of diabetes does not concern social learning within a group or social aspects of lifestyles and health practices. Although not easily separable, referring to "communal" or "collective" rather than "social" should avoid confusion. "Communal" should specifically alert to a collective identity, an "us Turkish Berliners", that is often evoked by research participants. Diabetes as the opportunity for *communal participation* is explored as independent of personal health concerns. It also involves people that are not personally afflicted by diabetes; there are, of course, family members of patients, and health professionals, but also charity and social workers, business people. Diagnosing diabetes as a communal burden that requires communal response has given rise to Turkish-language patient education, the self-help group and community information events. Although only a side note in this chapter, such communal engagement with diabetes care, however, of

course also affects individuals with diabetes, their practices of diabetes control, and how diabetes is experienced as an illness. They also get the opportunity to be socially and civically active in retirement or unemployment and to reap rewards from newly developed confidence in asserting better healthcare.

In this local field of informal diabetes care for Turkish Berliners, then, are many individuals involved that occupy varied social roles. Diabetes creates relationships, *positions* and roles in this biosociality around Turkish diabetes care. Participants are more than patients or patients-cum-activists. All participants take on multiple roles, either within collectives, as teachers, students or administrators, or due to individual motivations of financial or personal gains as business people or experts. Again, the distinction of individual, social or collective seems arbitrary. Interactions between groups and individuals are marked by *micro-politics*, economics, and ethical concerns. The financial element of diabetes care, in particular, leads to competition, tensions, and conflicts that also concern issues of authority and integrity. Many participants in these interactions explain such social tensions as the result of personal (individual) feuds or bruised egos that render this sociality and collective action challenging. That said, communal or political involvements in local diabetes care are linked to personal experience in another way. While I suggested that this section of the thesis is not about the diabetic body, the physical and emotional experience of diabetes lies, of course, at its heart. Those actively engaged in diabetes care are guided by personal and often emotive motivations, as they experience diabetes in their own bodies, in relatives or friends, or as part of their everyday work.

In sum, practices of diabetes control – knowledge, numbers, tactics – and politics of diabetes control – communal participation and roles and micro-politics in diabetes care – all touch on individual experience, idiosyncratic practices, in short, manoeuvring illness AND communal experience, local politics, in short, manoeuvring healthcare. Both aspects are intrinsically linked and shape one another. Even the concepts practices and politics are not separable. Diabetes education, self-testing and tactical diabetes management could be used as examples of micro-politics; communal participation, bio-activism and political economy of diabetes care

could be explored as practices of diabetes management. All in all, the notion of *tactics of diabetes control* summarises all chapters.

### *On interdisciplinarity*

A medical researcher would now ask: what are the implications? When conceptualising a research project as a medical anthropologist one's peers in both social anthropology and health research are always keen to find out as to whether the research aims to contribute to anthropological knowledge or tries to advance medical practice. It seems as if the answer can always just be an "either – or". Either my objective is that of advancing anthropological theory and/or methodology, or making a practical contribution to the healthcare of my research participants. This frequently demanded "taking of sides" appears to say that applied knowledge defies its value, and that one cannot attempt to negotiate between knowledge and its application across disciplines. One disciplinary means might find ends within a different discipline or outside disciplines within society but cannot have more than one/both ends.

There is a plethora of anthropological literature that contributes to such a discourse on interdisciplinary knowledge, from Arthur Kleinman's *Writing at the Margin* (1995), to Gillian Beer's *Open Fields* (1996) or Marilyn Strathern's *Commons and Borderlands* (2004b). I was drawn to these discussions as, after positioning "my" Turkish Berliners as much as "their" diabetics at the margins, I found myself at the disciplinary margins of social anthropology during the processes of peer reviews and funding applications. It was interesting to read Strathern's (2004) comment on a new "imperative" of interdisciplinary work in academia and was left wondering why one nonetheless largely encounters more doubts and reservations than acceptance and curiosity. With this thesis I aim to contribute to discourses on interdisciplinary work and applied theory.

