

Out of Control? –

**A qualitative study of diabetes management among
Pakistani migrants in North-West England**

by Kinga Egressy



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**A qualitative study of diabetes management among Pakistani migrants in North-West
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For MA: Health and Society in South Asia

Submitted by:

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Summary

Type 2 diabetes (henceforth referred to as diabetes) is frequently making the headlines of prominent public health journals; it is a challenge for many health systems, as populations grow older. Epidemiological evidence shows that Pakistani patients are at higher risk of developing the condition and also experience increased morbidity. There has been speculation as to the reasons behind this with different explanations being offered depending on the field of study; genetics, epidemiology, nutrition etc. In this thesis I do not attempt to solve this problem, but rather concentrate on the lived experience of diabetes. I spent three months in a town in North-West England, where I visited both patients and health care providers to build a picture of what diabetes is; what it means in everyday life. I adopt a praxiographic approach similar to Mol (2001) to highlight the complexity present in diabetes care and engage with some topical discourses. I purposefully concentrate on practices, because attitudes and beliefs are not necessarily expressed in action and I would like to describe what doing diabetes means.

Diabetes is a chronic condition; it doesn't go away. Therefore every day management becomes important in maintaining and prolonging patient quality of life. I examine the practices of management in the GP surgery and the home and highlight the tensions present between the two. In doing this I aim to broaden the scope for diabetes research, to extend it beyond the individual patient to the family, society and health system. Context therefore becomes important in understanding practices. Thus anthropologists can bring a contextual richness to diabetes research that is lacking in the natural sciences.

I also explore the moral discourses surrounding diabetes and discuss the relevance of notions of blame and responsibility in the specific context that I studied. In our society there is increasing pressure on individuals to look after their bodies and their health. Diet and exercise are presented in the media as means to the desirable outcome of a body that is physically and mentally strong and protected from disease. Diabetes is labelled as a lifestyle disease and this implies that diabetic patients have to a certain extent contributed to their condition. I aim to show that the situation is more complex than simple choice and outcome.

Based on my fieldwork I propose that diabetes is not a static entity, but rather a dynamic process that the patient negotiates with their everyday lives. Patients must learn how to change their practices and adopt new ones in order to live together with the condition. However changing practices may have deeper implications for identities, with diet forming the link to home and the concept of exercise not being present. Practices are therefore situated in broader frameworks of values and meanings and educational initiatives may need to take this into account. However even where practices are altered bodies remain unpredictable; they may not behave in the way we expect them to. Similarly life events are also unpredictable and in this way the importance attributed to diabetes may change through time. Diabetes changes the patient, but the patient also changes diabetes.

My fieldwork is too narrow in its scope to draw any general conclusions; the strength of this thesis lies not in its breadth, but in its depth. By presenting specific cases I aim to raise some important points regarding locating, sensing and changing diabetes. This approach allows me to present the complexity and diversity present in diabetes. Although medically it is seen as one disease diabetes is in fact multiple.

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Setting the scene

As I turn off from the main road I enter what is known as the Pakistani area of the town. This is reflected in the surroundings; the sights, smells and sounds. The women walking around on the streets are wearing traditional clothing, multi-coloured shalwar kameez with head scarves. Accompanying them are other women or small children; they are rarely seen alone. There are fewer men to be seen unless it is time for prayers and they are on their way to the mosque. Otherwise I see the men driving taxis or working in one of the many Asian shops in the area. The houses in this area are all very similar; typical terraced houses, which are small and narrow. A common solution to create more space is to extend the back of the house into a storage room by covering the back yard. Families often live next door or in close proximity to each other and go in and out of each others' homes. This means there is a lot of movement and life in the house especially when children are present.

This is the setting in which I completed my research on diabetes. Most of the people I talked to lived in this area of the town; this is where their daily lives were played out. The more time I spent visiting peoples' homes in the area and observing practices at the GP surgery that was located in the centre of this community, the more I learnt about these people and what is important to them. I will not reveal the exact location of the town due to ethical reasons, but I also do not think the name is pertinent in this case; from what I have read and seen this could be any town in North-West England. I talked to 24 patients in total and 10 health care providers in the area (see Appendix for details). I had read in the literature that 'Pakistanis share a religious and cultural background. These characteristics lead to a sense of community among Pakistanis in the UK' (Anwar M 1995:238-239). My initial impressions replicated the findings of Anwar's case study of Rochdale, another small town in North-West England. But as I got to know the inhabitants better I realized that family is the main unit of togetherness, the link between people, rather than ethnicity. Just like Shaw I also realised that there is a different picture to be seen from the inside and the outside (2000:6). This is why it was so important to me to visit people in their own homes and experience how they were living.

I had chosen diabetes as the subject of my study after completing a literature review on the health problems faced by Pakistani migrants in the UK. I found that they experience a 5-fold higher risk of developing diabetes than the white population (1999 Health Survey for England). The condition also develops earlier and with more complications, which increases morbidity among this ethnic minority group (Gholap et al. 2010). Diabetes is a chronic condition that requires constant treatment and monitoring. There are stringent medical guidelines for safe glucose levels and objective laboratory values that are used in diagnosis. Yet how do these values overlap with the subjective feeling of sickness?

As the prevention and management of diabetes requires behavioural changes, in terms of lifestyle, this is an area where anthropology can inform diabetes research and improve the control of Type 2 diabetes. Type 2 Diabetes is therefore not just a medical condition, but a social disease and a medical anthropology approach can help identify factors that are at play in creating and exacerbating this disease. As Type 2 diabetes increasingly relies on self management it becomes crucial to involve the patients and their experience of the disease in order to build a responsive health system. This is eloquently stated by Broom and Whittaker 'the management of blood sugar is not just a technical matter, but a complex and dynamic personal task for people with diabetes' (2004: 2380). Mol also stresses that the 'logic of care' dictates that diabetes control is a process, which is based on collaboration between many actors – doctors, nurses, patients, technical instruments – who all have agency individually, but are more effective when they come together to form a 'care team' (Mol 2006:23). Thus diabetes management has to be assessed from various perspectives in order to uncover the complexities involved.

Following Mol's approach I first explore how diabetes is enacted in different ways in different contexts – in the GP surgery, in daily lives at home. I am trying to locate diabetes in the broader context of the National Health Service, where care is not only based on the individual patient, but also on national targets that general practices have to follow in order to remain competitive from a business point of view. In this context diabetes is very much about numbers, which can lead to tensions in care. These tensions are also present in the home where the patient has to negotiate diabetes care not only on the individual level, but also as a body that is situated in the family and in the society. The practices I observe reveal these conflicts and tensions and start to paint the picture

of the complexity in diabetes care. It is not just a simple matter of numbers; complex negotiations are involved to fit care practices and health advice into daily lives of the patients. Although numbers may be seen as reducing this complexity they are the form of communication between the clinic and the home and therefore enact diabetes in a very important way. Therefore this chapter introduces the main actors present in this topic: the patient, the family, the health care providers and the numbers.

I then extend Mol's approach by exploring how despite numbers diabetes can remain an invisible entity for the patient. I discuss how technology has shaped modern diagnostics and the implications this has for patients, who now have to change their practices based on an abstract entity. There is an obvious moral discourse around diabetes as controllability and morality are interlinked discourses (Borovoy and Hine 2008: 9). Without control of glucose values, via diet and exercise; without constant monitoring diabetes is life-threatening. The patient is therefore made partly responsible for the outcome of their condition. This is illustrated by Broom and Whittaker: 'the multiple meanings of control form a central part of the moral discourse surrounding diabetes and people's efforts to claim some autonomy in their disease management' (2004:2372). I argue for the importance of physical symptoms in defining diabetes as a serious condition and changing behaviour accordingly. Where these symptoms are not present - as is the case in the early stage of the disease - patients may find it difficult to legitimate changes in practice. Yet if we follow the public health approach they are still made to feel responsible for their condition. As a contrast to this I also present some cases where diabetes is present in the patients' lives both physically and emotionally. This reveals the diversity present within the disease entity itself and the effects this can have.

I then go on to discuss the active part of the patient in *changing* diabetes and how this may conflict with their regular habits. I describe the link between diet and identity; thus any changes are embedded in a deeper context of meaning, which may make the changes unacceptable for the patient. Similarly the concept of exercise as a resource to improve health is generally foreign to most patients. Exercise practices may also conflict with activities assigned on the basis of gender roles such as looking after children or the household. However this would be a too simplistic interpretation of practices, ignoring more pragmatic factors such as co-morbidities, bad weather or laziness. So *changing*

diabetes is a complex task, as it involves the negotiation of various factors described above. Changing diabetes also has to be learned and mastering the condition takes time, maybe even years. Diabetes itself changes over time as the disease progresses and it therefore requires reaction on the part of the patient. This shows that diabetes is not just a condition, but a dynamic process. It is a vicious cycle: diabetes changes the patient, but the patient also changes diabetes. Furthermore diabetes is merely one aspect of the patient's life and has to be negotiated with various other events. The importance attributed to diabetes will therefore also change in the patient's life based on the presence of other events. Finally whether we manage to locate diabetes, sense it, change it at the end of the day bodies are unpredictable. They do not necessarily behave in the way we expect them to.