In her Isaiah Berlin lecture, Strathern (2005) reflects on "useful knowledge", interdisciplinary encounters and the anxieties those encounters create. I understand and share her plea for acknowledging the value of knowledge, even if it does not strive for applicability, communicability and accountability across disciplinary boundaries. I am thus not trying to contribute to the production of interdisciplinary

knowledge because I regard knowledge from humanities or social sciences as not “useful”, but suggest that utility and applicability are entirely separate issues. Rather than wondering if knowledge is useful, my question as a medical anthropologist is as to whether knowledge derived from one means can have several ends.

As a medical anthropologist research participants are often challenged, by their illness, their sick bodies, the environment that is unkind to sick bodies. Scheper-Hughes famously called for a “militant anthropology” (1995) that feels morally obligated to not only write about suffering but also help alleviating suffering. There is much to criticise about Scheper-Hughes’ paper, her morally rather questionable denunciation of peers as well as her simplistic view of the world, its “goodies” and “baddies” – and the assumption that ethnographers will always explore those suffering and not those who might cause suffering. Having said this, she makes a convincing argument that ethnographers should not take gained knowledge (especially that of processes that cause suffering) with them – merely using it for fancy theoretical arguments and spreading those in journals with (rather) limited readership. While our research increasingly looks beyond suffering, to explore practical engagement and agency, it is still often focused on people challenged by their bodies (cf. Mol 2008). Medical anthropologists seem to be caught in discourses of interdisciplinarity, as their alliance is indeed often closer to their affected informants than to (the theoretical novelty of) their written ethnography. A discourse on interdisciplinary knowledge is to me less a disciplinary conundrum than a practical task. I see “applicability” and “communicability” as the practical implementation of ethical considerations as an ethnographer. The “writing culture debate” pointed to the moral obligation of the ethnographer to – at least – feeding back results to those who helped producing knowledge (cf. Clifford and Marcus 1986). How can my research results translate to a different audience that is not used to read anthropological ethnography but prefers aims/objectives/methods/results/discussion-structured outcomes, or that is not academically trained at all. In the following, I aim to address possible interdisciplinary results of this thesis and suggest that it provides both implications for healthcare and healthcare research and a contribution to the advance of anthropological knowledge.

### *Implications for healthcare and healthcare research*

Although the thesis is has not been written with a specifically medically trained readership in mind, both research design and results can provide recommendation for healthcare provision and healthcare research. In particular, I suggest that this thesis can make two contributions. The first one is perhaps an obvious anthropological contribution to other disciplines. This thesis flags the significance of locality and complexity. This research captured Turkish Berliners' diabetes experience in a particular moment in time. Local particularities, such as the recently founded Turkish-language diabetes self-help group, are deeply influenced by current perceptions on illness burden, increasing public attention to obesity-related health issues, as well as experiences of deprivation, local economic and social structures and increasing political organisation. This also points to the importance to recognise that illness and healthcare is about both individual experiences and social and societal circumstances and changes. While medical research is not oblivious to particularity, locality or complexity, its criticism hinges on a subsequent problem of universality. If one is interested in applicability, how can one apply research findings that highlight their particularity in point and time to other settings? Indeed, one size does not fit all, but this can be a “universal” finding. Turkish Berliners have different needs, problems and opportunities than Turkish-origin people with diabetes in rural Bavaria, or than Turkish Londoners. Any intervention can follow a model or framework that has proven to be effective in varied settings, but one element of this model should be the acknowledgement of locality – local structures, politics and activities. Exploring how complex and fragile these social interrelations and sites are, can help to understand how delicately healthcare is therefore ultimately negotiated and delivered, and on which issues healthcare policy or intervention must concentrate their efforts. This perspective could help to recognise the importance of “good practice” in heterogeneous, complex and often challenged settings, as opposed to “best practice” that assumes equal foundations and resources for interventions.

The second contribution attempts less particularity, and is perhaps less challenging; it concerns methodology. This thesis specifically investigated active practices of healthcare. Rather than investigating what people perceive, tell, believe,

experience, this thesis mainly explored what is done: the practices and tactics, activism and social participation. And to do so, it is important to observe such activities, not simply inquire about them. Healthcare research projects increasingly aim for interdisciplinarity and add a qualitative research component to its otherwise quantitative methodology. Often this merely appears to mean that “factual” statistical data collected with questionnaires are illustrated by “anecdotal” patient stories taken from interviews. I suggest that if there is recognition for patient empowerment and patient-centred care and research, this has to be reflected in methodology. Even more serious attempts of qualitative social research are largely limited to interviews. I propose incorporating more ethnographic exploration and participant observation in health and healthcare research. For example, obesity-related research is interested in investigating levels of physical activity. Questionnaires measure self-reported physical activity (Craig et al. 2003). However, people may not be honest about their levels of activity or cannot recall their activities accurately. To test such reporting, some studies prefer more technical data collection and count the number of steps taken (unfortunately missing activities such as cycling or swimming) or measure heart rates with special physical activity meters (e.g. Trost et al. 2005). As such quantitative data collection can only (and perhaps unreliably) collect possible levels of physical activity, not why lives may be active or sedentary, research increasingly includes qualitative methodology, namely interviews (e.g. Lawton et al. 2006). While open interviews better add to the understanding of general barriers and facilitators to physical activity, they still fail to capture everyday practices or problems: that it was the unexpected visit of friends that brought good intentions to go for a walk to a halt, the rain that made one opt for the bus instead of the bike, the depression that is rarely mentioned and that makes it hard to leave the house, or in turn, the housework or long shopping trips that are failed to be noticed as physical activity. Ethnographic research with participant observation explores exactly such everyday lives, their complexities, unexpected turns and taken-for-granted aspects, and would greatly inform health and healthcare research.

*Contribution to social anthropology: beyond bio-power and biosociality*

The significance of complexities and particularities in everyday experiences can also inform social anthropological conceptualisations. Although anthropologists increasingly and enthusiastically acknowledge that social lives are disordered, theory often smoothes out such complexities (cf. Mol and Law 2002). This thesis has a broad ethnographic perspective on both individual and communal responses to chronic illness and was thus placed within a Foucauldian body of literature to look at disciplines of body maintenance and within a literature on biosociality to understand collective momentum in illness and healthcare. Testing such concepts with the perspective and experience of marginality, the thesis proposed to widen the scope of such frameworks and thus aims to contribute to the advance of anthropological knowledge and theory.

First, this thesis argued that one must look beyond bio-power. By that I mean that although disciplines of body maintenance, especially in a clinical context like diabetes management, invite Foucault's concept of bio-power (1998 [1976]), this concept may not aid well to understand why people engage in diabetes self-management. Foucault envisioned bio-power as a dispersed form of power that is represented, here, in medical institutions and professions, prevention and therapy strategies, and this might be an interesting perspective on mainstream diabetes care that teaches about healthy living disciplines as the responsibility of "good patients". However, in the case of Turkish Berliners bio-power does not seem to be very interested in controlling and monitoring its subjects. As formal healthcare is inadequate and often unreachable for Turkish Berliners with diabetes, they engage in self-help, namely peer education, in order to learn how to self-manage. Widening the perspective here away from this particular ethnography, contemporary studies on health(care) inequalities (Marmot 2006) indicate that such experiences of marginality do not only concern the Turkish Berliners in this thesis, and their experiences may resonate with those of other population groups.

This is, then, not a story of domination or resistance, but perhaps one of "technologies of the self" and self-care (Foucault 1990 [1984], 1997). Technologies of discipline or control, the clinical gaze, can be adopted by the patient and used to

their own ends. Exploring those ends suggests that one should also look beyond Foucault's notion of self-care. He described that self-care as a practice to achieve freedom, as an ethical exercise of maintaining a healthy body to become a good, autonomous citizen. While self-care may indeed assist people with diabetes to gain independence from clinical authority to a certain degree – and I argued that it is particularly the marginal that take care in their own hands as formal care is inadequate and clinical authority indifferent – I suggested in this thesis to motivations for self-care may be less normative.