1. Locating diabetes in the clinic

'People are chasing numbers'

The first time I visit the surgery is during Ramadan. The streets are fairly empty and quiet, there is not a lot going on. The surgery is in the middle of the Pakistani community and next to a mosque. We can sometimes hear the singing and see the men, who are lining up to go to prayers from our office window. As I enter the surgery I also enter the waiting room, where the patients usually sit in quiet and wait for their appointments. The only interaction is with the receptionist when they have a query or ask for further appointments. The room is small with a few windows and posters hanging on the walls explaining topical health issues. There is a glass partition separating the waiting patients from the surgery administrative staff. The phone rings every other minute, with patients asking when they can come. It is quite hectic. A data entry clerk also sits here and occasionally helps out on reception. The practice manager rarely stays in her office which is full of papers, she mingles with both staff and patients; she knows most of the regulars after being here for 16 years. The nurses also enter this area from time to time, to grab a tea or coffee in their break or to discuss certain cases. There is a friendly atmosphere and everyone is very welcoming. The GP's tend to stay in their consulting rooms and only come in to bring out prescriptions. So the surgery is separated into three basic areas: the

waiting room, which is the realm of the patients, the reception and adjoining tea room where the staff meet and the consultation rooms where the patients and medical staff meet each other.

As diabetes care is shared between the patients and the health care providers, with the two sides meeting in consultations it is important to understand what doing diabetes means in these contexts – which actors are involved, what discourses become apparent. Diabetes in the health system is enacted very differently from diabetes in the patients' homes. The targets that are set for the National Health Service (NHS) are based on population studies and statistics and therefore cater for the general population. The guidelines that are offered to health care providers have their roots in epidemiological studies and aim to improve the health of the whole population. As Mol states 'individuals and populations need completely different types of care', therefore the objectives of generalist public health approaches cannot meet the needs of all (2008:70). Indeed there are often tensions between what good care is for the individual and what is good on a population level. This becomes apparent when looking at the case of diabetes control in primary and secondary care.

'Sometimes they're overprescribed. They are prescribed medicines that they don't need. Like statins. People are chasing numbers. They want numbers because numbers get money. So if a GP has patients below Hba1c of whatever number, they get more money... So its money, the system... government wants GPs to look after them more and more because money, they want the money not to come to hospital, they want money to stay in the primary care, which is good, but they don't have that many resources, they don't have that much expertise and they are doing many other things as well.' (Dr. Shah, diabetic consultant)

When I talked to the consultant he was quite frustrated about the limitations on treatment posed by policies and he articulated this frustration through his comments and criticism of what happens in GP surgeries. He emphasised the role of market forces, numbers and money, pragmatically stating the clinical reality. Patients are sent to secondary care when their diabetes cannot be sufficiently controlled in primary care. Rather than fail to meet their targets, GP's will refer their patients to specialists, however

this often happens too late as the government wants the patients to stay in primary care for as long as possible. This approach precipitates certain practices in diabetes treatment that do not necessarily correlate with 'the logic of care' (Mol 2008). The consultant describes that many patients who are on insulin in primary care should not be. By putting the patients on insulin the practitioners hope to bring down the blood sugar to target level even if this target may not be best for the patient. Thus theoretically if an old lady had HbA1c of 7.8% but needed to meet the target of 7.5% she would be given insulin. However the insulin could lead to a hypoglycaemic episode where she falls and fractures her hip, whereas before the insulin she was actually feeling fine. As Mol suggests the 'subject of normativity' has shifted, therefore the patients subjective norms may differ from the target values and there is no clear-cut line between normal and pathological (2002: 128).

To understand the different forces in play we need to elaborate on some recent policy changes in the NHS. The new pay for performance contract was introduced into primary health care in April 2004, with the aim of improving the quality of the service offered, especially in terms of chronic care. This means that general practices get paid based on achieving national treatment targets. For diabetes this means HbA1c < 7.0%, blood pressure < 140/80 mm Hg; total cholesterol < 5 mmol/l or 193 mg/dl (Millet et al. 2007: 1087). Achieving these targets has a direct effect on the income of the surgery as a quarter of the total income is derived from meeting the quality targets set out in the Quality and Outcome Framework (QOF) (2007:1088). Therefore as Mangin and Toop describe, there has been a move towards a market model of healthcare, where numbers and contracts and outcomes become priorities and the QOF may not measure the outcome that is most important for patients (2007: 435).

Thus there are clear tensions in treating diabetes from an individual and from a public health-informed target-orientated approach and this is enacted in the conflict that can be observed between primary and secondary care, as in the case of the consultant criticising the GP surgery. His cynical remark 'that's again a job of a diabetes team is to look beyond diabetes, but why would a diabetes team look beyond diabetes if they are not given any money for that', clearly highlights the tensions in place. The staff working at the GP surgery I visited is also clear about their objectives:

'In general practice it's a business. You achieve your targets you get your money and some people are cynical and say you're only doing this because you've got to achieve that target... the bottom line is the business'. (Sarah, practice nurse)

However based on the observation and informal conversations at the surgery I would argue that the health care providers do look beyond diabetes and attempt to address some underlying problems. I heard many stories that describe a completely different role of the surgery in the community, where it becomes more than just a medical resource. People come for refuge from abusive partners, ask for help with paperwork for social benefits or just come and bring some food in for the staff. So although targets are important in securing income in practice the surgery seems to make a compromise and offer other more informal services to the practice population. There is a balance between treating the patient as an individual, improving the health of the community and meeting the targets set by the NHS to remain competitive as a business. I think it is important to be aware of these background tensions when looking at diabetic care practices in the clinic. Just as pathologisation of culture is dangerous, so is pathologisation of clinical practice. Diabetes care is embedded in a broader system of policies and targets and public health, as well as in the individual life of the patient.

So what keeps diabetes from becoming fragmented in the different contexts of patient life, clinical care and public health? Numbers coordinate and circulate between these realities to build different pictures. The numbers presented in clinical consultations serve to communicate between patients and health care providers, the numbers in the case files are ways of communication between primary and secondary care, the numbers on the diabetic register provide an epidemiological overview collating individual data into population-level statistics. Thus numbers are given meaning in each context and therefore diabetes is enacted by this number. But what exactly is this number? In clinical practice HbA1c is used as an indicator of how well diabetes is controlled. It is derived from a blood test and reflects the average blood glucose level over the last 2-3 months. It is therefore different from the finger prick test, which shows how much glucose is in your blood at the time of testing. Diabetic patients are generally advised to keep their HbA1c below 7.5%; this would be good control. Knowing diabetes is therefore a practice, where

physical steps (taking blood or pricking the finger) are needed to find out the blood sugar level (Mol and Law 2004:46).

The patient, a young man in his mid thirties was diagnosed 3 weeks ago. He has come back to speak to the diabetic nurse. After running through the HbA1c results from the last test (12.4% - very high), but at the same time reassuring the patient: 'it's nothing that you've done, it's the way it is' the nurse suggests that the patient has to do something about it. 'Start proper treatment, hit it aggressively'. He just nods and says right, right... She then explains that she has to check his feet 'because your blood sugar has been running a bit high we don't want any damage going on with the nerves and the circulation in your feet'. The patient takes his socks off and lifts his leg onto hers. She explains that she will touch the soles of his feet with a thin sensor that doesn't hurt and he should say yes if he feels it. She tests about 10 different points on the sole. He can feel all of them. She then says she will check the arteries for any blockages. She applies some gooey material onto the points where she will check, then uses a Doppler machine to listen to the blood going through, to 'see if it sounds right'. After a few seconds of crackling a regular whoosh whoosh sound can be heard 'like a train...all present and correct'. She checks at two points on each foot, and then wipes off the gooey stuff. His feet are ok for the time being. She tells him to be careful when cutting his toenails and generally take extra care of his feet. Diabetics may not feel injuries which can then become infected. This is something he can check himself at home.

Technology allows us to measure values that we perhaps cannot feel and gives us objective values that represent disease (Mol 2002: 63). In clinical consultations these laboratory values are the starting point for treatment. They highlight where the problem is and guide the medical professional so that they can give relevant medical advice. Here the HbA1c value is 12.4%, which is twice what it should be. This means that they should treat 'aggressively' in order to bring it down. We also see in this example that diabetes is not just a number. It is also something that can kill nerves in the feet, which may lead to future complications. It can also lead to obstruction of arteries, which is why the 'whoosh, whoosh' sound of the Doppler is comforting for diabetics. The consultation is a mixture of verbal and physical elements (Mol 2006:76); verbal to discuss HbA1c values and lifestyle changes and physical to check for any possible complications. The patient will also have

to be alert to certain physicalities himself, like taking care when cutting his toenails. Like taking the medicines at the right time and eating the right things. Therefore the practice of diabetes care is very much physical and active. If the Hba1c is consistently too high then the patient will have to change his/her medication and may eventually end up injecting insulin. Consistently high blood sugar will also lead to more long-term effects: complications will happen sooner and be more severe (Loewe et al. 1998: 1271, Holman et al. 2008). So numbers are powerful agents in the clinic. The right number will afford the patient praise and the surgery money, whereas bad numbers will do the opposite. Therefore chasing numbers is a very important aspect of diabetes care.

2. Locating diabetes in the home

'By the time they leave my door [doctor] I have no control'

However whereas surgeries are chasing numbers they are subject to boundaries in terms of their reach. After the patient leaves the surgery they may do what they want and the health care team will not know about it or be able to change anything until the next visit. As Balcou-Debussche and Debussche phrase it 'the individual returned to a social, economic, and family environment that was not focused on the disease and its management' (2009: 1110). In this chapter I aim to explore how diabetes is negotiated on individual, family and societal levels.