My departure is, therefore, not from Foucault's powerful theories, but from subsequent writings, that narrowly focus on Foucauldian framework to understand practices of body maintenance (cf. Petersen and Bunton 1997). Instead, this thesis suggested that self-care can be a much more mundane, practical exercise, in order to make one's body better, to feel better and avoid complications and early death. Bringing the body into analysis, as an anthropology of the body postulates (e.g. Turner 1992; Fraser and Greco 2005), in a way, is a contribution of clinical research to anthropology. Not only does medicine frequently provide medical anthropology with research questions, it also shows us to look at the body, at symptoms, at pain. Diabetes is about tiredness, numb feet and hands, bad eyesight and failing kidneys and such physical experience needs to be acknowledged (Millward and Kelly 2003). Conversely, ill bodies can be just that. By that I mean that life with chronically ill bodies may affect life trajectories for some (cf. Bury 1982; Williams 1984), but they might only be part of what are complex and sometimes challenged social lives. A diabetic body does not create new identities or notions of personhood, when deprivation or depression may be as formative as a diabetic body. On the other hand, an illness, or rather its tactics of self-care could, in challenged lives, provide an opportunity to cope.

As its second major argument, this thesis proposed to expand upon conceptualisations of biosociality. Biosociality was conceptualised by Paul Rabinow (1996a) as social groups of patients or patients-to-be that form around biotechnological innovations. Human genetics, in particular, alter life and biology and can thus change how bodies, illness or illness risk is perceived. Biosociality is

thus an interest group that forms around a shared and (re-)imagined biology, and although Rabinow himself was more interested in the science labs that created such new biologies, subsequent research that took on this concept ethnographically explored what such biosocialities could look like (cf. Gibbon and Novas 2008a). I critiqued two aspects in this body of literature. First, I argued that biosociality can happen at the margins and can even be tool of the marginal. While previous literature claims that those at the margin of society, in particular those living in deprivation, lack the means to engage as biosocial advocacy groups but are merely bio-available (Bharadwaj 2008; Sunder Rajan 2008), research participants in this ethnography formed a sociality around their diabetes specifically as they found themselves at the margins of a formal healthcare system. Also, it was not biotechnological innovation that created sociality around their biological, diabetic bodies, and this sociality was not marked by technological organisation or patient rights' advocacy for access to technological innovations. Instead, Turkish Berliners organised sociality around diabetes care in a societal momentum of deprivation and provision gaps as well as increasing stratification, professionalisation and political organisation. Biosociality is, then, a means for practical bio-activism for individual and communal support in healthcare. To broaden the perspective, I suggest looking beyond Turkish Berliners' experience; as diabetes is a mundane illness, and often overlooked in anthropological research, there is a plethora of such mundane illnesses and it seems fruitful to look at the socialities they create, which may not always be high-profile in their motivation, concerning high-profile illness or exciting or frightening biotechnological innovations.

Moreover, investigating who is involved in such biosociality, I proposed a more complex structure than previous research seemed to suggest. While the involvement of various domains is acknowledged in this literature, namely science, industry, the state, the voluntary sector (Gibbon and Novas 2008), this ethnography explored who represented and occupied these domains. Rather than finding separable positions, people occupied multiple and fluent roles. While previous literature may imagine the patient-cum-activist, the participants in this ethnography had multiple roles added by their diabetes care involvement: a patient or doctor could also be expert-cum-teacher-cum-activist-cum-businessperson. Such complex biosociality

around informal diabetes care, then, also interlinked these various domains of economics, politics, medicine/healthcare and activism in local micro-politics. I thus finally argued that the concept of biosociality should not only consider economics in terms of the biocapital of pharmaceutical biotech industry (e.g. Sunder Rajan 2006) or politics in terms of the influence of the state and advocacy for patient rights (e.g. Gibbon 2008). Economics also relates to conflicts and alliances around everyday funding concerns and local entrepreneurialism, everyday politics revolve around local struggles over authority. Ethical concerns are not occupied with universal human rights issues but frame everyday conduct within a biosociality that is negotiated around cooperation and conflict, care and capital, communal self-help and political and economic agendas.

Finally, I hope to contribute to understandings of marginality with this thesis. As anthropologists like to point out the importance of locality and complexity, another popular concept is agency. My research participants may live in social deprivation and ill-health but they are actively engaged in health practices, healthcare provision, peer education and community health advocacy. My contribution to anthropological knowledge, then, should be more than the argument that marginality can nonetheless involve agency, as agency is a problematic concept. Rather, this thesis explored what this agency involves in terms of active engagements and practices. This thesis could confirm that marginality should be understood as a relational concept, where positions of the marginal and central are not fixed entities but stand in relation to each other (Ecks and Sax 2005). Turkish Berliners experience marginality in the everyday deprivation and inadequate healthcare provision but Turkish-origin doctors occupy different positions to their patients, self-help group members make different experiences to other Turkish Berliners with diabetes, and to those without diabetes. Illness and deprivation, but also social and political organisation shifts positions. Marginality is thus not only relational, experiencing marginality does not simply mean to be confined to the societal periphery, but it is shaped by its activities rather than inertness. This thesis framed agency as tactics of diabetes control and explored what these activities and activism involved: agency could mean the everyday practices of diabetes control, learning about diabetes, monitoring their diabetic

bodies and managing lives with diabetes; agency meant the social momentum in diabetes care, the social relations and roles that diabetes created, and the micro-politics that shaped any involvement in diabetes care.

All in all, the ethnographic data in this thesis could speak to a range of theoretical concepts, pointed to their strengths but also limitations and proposed alternative avenues. This is as this thesis set out to explore a broad range of experiences with diabetes in Berlin's Turkish population. I believe that understanding this experience comprehensively (in Weber's sense, *Verstehen*, 1922), required ethnographic "thick description" (Geertz 1973). This thesis thus told the story both of personal experiences with chronic illness as a Turkish Berliner and everyday practices of diabetes self-management, and in what way diabetes demanded a communal response within the Turkish-origin population in Berlin, in order to capture and account for the interrelations of individual and collective experience of illness and marginality.

#### *Limitations and future research: outlook on bioethics*

Following the contributions, I will finally briefly discuss the limitations – in conceptualisation and scope – of this study and propose future research projects. First of all, this thesis is a privileged view on those Turkish Berliners who are engaged in their diabetes care, those who are taken care of or take care of themselves. The decision to put these people centre stage is to show that such experiences of active healthcare practices exist and are significant in individual and communal lives. In order to expand from this particularity, I suggest that such activities should be explored in other localities than Berlin, by other marginal groups than Turkish migrants and concerning other issues than diabetes. A complementary research project, on the other hand, could or should seek out those others who decided not to join such groups, or those who fail to be addressed by them, those who feel defeated by their diabetes, or in fact those who are organised in different ways, perhaps not in terms of Turkishness but perhaps religion, locality, or gender. Planning such research such people could be reached by looking at non-health related social groups. Berlin, for example, also has numerous women's groups. As this research project was limited to a female researcher, the main informants that provided insight into the

everyday lives of diabetes management were women. A future research project could include a mixed team of researchers, male researchers to reach men, perhaps Turkish-origin researchers to gain access to patients that did not open up to the German researcher of this project. Future research with those who are not involved in such organised diabetes self-management could address new research questions that explore if tactics are indeed reserved to the “copers” (Kelleher 1988), or do those who feel defeated by their diabetes nonetheless engage actively with their diabetes?