With technological advances and decreasing dependence on primary care, self-management has become the norm in treating diabetes. The development of insulin saved lives but was also a precondition for the transition of diabetes from a life-threatening to chronic disease (Feudtner 2003). The recommended management strategies for Type 2 diabetes include diet change, increased physical exercise and glucose-controlling medication (Feinglos and Bethel 2008) and attaining a balance between these elements is the key to success. As Mol says 'adaptive calculations have replaced relentless restrictions' (Mol 2008: 48). These 'adaptive calculations' can be seen in practice and reflect some of the tensions and conflicts inherent in diabetes care. Let's take the example of medication. Most patients I spoke to were taking oral blood sugar

regulating medication and/or insulin. In addition to this they also received statins to reduce their cholesterol, and blood pressure tablets. These are prescribed as a preventative measure to reduce future complications. But, whereas patients are given instructions during consultations on what to take and when, theory put into practice often differs. Indeed medicines had their own 'social lives' in the home and this may be because 'whereas medical professionals speak of controlling or managing a disease with medication, the users of medicine are usually trying to control not just their physiological symptoms but also their situation' (Reynolds Whyte, Van der Geest and Hardon 2002:15). Medications were often forgotten, they may have been shared in the family or the dosage negotiated. For example:

Rashida thinks that she is taking too much medication. She was experiencing gastric problems since taking metformin: 'long time no suit me every time I eat it then diarrhoea'. However 'instead of the doctor stopping her tablets she just gives her omeprazole tablets' to deal with the side effects. She has now reduced her metformin dosage to one tablet a day instead of two and says she feels fine. She hasn't told her doctor.

Rashida has decided herself that she would rather negotiate her medication dose than compromise her everyday wellbeing. She made this decision after waiting for a few months for the stomach problems to settle down, but after her tablets were changed again the problems came back. She justifies her actions by saying that she feels fine since. Whereas the doctor is giving her more and more tablets she responds by decreasing the dosage of others. Although notion that too many medicines are dangerous '*garm*' has been said to be quite common in this community (Shaw 2000: 203), I argue that it may also be the physical realities that stop patients from taking their medication – the side effects, the pain of injecting, feeling fine. As Dr. Meyer phrased it patients 'start to economise on what they're taking'. Negotiation can also be seen in insulin practices. Many patients are reluctant to go on insulin because it is more physical than taking a tablet and it also symbolizes a more serious stage of diabetes. Furthermore as Dr. Meyer points out physicians use the threat of insulin 'as the weapon to get them to comply better with the medication; if you don't take your tablets you will have to go on insulin, so that makes this sound really terrible and therefore by the time they get to the point

where they have to be on insulin it sounds like a punishment'. Therefore insulin often carries symbolic meaning.

Yusuf, who has been on insulin for about 10 years complains that his stomach is getting black, even when he changes the injection site Injection is also a painful procedure. He realises this is for life. Every day, twice a day. Unfortunately the tablet couldn't bring his sugar down. 'I use insulin, it's just like putting water on a fire you know what I mean' and when he misses a dose then 'my toe getting burning you know'. He doesn't have a choice. 'I'm sick of insulin' it's really painful, really stings, he feels like throwing the needle away.

Yusuf has told me about the physical reality of injections: the black stomach, the swelling, the pain. Yet he has to inject every day, twice a day. He can feel the beneficial effect of the insulin and this is balanced against the pain and discomfort of the injection itself.

When people are on insulin the practice of home-monitoring also becomes important in order to prevent hypoglycaemic episodes, which can be life-threatening. So not only does the patient have to inject with a needle twice a day, they also have to prick their finger, get a drop of blood and wait for the machine to analyse. Yusuf monitors his blood glucose every day, sometimes even twice a day and writes the result in a book. A good number for him is around 7/8. Best number should be 5.8, i.e. for a person who doesn't have diabetes. But he is still happy with less than 10. Coming back to the discussion about numbers earlier, this statement shows that targets are not universal; patients need individual, realistic targets to work towards (Mol 2008:45-46). As one of the nurses told me, some people will never get below 10mmol/litre, whatever they do. As the result of the test holds meaning to the patient testing is not only a physical process, but also an emotional one. Kazim was asked how often he tests:

'After fortnight, to tell you the truth. Because it worries you... when you look at the result you feel that it is going bad, so when you don't do it then... but you can feel it and when the feelings are you, your blood pressure, your diabetes is going high, simply use more salad and err yes it will become normal.' (Kazim 71)

The anticipation before checking and the worry following the result are strong enough to stop some people testing more often. There is an element of denial in this; they would rather not know than worry about what to do if the result is too high. There is tension

between wanting to monitor and avoiding the anxiety that comes with this. Thus technology has both positive and negative effects. On the one hand it is a tool to measure blood sugar and these measurements may lead to better control. On the other hand the machine symbolizes the imminent threat of knowing that you have high or low blood sugar and causing anxiety. Kazim mentions a way of knowing without testing and this is self-awareness, attuning your senses to the voice of your own body (Mol and Law 2004: 47). So when his BP or diabetes is high, Kazim eats salad. Sometimes however people like to test even if they are not on insulin; they are fascinated with technology.

'I can check myself or I can check anybody's and this is err very good things. This is 6 needles go in one at once and is used to be a different type of pens and different type of needles and they hurt. These ones is really don't hurt they are very very good ones. (He shows me needles in a cylinder, how a new needle comes out each time). I use once and now, next time I use this one. Very very easy. This is the last time he gave me I got ... at least 3 months record in this one. (Shows card). He can see all... and all the things he knows then he decided what he need to give to me, what I need really... metformin straight away he gave me.' (Hamid)

The newer monitoring sets are developed to minimise pain, the lancets are sharper, the depth of penetration is adjustable and multiple needles are stored in one cylinder. Diabetic patients are therefore customers of these new technologies (Mol 2008: 14). And with an extra twist the patients move from the *monitoring* to being the *monitored*. The physician can check up on the patients testing practice via the small memory card in the machine, which records all measurements that have taken place. This device means patients no longer have to note down values, but it also makes the patients' actions more transparent to the medical team. This machine is another link between practices at home and the clinic. It also brings in morality; 'in diabetes care, clinical goals become an everyday, sometimes moment-to-moment, index of inner morality through the use of the glucometer... Technology trumps the evidence of experience.' (Borovoy and Hine 2008). So the numbers become more important than lived experience and also provide ammunition for moral judgement. Doctors often recognise anomalous values within this data, which shows that the machine has been used by someone else. Indeed I found that machines, just like medication are shared in families. Diabetes is shared in the family, not

just genetically, but also socially. In this way the body not only becomes a 'commentary on the self' (Ferzacca 1990: 4), but also on the wider social arena.

'Generally health issues seem to be family problem or entertainment and...certain types of health issues get discussed quite readily within the family circle and everyone is involved in it, and ideas and old remedies get shared, tablets get shared, creams potions lotions, experiences get shared and people who see a doctor regularly for a multitude of problems become the expert in treating that problem'. (Dr. Meyer, GP)

Family or kinship groups are very important in the Pakistani community (Shaw 2000). People still live in extended families, with sometimes three generations living in the same house or in close proximity to each other. Thus characteristic networks develop in the communities (Anwar 2002: 239). Diabetes is enacted differently in the family than on an individual level. It is no longer the sole responsibility of the patient to take care of himself, but becomes the task of the wider family. This is in line with the cultural notion that younger people should take care of the elderly and it is generally daughters or daughter-in-laws who do the caring. The family can provide not only medical support, but also emotional and financial support. In the case of Yusuf who we met previously when he told us about injecting insulin, his family really provides for him and most importantly the contact with the grandchildren helps him forget his diabetes. I could see how happy he was when his youngest grandchild was brought in during our interview. The baby received all his attention and love.

Yusuf lives with his son and daughter-in-law. 'We stick with the family you know what I mean'. The daughters go to another house when they get married, but the son always sticks with the parent. The family is supportive, all daughters especially one of them: 'she's like a nurse to me', every morning she rings or comes and asks if he's done this and that. 'They support me and everything you know what I mean, but they can't take the illness from me, so that's the main problem...they can get me to change all like, I forget about my illness... I just look at them and I think I'm ok you know what I mean, but if I just sit there just by me own about half an hour then I'm completely.. I can feel I've got a pain in there'.

'I have a grandchild who is 2 yrs old. He is very... he's my best friend. So I spend more time with him, so I don't have any worries when I'm with him. So I walk with him, I go outside and inside the house and I'm playing' (Kazim)

In these scenarios diabetes vanishes for short spaces of time, the worry being washed away by the companionship of grandchildren. So the social surroundings of the patient can have a direct effect on their perception of diabetes. However family is not always a positive influence. This came across in conversations with health care providers and mainly female patients. I think the 'negative support' as one of the nurses called is an enactment of gender roles. Women are responsible for feeding the family, keeping the house clean and nurturing social ties (Shaw 2000: 227). They often put the family commitments before their own health. Gomersall, Madill and Summers found that 'women often subjugated their own needs to those of other family members, usually husbands and children, who preferred non-diabetic-friendly foods' (2011: 864). If they have been told by the practice nurse to eat differently they have to first negotiate this change with their family. Dr. Patel told me women often either don't or can't insist inside their family about what food to cook. Lillian, leader of the fit club also agrees that implementing changes is very difficult, because *'their family runs around food'*. Sitting down to big family meals is a social occasion and cooking something separately not only incurs financial costs, but also isolates the person doing it. In this sense diabetes control is a negotiation between social roles and expectations and medical advice. Asma portrays extended family in a very negative light:

'But err I would say Asian people like I said, they have too much what do you call it...like... extended family, they live in extended family so you know like too much involvement within the families and everybody share everybody's problem everybody hear everybody's problem you know what I mean...' (Asma)

A similar process takes place at social occasions, where the patient is confronted with tables full of food that they have been told not to eat. In Pakistani culture giving and receiving is a very important way of building and maintaining social networks (Anwar 1995, Shaw 2000). Therefore taking food is not just pleasant, it is also a social obligation. Even I was always offered some tea and biscuits or Asian sweets when I interviewed

patients in their homes. One woman also asked if she should bring some rice and curry for me, as we had been talking for quite some time and it was nearing meal time. At first I didn't want to accept anything, but then I realised that doing otherwise would be offensive. Greenhalgh, Helman and Chowdhury in their study of Bangladeshi migrants in London state that 'a calculated compromise between dietary compliance and social duty was usually made' (1998:981).

'Is a party you know can't do anything because it's fried stuff in there and err yoghurt and pacoires and everything and there I take. Not taking a lot of still I mean not every time.'
(Nargis)

'To tell you the truth you lose the control there but it's only ... you don't go to these places every day. Its once a month or 2 months or 3 months so you feel it's ok once... and I don't eat thinking that this is the only chance I should eat, still I control myself because mostly there is salad there is good food there so you can pick.'(Kazim)

For Nargis the compromise consists of taking less and limiting the intake of these foodstuffs to social occasions. Kazim admits that he may 'lose control', but this is only once in a while. And even at these occasions there are healthier options that you can also pick. So through these compromises they manage to satisfy both social obligations and their own dietary needs dictated by diabetes. Borovoy and Hine looked at Russian émigrés in the US and found that 'although she keeps careful track of her blood sugar levels in daily practice, holiday rituals, because of their close connections to perpetuation of family and tradition, are subject to a different set of calculations when it comes to the question of risk' (2008: 11). Therefore diabetes is about being flexible, adapting your practices to the everyday context of individual and social obligations. It is about making strategic decisions (Hunt and Arar 2001). This is especially true during Ramadan, when religious obligations make diabetes control even more complex. Diabetes management during Ramadan is a particularly interesting area to study, as Ramadan is a unique social and cultural event that takes place every year in Muslim communities. Ramadan is especially problematic for patients suffering from diabetes, as fasting can exacerbate the condition, leading to complications and even death (Al-Arouj et al. 2005, Salti et al 2004, Hui et al 2010). Although Muslims with diabetes are exempt from fasting, the EPIDIAR

study – drawing on data from 13 countries - showed that 79% of those with diabetes fasted during Ramadan (Salti et al 2004: 2306). Again rather than attempting to provide generalised conclusions from my data I will explore some care practices during Ramadan to illustrate the different factors involved in fasting with diabetes.

'Yeah every day is totally different because you have to wake up at night-time and you have to eat your meal in night-time about 3 o'clock... and you can't eat after half 3 til in this Ramzan it's a long day, til quarter past 9 in the evening. Open your fast about 9.15. So. But in Ramzan everything's all right yeah. My diabetes is all right, everything's fine...Just once in the morning time 3 after I eat my meal. Because open my fast it's just really between 2 and 3 hours innit so I just take one tablet.' (Shireen)

It becomes obvious from Shireen's account that the daily routine completely changes for the duration of Ramadan. People are sleeping during the day and eating at night. This year was especially long, about 18 hours of fasting. Shireen describes how she changed her tablet intake according to how much she was eating and when. She did this independently without advice from her practice nurse. And she says that she felt fine. This shows that she is confident in her self-care and doesn't feel the need to consult the health care provider; she is independent. She also told me later that all her kids were fasting (luckily it was school holidays) and they all had their meals together and synchronized their days. So fasting is something that the family does together; they abstain from eating and they indulge together at the end of the day. Therefore if someone has diabetes and they do not fast, they might feel ostracized from the family community and harbour feelings of guilt. Dr. Meyer told me that the social pressure to fast is underestimated, that fasting is a 'social event' and that those who do not fast are treated as an 'outsider'. This leads to some patients who 'would rather put up with being unwell' than be 'outsiders' in their own families and communities. At the end of the day 'it's a personal choice for a patient whether they feel that their spiritual wellbeing or their physical wellbeing is more important'. So Dr. Meyer herself does not make any blanket remarks warning against fasting before Ramadan, she merely informs patients about the potential consequences.

'And that's another thing that makes me feel oh what is wrong with me why shouldn't I do it... that's why I kept them, trying to prove to myself that I'm ok, I'm fine and I did all right'. Never felt hungry or thirsty. Took 2 tablets in the morning. 'sometimes I used to take one because I was thinking that you're not eating anything so your sugar levels are going to be dropped anyway so you don't really need to take the tablets to drop them. I don't know if I was in the wrong.' (Faruq)

Faruq who has been diagnosed recently kept his fasts as a way of proving that he is fine. This is a form of resistance – of showing to himself and his family that he is still healthy enough to fast. Similarly to Shireen, Faruq negotiated his medication intake in order to avoid hypos, however there is some ambivalence in his account 'I don't know if I was wrong'. Whether the decision to fast is individual or social is difficult to say as the boundaries become blurred. As Sarah the practice nurse told me 'within the spectrum they have their own little mind as well, what they think is right', therefore there is no one rule that applies during Ramadan, some diabetics fast, other don't, some say it's ok to take blood, others don't let that happen.

What emerges from a focus on practices is that self-management is complex, because diabetes is a complex condition. 'The nature of NIDDM [non-insulin dependent diabetes mellitus] in particular is such that one is constantly managing one's daily life toward the often abstract end of lowering blood sugar' (Borovoy and Hine 2008:8). By exploring the everyday practices of diabetes care I have aimed to show that Type 2 Diabetes is not just a medical condition involving numbers, but a social disease. Treatment is embedded in a social world; it involves families, encompasses the daily stresses of life and is even negotiated with the religion that the patient follows. As Broom and Whittaker state 'the management of blood sugar is not just a technical matter, but a complex and dynamic personal task for people with diabetes' (2004: 2380). Based on the practices that I noted I would even extend the 'personal' in Broom and Whittaker's statement to include the role of the family and community as well as that of the 'care team' (Mol 2006:23). In diabetes care there is no one size that fits all, people are individuals embedded in families, which are in turn embedded in communities and subject to their own values. Therefore diabetes care has a different meaning and is practiced differently on each of these levels. This is in contrast to diabetes in the clinic where primarily numbers dictate the practices

of care. So we have now located diabetes in the clinic and in the home and on different levels and gained some insights about the practices involved. However locating diabetes is not enough, we have to go further and explore what sensing diabetes – or not sensing it- may mean for the patient. We will then see that locating diabetes and sensing diabetes conflicts.

3. Sensing diabetes – or not

‘I sometimes keep thinking have I really got it?’

Diabetes is asymptomatic in the early stages, which is why it is referred to as a ‘silent killer’ by patients and physicians alike. The patient doesn’t feel that there is anything wrong with them and thus his/her care practices may not change. Therefore ‘for diabetic patients, “moralistic readings of the body” are particularly troubling and problematic since many patients are asymptomatic. For many patients, control must be undertaken seemingly for control’s sake alone.’ (Borovoy and Hine 2008:21). This means that diabetes remains an abstract entity for the patient especially in the early phase of the disease. Therefore there is an inherent tension with diabetes being construed as a ‘lifestyle disease’ where the patients are often held responsible for their condition – they have eaten too much sugar, not done enough exercise, not complied with their medical regime. The two realities – that of a phantom disease and that of a moral disease cannot cohere in this case. The notion of morality becomes nonsensical if the patient doesn’t believe that there is anything wrong with them. In this case there is nothing to attribute blame for. The patient considers himself fine.

Hanif has had diabetes for a year. It is not giving him any problems ‘sometime goes up to 6.2, but mostly my diabetes is you know 5.4 5.6 around there’. The other day it was nearly 7 in the morning, but normally doesn’t go up to 7. Also doesn’t go too low. Always around 5. ‘I don’t feel like it that I have diabetes’ only knows because they told him. ‘I don’t feel anything, any differently since I’ve had diabetes, it’s only that in my head that I have to eat that tablet’.

Hanif went to the doctor because he had some pain in the leg. At this point his blood sugar was checked and he found out he had diabetes. He was told to change his diet and take metformin tablets, aspirin and cholesterol. He refers to the blood sugar values to suggest that he might not have diabetes, as they are in the range of a normal person, around 5mmol/litre. He stresses that the numbers hardly ever go high or too low and therefore enact good control or what he feels like is the absence of diabetes. He doesn't have any symptoms, but the cholesterol tablets give him pain in his leg as a side effect 'like some kind of needle inside there'. He has already changed his tablets twice, but the same thing happens. Even when he eats cholesterol-reducing margarine he feels the pain. So in this case he has acquired an extra problem due to the treatment of diabetes, a condition that hadn't caused him any complaints. This highlights further tensions between clinical guidelines and the lived experience of the patient. As Dr. Meyer says:

'In their perception they've acquired a problem that they didn't have before and they can't see the benefits of bringing the BP down, bringing the blood sugar down and what that will do for their health'. Where symptoms are the trigger for seeking medical advice, there compliance is better. When the condition is picked up on a routine blood test then the perception is that doctors are acting in their own interest, as they were fine before. 'Haven't asked for blood test, or have treatment for something they don't perceive to be a problem.'