The second limitation of this study is that, although gender appears as a recurring issue in this thesis, it was not explicitly addressed. I decided that an adequate discussion of gender issues would have been beyond the scope of this work and did not fit the line of argument in which this ethnography was crafted. Studies, however, suggest that Muslim women in particular face barriers to health and healthcare (e.g. Lawton et al. 2006, on barriers to physical activity in British South Asians with diabetes). An indication of this can be found in Chapter 7.2 that mentions in which way some women in the self-help group experience tensions in their family due to their active social lives around diabetes care. Another limitation is that ideas of ethics were raised but only assigned marginal significance; in Section 2, Foucault’s questions around ethical practices were considered marginal to the lived bodily experience of illness, Section 3 only mentioned ethical debates in terms of how they guard and qualify social interaction. That said, I encountered in the course of this research project that there are inherently ethical questions involved in chronic illness prevention and care that can be addressed and explored by anthropological research.

For future avenues of research I thus like to end this thesis with a proposition beyond the exploration of everyday healthcare practices and politics. I pointed out that diabetes is perceived as a mundane illness, perhaps unspectacular, without much medical or technological innovation, and yet, I argued that it is a fruitful field of anthropological inquiry, as I joined experiences of chronic illness and marginality. Here, I would like to propose an exploration of bioethics.

Social scientists already contribute to interdisciplinary bioethics debates in the realm of biotechnologies by investigating how users of human genetics and reproductive medicine experience challenges to their biological identities and body

integrity. I suggest that issues of obesity and chronic illness should receive similar attention and be addressed in similar ways. However, anthropology seems reluctant to take on such issues. Interrelations such as HIV/AIDS and poverty are enthusiastically discussed, perhaps because anthropologists' stance seems unambivalent: people with HIV/AIDS should receive recognition for their plight and, most importantly, medication, irrespective of their financial means, geographic location or cause of infection. Issues around obesity-related illness are less clear cut: of course, people should receive care, irrespective of their background, but if care involves changing lifestyles, public opinion is torn. Can people be told off for serving their children frequent take-aways? Or is the issue one of teaching them how to cook healthy meals? Should society intervene in the first place, or would non-intervention be equivalent to not providing adequate healthcare?

If Turkish Berliners with diabetes learn that *pide* bread should be replaced by whole-meal bread, is it really their choice if the alternative may be a future life with blindness or dialysis. My research participants would answer that lifestyle changes are acceptable if they are practical in their everyday lives and make everyday lives more habitable and that the question of ethics is one of access to information and care. I do not suggest that anthropologists should necessarily position themselves in this debate but to explore everyday negotiations of such ethical debates and how varied and heterogeneous perspectives may challenge established values of health, care and choice (cf. Mol 2008). What I propose is for medical anthropologists to discover obesity, diabetes and cardio-vascular diseases as fruitful and complex fields of and contributions to bioethics.

## GLOSSARY

DDG	German Diabetes Union ( <i>Deutsche Diabetes-Gesellschaft</i> )
DGV	German Anthropological Society ( <i>Deutsche Gesellschaft für Völkerkunde</i> )
ADA	American Diabetes Association
DMP	Disease Management Programme
GDM	gestational diabetes mellitus
HbA1c	Haemoglobin A1C ('glycosylated haemoglobin')
HDL	high-density lipoprotein ('good' cholesterol)
IDDM	insulin-dependent diabetes mellitus
IDF	International Diabetes Federation
IGT	impaired glucose tolerance
IQWiG	Institute for Quality and Efficiency in Health Care ( <i>Institut für Qualität und Wirtschaftlichkeit im Gesundheitswesen</i> )
LDL	low-density lipoprotein ('bad' cholesterol)
MODY	maturity onset diabetes of the young
MRDM	malnutrition-related diabetes mellitus
NGO	non governmental organisation
NICE	National Institute of Clinical Excellence
NIDDM	non-insulin dependent diabetes mellitus
UN	United Nations
WHO	World Health Organization

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