As routine blood tests are becoming more common, with the increasing awareness of diabetes prevalence in this ethnic group there are more and more cases like the one outlined above. Here again epidemiological data provides the statistical backdrop for informing health care actions and policy. And technologies provides the tools, but in doing this they 'shift both the practical and moral frameworks of our existence' (Mol 2008: 78). Through the diagnosis the patient receives moral baggage. Whereas the health care providers 'want to catch it at an earlier stage so that we can educate the patient, we can treat the illness and then we can be able to prevent long-term complications of diabetes' (Dr. Patel) this does not necessarily correlate with what the patient perceives as an acute or dangerous problem in terms of their health. Physical symptoms are important in legitimating the disease from a patient perspective and if the patient is diagnosed with diabetes in their absence then they can find it difficult to reconcile the presence of

disease with the absence of subjective symptoms. Indeed Pakistani patients more often than not present physical symptoms to their GPs (Shaw 2000: 198). Thus diagnostic procedures, where numbers are indicators of a disease state and create a disease entity in the clinical sense, cannot necessarily be translated into disease on the patient level. Therefore patient experience and provider tests may need to coincide to produce a reality that is acceptable to both parties. I argue that physical symptoms are needed as a translational device, indeed Dr. Meyer also states that where patients have come to the doctor with physical complaints and were diagnosed following this, the compliance with treatment is better. This implies that diabetes is accepted as a disease entity that requires treatment.

The perception of what constitutes disease is also influenced by how health is defined. This definition may vary with education level, culture, socio-economic status. 'Health is increasingly viewed in the United States as an achieved rather than an ascribed status, and each individual is expected to "work hard" at being strong, fit, and healthy. Conversely, ill health is no longer viewed as accidental, a mere quirk of nature, but rather is attributed to the individual's failure to live right, to eat well, to exercise, etc' (Scheper-Hughes and Lock 1987: 25). Therefore in the US health and ill health is presented as a matter of individual responsibility, which is expected of each citizen. There are moral overtones in this statement, as it is those people who don't work hard enough at keeping fit and strong who then get ill. It is seen as an individual failure with external circumstances remaining hidden. The sole blame is on the individual. Peterson and Lupton also outline health as an unstable property, something that has to be constantly worked on where the dutiful citizen is embodied by a healthy body (1996: xiv). These discourses link health and morality and this is also reflected in the clinical setting.

'I see diabetes as being a horse, if you let that horse get away you're in trouble because you can't pull it back. So we are the reins holding it back yeah? The more we can hang on to it and keep it under control the better it is for us. But the horse, the diabetes will want to get worse and worse, but we keep it as good as we can for as long as we can. This is how I understand it yeah? It's silly I know but... so we've got to keep the horse under control... the chances of things like heart attacks and strokes get bigger and bigger... that's what we don't want to happen we do it now while we've got the chance... as long

as we can keep it on the straight and narrow we're fine those risks become less and less, but if you choose to ignore it and do anything you want.. they're the ones you end up having a heart attack... we've got to treat diabetes with respect because it will kill you if you don't do so.' (Julia, practice nurse).

Here the practice nurse uses the metaphor of a horse running away out of control to present the imperative of tight control. At the outset the nurse puts the responsibility in the hands of the patient: If *you* let it go then *you* will be in trouble. However then she switches to *we*. The patient and nurse together are embodied as the reins on the horse, responsible for holding it back. It is a joint effort and 'the better it for us' is a double-edged sword; the GP practice will benefit financially from patients under control and the patient will delay complications as long as possible. The importance of doing *now* is emphasized, but it is also clear that there is no cure, progression of the disease is inevitable, you only have temporal control i.e. how many more good years you can have. To 'keep it on the straight and narrow' takes us back to morality, it is the language of right and wrong. At the end the nurse switches back to *you* choosing to ignore it, placing the responsibility, the reins - to use the metaphor - clearly back in the patients' hands. So the monologue ends on a slightly threatening tone; if you do things right you will be fine, if not you might end up having a heart attack. Even the dietary advice leaflet 'Healthy eating for the South Asian community' places an emphasis on individual choices, on making the right dietary decisions. However according to Dr. Meyer in the Pakistani community health is seen as a state of being that you have and disease is something that happens to the body, not something that you can control or influence. This may link to religion as found by Shaw 'ultimately health, illness or misfortune is God-given...and as such is to be endured' (2000:204) and may make patients less active in health-seeking. There is also a limited concept of preventative care as Dr. Meyer articulates:

'The idea that taking something now, that may give you some side effects that you probably get used to... but will give you long term benefits. This long term benefit is a theoretical concept that may or may not be true. At the end of the day if I tell them their cholesterol is high it's just a number on a piece of paper. It's not an illness value for them... it's usually more successful if you have the children in the surgery to translate for the

parents and say ... if you want your mum or your dad to be there for... then make sure they take their tablets, because otherwise they'll be dead by then'.

Dr. Meyer highlights an important point here about differing illness values. In the clinical setting numbers are illness values, yet as I have described they may be meaningless to the patient. Therefore the values of actions based on these numbers, especially long-term benefits are also difficult to translate. Changing diabetes is a process 'the tight regulation in which you engage does not make you feel better now. Instead you hope it will postpone the complications of your diabetes. It is good for later. The logic of care does not unfold in time. It folds time.' (Mol 2008: 54). However the logic of care may not cohere with the individual logic of the patient. Indeed a translational device that Dr. Meyer enlists is telling the children of the patients that their parents will not be around for long if they do not take their tablets and change their lifestyle. This translates the abstract numbers into a value that is meaningful for the patient and their family; the value of taking the tablets so they can stay together. It is also important to note that the concept of self in the Pakistani community is less individual and more collective. Therefore the concept of taking care of the self and individual responsibility may not fit in this context. For example the role of a woman in the family may overshadow the importance of her own health.

'But you know like with my lifestyle and my children err I don't have a nice environment where I can sit back and relax and say to myself you know this is my time right this is my time for me to look after me number one priority I can't have that time yet' (Asma)

Asma simply doesn't have the opportunity to treat herself to relaxing. She had to look after her younger siblings when her mum died and then she herself was pregnant. Therefore she is not number one priority in her own life, at least not at the moment. As Gomersall, Madill and Summers note 'individualism might conflict with aspects of patients' cultural meaning systems' (2011: 863). One of the nurses told me of a conversation she had had with a diabetic a couple of years ago. The patient's blood sugar was very badly controlled, but 'it didn't matter because she'd had her children and her children got children and her role was over, that's it. She was finished.' Whereas In the Caucasian society 'active aging' is promoted, Pakistani women see their main role in life

as being fulfilled when the children have grown up and may adopt a more fatalistic attitude to their own health. On the other hand the eldest man has the most authority in the family, that is he gains respect with age (Shaw 2000: 93). Therefore gender roles may also be enacted in diabetes care practices.

By looking at different perceptions of health and illness and the wider socio-cultural setting it becomes obvious that self-management is perhaps not so obvious after all. The concept of self-management relies on certain definitions of the self, health and responsibility and as we have seen Pakistani patients may have different definitions. Whereas 'in institutional settings, individual distress is systematically transformed into the amoral, de-contextualized signs and symptoms of biomedicine, or is alternatively psychologised and moralized with implications for the allocation of responsibility' (Lock 1993: 141-142), in the home setting this no longer holds. In the home setting individual distress is first turned into a collective problem and doesn't necessarily evoke discourses of morality and responsibility. How can you begin to judge the moral values of a patient who doesn't have symptoms and is expected to change his lifestyle because he has been diagnosed with an entity that is invisible to him/her. Is it a wonder that patients then make the following statements?

'No I'm not bothered about diabetes to be honest with you. Don't eat sugar that's what it is' (Ali)

What sense does it make to take pills in this case? Pills equally treat the condition and confirm its existence (Martin 2006). 'They serve to reproduce a label each time they are administered' and are 'relatively ephemeral' therefore illness has a 'precarious status...as a thing, or entity' (Cohn 2010: 65). When approached from this angle non-compliance with medication may be seen as embodying a denial of the disease category itself. And this denial is logical for patients like Hanif, who feel completely fine. The above discussion shows that the boundaries between having diabetes and not are fluid and depend on the definitions of health and illness present in each context. Thus in the case of Pakistani patients numbers may be inadequate indicators of diabetes. This is in line with the care practices I described during Ramadan, where diabetics will wait until they get physical symptoms before going to the doctor and thus legitimizing their exemption from fasting.

Taking this into consideration it is not individual choice that should be foregrounded, but rather individual care (Mol 2008). We need to move away from allocating blame and rather find better ways of offering care.

'I got sugar'

In other cases diabetes *does* manifest itself in the lives of people, whether physically or emotionally. 'Daily life is what, when it comes to it matters most to people' (Mol 2001: 184) and diabetes is enacted in the limitations posed on daily activities.

'She doesn't have energy to work and clean the house, even do the Hoover, she can't stand, she feels so weak all the time, she's always having to sit down and rest... she's always waiting for someone, us lot (family) to come and do it for her because she has no energy.' (daughter about Rabia)

Rabia who is in her fifties has had diabetes for 12 years. She lives on her own since her husband died. She has become dependent on her family to help her with housework, as she doesn't have the energy to do it herself. She is also dependent on them for emotional support and the daughter says they visit her every day. She recalls that her mum was only a little worried when she was diagnosed, but the illness and death of her husband 6-7 years ago caused her additional stress and her diabetes has got a lot worse during this time. When I ask what the most difficult thing about diabetes is she doesn't answer with physical complaints but rather:

'Just worrying about it all the time. That I've got sugar, diabetes what's going to happen to me. Quite a lot of people that she knows have passed away because of diabetes; she's always worrying about it. We always say don't, but that all that's in her head and she always worries about it.' (daughter about Rabia)

Therefore the emotional reality of living with diabetes can be just as challenging as the physical limitations. The medications can only do so much, but they can't control what goes on in your own head. And as there is a link between stress and diabetes (Surwit, Schneider and Feinglos 1992, Cohen 1994, Hunt et al 1998) the diabetes can get worse through worry and stress. It doesn't necessarily have to be sugar or chocolates. This was

also shown by Schoenberg NE et al. (2009: 105). Diabetics therefore have to look after not only their physical but also their emotional well-being. The case of Parwin shows this. She describes what it's like to have a hypo:

'Makes you drowsy and want to eat and I love it when that happens because I can have sugar... I can be naughty with my diet sometimes, not all the time though...I was having all sorts when I was depressed. The worst I've been was when my father passed away' (Parwin)

Instead of worrying about the consequences of a hypo, Parwin embraces it as chance to be 'naughty' and have some of the things that she doesn't normally eat. The hypo gives her a license to eat; it frees her for a moment from the self-discipline that she usually practices. She knows how to control a hypo, but she becomes helpless when faced with an external event of large impact, like the death of her father. Here all moralities aside, she has to deal with it and she does this through food. She tells me that it took her a long time to recover from this shock. Even now when she talks about it I feel like she is about to start crying. No matter how much you control your diabetes, unexpected events can always happen and throw you off track. Diabetes does not exist in isolation. Broom and Whittaker also found that stress in daily lives is connected to health problems, such as diabetes and this reflects how people see health in the larger context of their social lives, as influenced by external factors (2004: 2376).

'Sometimes I feel I have leg pain, lower leg pain and feel very tired you know, can't do anything sometimes. And sometimes ok. Night-time really difficult for my leg pain, I don't know ... hot in my head night time.' (Nargis)

Nargis refers to various physical symptoms that she experiences as a result of diabetes. Her main problem is leg pain, which comes and goes and is mainly troublesome in the night. However on the other hand she is sometimes ok. Her body is therefore unpredictable, which will be the focus of the next chapter. But before jumping ahead I would quickly like to summarise our progress in locating and sensing diabetes. We have seen that diabetes can be located both in the clinic and in the home, on the individual and collective level. Diabetes is not a static define-able entity, but rather comes into existence through different practices in different local contexts. Sensing diabetes

provides another lens with which to see diabetes practices. It assumes that subjective feelings and illness values also influence diabetes practices and questions the validity of a morality discourse around the condition. There are inherent tension between locating diabetes in the clinic through diagnostics and sensing diabetes in everyday lives. There is also tension between locating diabetes in the family and sensing that you need time for yourself, as in Asma's case. Diabetes care is riddled with tensions; this is what I am trying to highlight. By portraying some of these tensions and contrasting discourses with practices I aim to paint the complex picture of what diabetes is and how it impacts on everyday life. After locating and sensing diabetes we must look at how diabetes is both changed and how it changes.

4. Changing diabetes

Changing old habits and adopting new ones

Learning to treat diabetes is a process. Patients who are newly diagnosed have different habits from those who have had it for some years and this reflects the way that diabetes has become embedded in their lives. Diabetes care centres on medication and lifestyle change (diet and exercise). Lifestyle changes take time, as they often demand alteration of habits that are ingrained in personal and social lives and moving towards new practices. Where there is a big gap between habitual and expected practices people may incur major difficulties in making the move towards a 'healthier lifestyle'. The Pakistani diet was described by Dr. Meyer as 'diabetogenic' in that it has a high sugar and fat content. However food also has symbolic meaning ; as Mintz puts it 'like all culturally defined material substances used in the creation and maintenance of social relationships, food serves both to solidify group membership and to set groups apart' (1999: 109). This was echoed by the findings of Lawton et al. who found that food plays an important role in maintaining identity and building communities in South Asian Diaspora (2008). Indeed dietary practices of Pakistani migrants in the UK are sometimes the only perceived link to home; as Dr. Meyer says the 'umbilical cord to home'. Therefore when requested to change their diet patients find themselves in conflict between their identities and their health. The topic of food often leads to nostalgia about Pakistan itself. Many of the

people I talked to told me how food is healthier back home, everything is grown naturally and the practices around food i.e. working the lands are also healthy. Maybe it is this nostalgia that is enacted in the dietary practices evident in the UK, as an attempt is made to hold on to traditions by cooking similar things.

'Obviously because you were born there and well it soothes you and maybe that's why. And our food soothes me; this country does not soothe me at all to be honest with you...obviously they had different sort of production. They were like growing up and they were eating different sorts of food... like home food, home-cooked homemade. Like back 100 years ago you see rural area... You growing your own field and you getting food so you don't get diseases. Now everything is packed, food is packed you know.' (Ali, 35)

Ali's account of Pakistani food connects the food of the home country with 'soothing' emotions. He links the natural way of cultivating food to a healthy state of the body, thus implying that the diabetic body enacts an alternative type of production, where food is processed and packaged. It is interesting to compare this account with Dr. Meyer's perceptions about Asian dietary practices. She says that the food practices from the past, from Pakistan are not adaptive in this new migrant future. For example the act of frying food in plenty of oil was to get rid of bacteria, however in the UK these practices become outdated and instead the high volumes of oil are actually damaging health. She also describes food from Asian shops as having little nutritional value, because they are picked too early to be exported to the UK. The dietary advice in the clinic emphasis small changes in the diet: white to brown bread, white flour to brown flour, big portion to small portion. It presents the patient with a gradual framework within which the dietary habits can be change with time. Shazia came to the UK when she was 50 years old, in order to take care of her daughter who was bed-ridden and could no longer look after her family. She came with the intention of staying for a year but ended up staying until the present day.

She took over the household really! She used to say 'curry and chapatti is the best food than anything else'. She found weetabix bizarre as breakfast. She now has toast: 'got sick of watching us all so she just joined in... She said if I was to go to Pakistan I'm sure my diabetes would go away with the climate over there cause she said in the hot all the

toxins get sweat out and people are actually very healthy in Pakistan, you don't hear of somebody having really bad joint pains...She came back and she was glowing and she'd been in the summer, she hadn't had anything in her stomach her knees anything'. (grand-daughter about Shazia)

When Shazia came to the UK she first attempted to keep her habits that she brought with her from home, eating curry and chapatti at every meal time. However after years of living there she acknowledged the practices of other members of the family and changed hers accordingly. The notion that diabetes would get better in Pakistan was quite common among the people I interviewed. Indeed the concept of sweating out toxins is very widespread. Thus in some cases there is a stronger link between diabetes and sweating than between diabetes and food. As I have already discussed there is a very tentative link between individual actions and health and unless patients can make the link between food and diabetes then there is little motivation to change their habits. Similarly if they perceive no tangible improvement with regards to their diabetes patients may stop implementing change. Diabetes is a chronic condition and care is a process rather than a quick-fix solution. And in order for practices to change mindsets must also change.

'In many societies (including our own) the culturally and politically "correct" body is the beautiful, strong, and healthy body' (Scheper-Hughes and Lock 1987: 25). The lifestyle advice given to diabetics echoes this in wanting to create an ideal body that has an ideal blood sugar, low cholesterol, low blood pressure and a minimum level of physical activity. As we have seen with the example of diet, bodies that are rooted in identities and traditions may hold a different ideal type. A similar thing happens with the ideal fit body. Lillian holds a women-only fit club once a week at the local community centre where women get weighed and then discuss 'healthy lifestyle' issues, such as what food to eat, portion control, physical activity etc.

Discussing after the session with Lillian she stressed: 'it's not the norm for them to go out to a community centre and do a weight management course and do an exercise class... it just feels as though they've got everything going against them and to fight through that and to turn up to me is just brilliant' (Lillian, from council)

Physical activity is a way of balancing food and bringing down blood sugar. However it became clear through my interviews and observations that exercise is a very new concept for most Pakistani patients, especially women (see description of exercise class in Appendix). According to Dr. Meyer 'there isn't a culture of exercise for health's sake' and I found this echoed in the practices of patients. Walking was the most common form of exercise that patients engaged in and this practice was limited by the weather. For women exercise often had to be negotiated with their role in the family (Shaw 2000: 94-95). As mentioned previously their main priority is family and housework, indeed many women referred to housework as a form of exercise. Dr. Meyer says 'certainly for young girls exercise isn't something that you should be doing'; however older women often faced physical limitations like arthritis. Although some people are positive about the future:

'I think we're coming to a stage where we're pushing their barriers now and we are getting there... if there's positive people out there... We will get there, we'll get there in the end. Get them all fit and healthy.' (Mirah, exercise class leader)

I think a more cautious outlook is more realistic. There is also a blur between practices and culture and identity, which makes the situation more complicated and delicate.

'It's a society within a society with very few links to the outside world and reaching them and trying to re-educate is always trying to sort of walk on raw eggs because a lot of people are very sensitive towards trying to influence anything that they perceive as their cultural identity. And at the end of the day food and lifestyle are fundamental factors in cultural identity and you try and undermine that and you go right to the core you take over their cultural identity and therefore they don't want to.' (Dr. Meyer)

Lawton et al. also found that food practices are embedded in culture and society (2008). However it is important not to re-enforce the segregation of the Pakistani community as 'a society within a society' by concentrating on culture-specific risk factors like diet. Certainly cultural awareness on the part of health care providers can improve understanding of the patient population, but it should not serve to homogenise a diverse population. Indeed I myself have observed a mixture of practices from eating mainly traditional Asian food to mostly English meals or a mixture between the two. The same is

true for exercise. Some women go to exercise class every week, others don't; some would like to, but cannot because of co-morbidities. As Lawton et al. also found the barriers to physical activity are complex (2006). Therefore there is a continuum of practices that are situated in their unique contexts and cannot be simply cast within the boundaries of compliant and non-compliant, right and wrong. Whereas two wrongs don't make a right, different practices of right can co-exist. Indeed the definition of right is fluid as the discussion of morality in diabetes care shows. Measures of success should therefore also not be limited to abstract measurements of HbA1c levels and arbitrary check-up values. I argue that a diabetic patient can be experienced and successful if they have managed to make their diabetes and their everyday lives cohere. Where diabetes care practices have become embedded into their actions in such a way that practices have become routine.

The experienced patient

'It was a shock but initially I thought: can't help now, have to live with it the whole life so I thought have to accept it as a companion for whole life... what else you could do? Otherwise if you start worrying, there's no point is there?... It's alright now. I know how I'm coping with it; I have the company of it so I'm spending time with it. Alright... it's a carry-on thing... so after 50 years the lifestyle actually changes, you don't become careless, you have to have at least drink or you have to eat some err like snacks or ... It has become really routine now so you are living this type of life that you don't worry about any of the things...' (Kazim, 71)

Kazim has had diabetes for over 20 years. He has accepted the disease 'as a companion for life', which in practice means that he doesn't worry about it every day, but rather just carries on with life. He tries to be less careless and take care of his body and these actions become routine after the years. There is an acceptance of his fate, but not in the sense of fatalism, which has previously been cited as a negative factor in diabetes control (Lawton et al. 2006: 51). No, instead of experiencing diabetes in a disempowering way, Kazim does link his own actions to his health. And this allows him to carry on after 20 years. Another example of diabetes being embedded in practices is the precautionary action of taking something sweet with them when leaving the home. As diabetic sugar is balanced by

food and exercise, going for a walk may tip this balance to the burning sugar side and cause a hypo. Therefore it is important to have a source of sugar handy.

Aamir keeps sweets and drink in the car, he feels tired when his sugar is too low. This warns him that he should take something. He says 'I'm very careful when I left home'.

'Sometime I think about I'm gonna go somewhere nobody with me my sugar is low go, I'm thinking about no good, that's why I'm going out with friend.' (Shah)

One might keep a stash of sugar source in his car; the other will take a friend on the walk. There are different practices that counter hypoglycaemia. Adjusting the medication dose based on what he or she has eaten is another sign that the patient is engaging with the disease on a more personal level rather than just following the orders of a doctor. I described this previously under the term negotiation. Self-awareness can also be interpreted as a sign of experience. Indeed past experience is a pre-requisite for self-awareness; events must occur more than once for patterns to emerge and links to be made. For example Aamir above says he feels tired when his sugar is low and then takes something. Interestingly self-awareness can also be shared, i.e. it is not the property of a single individual. This is evident in Nasrin's case. Although they don't live together she is helped a lot by her daughter-in-law and eats mostly at her house as well. Control of Nasrin's diabetes is seen as a shared task, symbolized by the 'we'.

'Otherwise I think she is very much controlled now, because we watch what she eats. Earlier she would drink coke, fizzy drinks, eat big bars of choc 'so obviously you can tell the reason why it was so high'. Now she eats fruit, wholemeal food; everything in moderation. 'Personally I know how much without checking'. It was difficult, but with time they can see healthy eating benefits. She's ok now, not many problems. They have all changed as a family. Its awareness 'once you don't know then you don't know so anything going, but once you realise the benefits and this advantage with one thing is coming'.

There is a distinct line drawn between earlier and now, now being a time when she has adapted healthy eating advice into her daily practices. In fact the advice and change in behaviour has been seen to have benefited not only the patient, but the whole family. Thus just as diabetes treatment is situated in the collective rather than only by the

individual, so the collective can also benefit from the diabetic care. Indeed learning from other peoples experience is an important process of knowledge transfer and can be inductive to broadening health awareness. Through this short outline of what I call 'experienced patients', we can see how diabetes can be brought to co-exist with every day practices. It is difficult to strive for anything more than co-existence as diabetes cannot be cured.

Aamir says 'I've got control, but no improvement anyway'. Metformin only stops it getting worse 'still the same level'. Thinks the metformin is working but unfortunately not much, if he left it, it may get worse but he's taking it regularly 3x a day.

Even this perceived control is often elusive or has to be negotiated...

Aamir is taking all sorts of medication – he has two full briefs for am and pm. About 15-16 medicines in total. He takes some early morning, then the next ones follow at 10, the next batch is in the afternoon at 4pm followed by evening medicine. He says: 'I'm fed up...no space in my belly... without water I can't... so it's too hard for me when I'm taking at 11... Sit down one put in mouth sip of water then stop it'. He can't take all of them together, there are too many medicines. Yet despite these difficulties he considers himself lucky 'so many people friends of mine they inject you know but I think this is very hard job I'm lucky... so I think I'm ok'.

Aamir thinks he has good blood sugar control because he always takes his tablets, even when there is 'no space in my belly'. On the other hand he also mentioned in our conversation that he thinks too much medication actually caused his diabetes. So whereas tablets may be dangerous they are the means by which Aamir achieves control of his blood sugar. He has now become dependent on his medicines, he has a tight schedule of what to take when and despite the large quantity he still considers himself lucky that he is not on insulin. Indeed he can consider himself lucky that he has achieved perceived control. Others are not so lucky. Experience doesn't necessarily equate to better control, indeed some people never gain full control. 'The fetishization of "control" and "risk aversion" in diabetes clinical treatment recommendations has created a treatment protocol in which diabetic self-regulation is imagined to be limitless' (Borovoy and Hine 2008: 7). However lack of control should not be seen as a limit of the individual,

but also a limit of our current medical understanding. Rabia has been struggling to gain control of her diabetes for 12 years, but this control is still elusive.

'Before that I thought it was ok. She doesn't understand why insulin units started at 15 up to 32 and the sugar level is still the same 14-15. Why it's still not settling down. She don't feel as if it's working that properly yet. I think it will work, I think she's worrying a bit too much. They do explain it will take quite a while; we don't want to rush it. Sometimes she gets a bit impatient why it's taken so long, but well get there.' (Daughter speaking about Rabia)

Although Rabia has followed the advice of health care professionals her blood sugar has been up and down in the recent years. Even though she has increased her insulin dose to almost almost double, her sugar level has remained the same at 14-15 mmol/litre, which is still very high. Bodies are unpredictable (Mol 2004: 14-15). They do not always behave in the ways that we expect and want. This can make diabetes care very frustrating, as in Rabia's case. After our interview I asked if she had any questions for me and she wanted to I know if I from my experience could say how she can get better. This plea for help was really touching and I wished that I could give her the answer that she wanted to hear; the answer that would allow her to get better. Reflecting on this situation I realized there is an unmet need for help and advice. Rabia needs someone who can reassure her and give her positive support, to lift the burden of worry off her shoulder. It is not only Rabia's individual body that behaves in an unpredictable way. As I had already mentioned in the previous chapter Rabia's condition significantly worsened following her husband's death and she hasn't been herself since. Just like atherosclerosis 'is not the only reality that patients live with' (Mol 2001:127) similarly 'people with diabetes are not only 'people with diabetes'' (Mol 2004: 56). Diabetic patients have many other problems to deal with: personal, health, social, financial. Diabetes is just one thing that they have to negotiate with their everyday lives. It does not exist in isolation but practices are embedded in the context of everyday lives, which are in turn influenced by wider socio-political factors. Therefore treatment also has to be balanced with everyday non-medical factors (Hunt and Arar 2001: 362). Tensions between the diabetic body and the social body may develop as a result of this.

Alia came to England with her family when she was 10 years old. Her dad married her off when she was only 15. According to her passport she was 18. Her husband had grown up in the UK and was very controlling. He treated her 'like animal, didn't let me go anywhere'. She had children very young, but apart from them she was completely alone. She was abused for years, which left her with emotional and physical scars. 'It's over now but that time nearly about 12 years I was like you know what do you call all the time day and night I'm crying, no sleep'. Eventually she left her husband, but he got custody of the children. She was depressed for years, which is when she was eating a lot of chocolates and 'might be I got to catch it [diabetes] that time'. She remarried 10 years ago because it's frowned upon in the community if you're not married. New husband is nice, he is 38, but she feels sorry for him as he wanted children. She has had 3 miscarriages because of diabetes and her kidneys are failing. She is scared that he'll leave her and get married again to have children. Now 'he's just cutting off bit and bit'. She can't sleep in the night, thinking and worrying if husband will leave her. 'In the morning my diabetic is go more because I wasn't rest'.

Alia has had a life characterized by violence and worry. She was in a very vulnerable position when she got married young and didn't have anyone to turn to when her husband started abusing her. She links being depressed at this difficult time to the onset of diabetes. Her children were taken away from her because she left her husband and later in life she can't have children with her second husband. She attributes the miscarriages to diabetes. So there is a cycle of suffering apparent; she got diabetes because of abuse and diabetes is threatening her current happiness, as her husband might leave her due to childlessness. As we were sitting in the park Alia said hi to all the babies who were rolled past in carriages. She looked very wistfully after them. She is really praying that her life will not get any worse. In this case diabetes is an embodiment of social suffering (Rock 2003, Mendenhall et al. 2010). Diabetes has become interlinked with her life history of suffering. Therefore the diabetic body is also a 'mindful body' and as a consequence there are 'emotional, social, and political sources of illness and healing' (Scheper-Hughes and Lock 1987: 30). And this is not necessarily acknowledged in clinical practice. This case also reveals that diabetes may not be the number one priority in the patient's lives. The most important struggle for Alia at that time in her life was to get her

children back; diabetes was a side effect and unfortunately long-term stamp of this struggle. Borovoy and Hine made a similar finding in their study of Russian émigrés stating it as the ‘disjuncture between... assessments of life priorities and the biomedical model of risk’ (2008:10). Alia did not consider the risk of diabetes that eating in an uncontrolled way entailed; her priority was elsewhere.

This chapter has discussed changing diabetes: changing diabetes as an active role of the patient that requires behavioural changes, changing diabetes as a process that requires time and patience and involves interacting with *changing* forms of diabetes. These discussions lead us to the conclusion that the outcome of changing diabetes is unpredictable; individual bodies are unpredictable, control is elusive. This is compounded by the unpredictability of the social body, as already alluded to in the section exploring stress and diabetes and explored through a case study in this chapter. This leads me to question the relative importance of diabetes in the patient’s lives, whether diabetes as a public health priority (Zimmet, Alberti and Shaw 2001) is recreated in the lived experience of patients’ lives. Dr. Shah told me: ‘looking beyond the numbers because a diabetic person doesn’t have just diabetes, other issues; depression, psychiatric problems, immobility, their vitamin D deficiencies’ would be an important step in providing good care. This is true, but the ‘other issues’ category needs to be expanded to include financial, social, familial, personal issues rather than just the medical ones mentioned.

Conclusion

By adopting an analysis analogous to Mol’s exploration of atherosclerosis I have attempted to uncover diabetes from different angles. And indeed what emerged is that diabetes is multiple; it is enacted differently in the patient’s home, in the clinic and in the community. As I concluded in Chapter 1, diabetes in the clinic is an entity made measurable by technology and enacted by a number; it is also a means to extra income for GP surgeries. In contrast to this in the home diabetes is negotiated on many levels, including family and religion. In the home numbers lose their meaning and physical symptoms or lived consequences of the disease are fore grounded. The tension that exists between these different enactments of diabetes was highlighted in Chapter 2, with

an emphasis on the moral discourse behind the self-management of diabetes. Here diabetes may not be present in the patients' lived experience even though numbers indicate otherwise. Chapter 3 presents diabetes as a dynamic process, which involves learning and changing habits. It is up to the individual patient how far they incorporate diabetes into their lives. This in turn depends on many factors some directly related to diabetes others present in the wider context of their lives.

The multiplicity in diabetes can be partly explained by the multiplicity of bodies: the individual body, the social body, the ideal body, the unpredictable body all differ and make appearances throughout patient lives. Diabetes both changes the body and it requires changes on the part of the active body. I would also argue that diabetes itself is changed by the body; as we have seen in the various cases I have described there is no single diabetes, it arises in the context of each patient. In some cases diabetes may be silent, denied; in others it has physical effects; in yet others it is the least of the patient's worries. The boundaries between diabetes and body are fluid and the interaction is not a one-way process, but rather a relationship of interdependency. Scheper-Hughes and Lock have also highlighted some of the links between different bodies and sickness and this quote eloquently describes the case of diabetes, where nature, society and culture all play a role.

'Sickness is not just an isolated event, nor an unfortunate brush with nature. It is a form of communication-the language of the organs-through which nature, society, and culture speak simultaneously. The individual body should be seen as the most immediate, the proximate terrain where social truths and social contradictions are played out, as well as a locus of personal and social resistance, creativity, and struggle.' (1987: 31)

One of the patients I talked to, Rashida told me after the interview that it had been really nice to talk about things and that 'it was like a reflection because you kind of forget about your long-term illness'. I think it is important to remember that 'people with diabetes are not only 'people with diabetes'' (Mol and Law 2004: 56). They should not be defined on the basis of their condition; they should not be reduced to a diabetic person. Rashida has 'kind of forgotten' about her diabetes, because it is a chronic condition that is there every day and because it is there, diabetes is embedded in everyday practices. What I have

learned is that as researchers, we too have to learn to look beyond diabetes to the different bodies behind it. And we have to leave behind our own expectations and preconceptions to be able to see what really matters to people we talk to.

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Appendix

1. Summary of patients interviewed

Pseudonym	Sex (F/M)	Age (years)	Time since diagnosis (years)	Time in UK (years)	Family History (Y/N)	Insulin taken (Y/N)	Monitors regularly (Y/N)	Fasting (Y/N)
Iman	M	85	5	55	?	Y	?	Y
Ali	M	35	3	12	Y	N	N	N
Kazim	M	71	20	49	Y	N	N	N
Yusuf	M	60	14	45	Y	Y	Y	N
Abbas	M	50	7	?	Y	Y	Y	Y
Faruq	M	37	1	37	Y	N	N	Y
Aamir	M	73	10	50	N	N	N	N
Shah	M	34	4	16	N	Y	Y	N
Hanif	M	56	1	44	Y	N	N	Y
Hamid	M	50	1	36	Y	N	Y	Y
Rabia	F	50	12	30	Y	Y	Y	N
Nargis	F	50	5	31	N	N	Y	N
Uzma	F	44	4	?	N	N	Y	Y
Parwin	F	38	2	38	Y	N	N	N
Samra	F	68	5	42	?	N	N	Y
Fatma	F	66	15	?	Y	N	Y	N
Rashida	F	45	6	25	Y	N	N	N
Hina	F	58	11	40	Y	Y	Y	N
Shazia	F	73	13	23	N	N	N	N
Leila	F	86	6	6	N	Y	N	N
Nasrin	F	76	9	50	?	N	N	N
Shireen	F	40	3	23	Y	N	N	Y
Asma	F	42	11	30	Y	Y	Y	?
Alia	F	49	20	35	?	Y	Y	Y

2. Summary of health care providers interviewed

Doctors	
Dr. Meyer	General Practitioner
Dr. Patel	General Practitioner

Dr. Shah	Consultant Endocrinologist
Nurses	
Anna	Specialist Nurse Rheumatology
Julia	Specialist Nurse Diabetes
Sarah	Specialist Nurse Diabetes
Emma	Health Care Assistant
Community	
Mirah	Exercise class leader
Lillian	Fit Club leader
Other	
Ms Roberts	General Practice Manager
Emma	Health Care Assistant

3. Description of exercise class

The gym is a fairly large room, with one entrance and windows only at the top. As I went in there were already about 10 people inside, mostly Asian ladies, standing in little huddles and talking to each other. They pay 50p for each class at the beginning which is collected by one lady who then writes down the names. Curtains were put up on the double doors by one of the women, blue narrow ones to cover the transparent areas in the door. Obviously privacy is very important to these women. The clothes worn by people were mixed. The older women generally stayed in Asian clothing, taking their headscarves off. One of them took off her post-box outfit underneath which she had black sports clothes, a loose t-shirt and tracksuit pants. She kept a scarf on her head but used more as a headband. The younger women were wearing similar baggy t-shirts and pants.

Mirah, the trainer came with a scarf wrapped round her head, but otherwise western clothing and a white baggy t-shirt, black pants and trainers. Most of the women were wearing trainers but some had sandals on. The younger girls stood at the front, there were three very enthusiastic ones, who seemed to follow the moves very well and were extremely energetic. One of them had brought her daughter along as well. A disabled girl

stood in the middle, watched by the carer from the side. She didn't really follow the moves, just kind of danced around in her own world, but her carer said that she really enjoys it. Mirah later mentioned that she claps and woos for her, it is a way of communicating with her. The older women stood more towards the back, where I was to get a good view of everyone. They followed the initial moves fairly well, but started to lose interest as things got more complicated. But all of them kept moving even if they weren't doing exactly what was shown at the front.

The class began with stepping side to side and got more complicated with different moves being added. They involved steps with corresponding arm movements, shuffles from side to side, jumps, leg lifts in different sequences. The movements were practiced on their own and then put together. Mirah said that she tries to make it fairly simple so that everyone can follow and does the same routine for about 6 weeks. There was a small water break halfway through and it had got really hot in the room. Linda the only British woman there came over and opened the fire door at the back to let some fresh air in. She has been coming to the classes regularly for over 5 years and does various other exercise groups, sometimes also taking her mother along. They had even done zumba together! The organiser lady also came over to me and introduced herself explaining how things work. I found this very nice and welcoming and I think this is what generally happens when a new face joins the group.

After the routine we did some lunges and marches from one end of the room to the next. Then we got some mats and did crunches and a few back exercises. People generally helped each other getting and putting away mats. The atmosphere during the class was really good, people seemed to be enjoying it and enjoying the social event part of it as well. I was surprised at the music that was playing as it was western pop music, from the charts which juxtaposed a room full of south Asian women! Apparently there are normally more people than today, where about 15-20 people turned up. Mirah says it's always like this after Ramadan – that it takes people longer to come back to the classes and especially women. After class we all clapped and people went their own ways, either alone or in groups.