

THE EVERYDAY GEOGRAPHIES OF LIVING
WITH DIABETES

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ABSTRACT

Diabetes is a condition often placed on the margins of ‘seriousness’. It is often believed to impact minimally on an individual’s everyday life and, while this may be true for some people, living with diabetes is not always experienced so ‘easily’. Research from myriad disciplines has begun to shed light on the complex personal issues of living with the condition, but, with a few exceptions, there is little input from human geography. This thesis hence explores the ‘geographies of diabetes’ in more detail. The findings hinge around a ‘recession’ of the diabetic body in public space. This recession is both discursive and material, caused by the assumptions and expectations of others that diabetes is among the minor of chronic conditions, largely overcome by insulin and ever advancing technologies which enable greater self-control over the diabetic body. Visible diabetic bodies are hence subject to a disciplining gaze, for having transgressed these expectations.

This thesis finds that, despite many people displaying their diabetes minimally in public, the condition impacts greatly on a personal level. People with diabetes are aware that their bodies are at risk of both short- and long-term complications more so than if they did not have diabetes. These vulnerabilities serve to create anxious bodies for whom everyday spontaneity is curbed and dependency is heightened. In order to conceal the visible signifier of diabetes, to avoid the disciplining gaze, people ‘perform’ aspects of their self-management, hence further obscuring the anxious realities of living with diabetes. The embodied differences of having diabetes along with the discursive ‘recession’ of the condition, contribute to an ideal of ‘diabetic citizenship’. It is to this ‘diabetic citizen’ – who experiences the condition with few problems, and with any difficulty attributed to personal and moral failing – that many people with diabetes express their frustration. Through the methods of online questionnaires and face-to-face interviews, this thesis raises awareness of the clandestine geography experienced by people with diabetes.

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AUTHOR'S DECLARATION

I declare that this thesis is the result of my own work, except where explicit reference is made to the work of other. This thesis has not been submitted for any other degree at the University of Glasgow or any other institution.

A handwritten signature in black ink that reads "Mark Lucherini". The signature is written in a cursive style with a large initial 'M'.

Mark Lucherini
21st July 2015

GLOSSARY OF TERMS

CSII – Continuous subcutaneous insulin infusion (insulin pump)

Blood sugar level – The measurement of the amount of sugar in one's blood

DSN – Diabetes specialist nurse

Glycaemic control – Blood sugar control

HbA1c – Three month measurement of average blood sugar levels (given as a percentage rather than in mmol/l)

Hypo – Hypoglycaemia (episode of low blood sugar)

Hyper – Hyperglycaemia (episode of high blood sugar)

MDI – Multiple daily injections

mmol/l – Millimoles per litre (the unit of measurement for blood sugar levels)

PWD – Person/people with diabetes

TIM – Testing and injecting (self-)management

CHAPTER 1

INTRODUCTION: WHAT IS DIABETES?

INTRODUCTION

To begin my thesis, it is useful to provide a brief history of diabetes, focussing, in particular, with the discovery of insulin in 1921, undoubtedly one of the greatest medical discoveries in modern times. Insulin turned an acutely fatal disease into one that could be treated (if not cured) and laid the foundations for a more hopeful treatment of diabetes that is still developing with new research, technologies and practices. Tattersall (2009), in his book *Diabetes: The Biography*, notes some of the earliest mentions of diabetes: one on Egyptian papyrus in 1500 BC, while a Hindu physician also mentions it in the sixth century BC. However, these descriptions were limited and the first significant description of diabetes was that of ancient Greek physician, Aretaeus, who poignantly describes many of the symptoms of hyperglycaemia:

The course is the common one, namely, the kidneys and the bladder; for the patients never stop making water, but the flow is incessant, as if from the opening of aqueducts. The nature of the disease, then, is chronic, and it takes a long period to form; but the patient is short-lived, if the constitution of the disease be completely established; for the melting is rapid, the death speedy. Moreover, life is disgusting and painful; thirst, unquenchable; excessive drinking, which, however, is disproportionate to the large quantity of urine, for more urine is passed; and one cannot stop them either from drinking or making water; Or if for a time they abstain from drinking, their mouth becomes parched and their body dry; the viscera seem as if scorched up; they are affected with nausea, restlessness, and a burning thirst (Aretaeus quoted in Tattersall 2009: 11).

It seems that diabetes was rare in ancient times: another ancient Greek physician, Galen, only ever recorded two patients and Tattersall (2009) speculates that this rarity may have been because relatively few people were overweight in ancient times. Thomas Willis¹, who is perceived to have given the first modern medical account of

¹ I do not intend to give an account of the ‘great men’ in the history of diabetes and the discovery of insulin but I will provide brief biographical details by way of footnotes. Thomas Willis (1621-1675) was an English physician pioneering in neuroscience and is considered to have given the first clear descriptions of many diseases, including diabetes (Hughes 2000). Willis described diabetes as the

diabetes in 1679, supports this claim, writing that, “in our age, that is given so much to drinking and especially to guzzling of strong wine”, diabetes is more common (Willis quoted in Allen 1953: 74).

Despite knowledge of the condition existing in ancient times, the causes of diabetes were long obscure, thereby positing the diabetic body as something of a mysterious space. Tattersall (2009) mentions that in the early-nineteenth century autopsies were useless in determining the cause of diabetes because the organs all seemed normal upon inspection, leading diabetes to be considered as a “ ‘general disease’ which has no local seat ... We therefore place it by itself as a non-febrile general disease, with no ascertainable pathology or anatomy” (medical textbook quoted in Tattersall 2009: 32). Further describing the interstitial spatial confusion that surrounded diabetes, Tattersall notes that several physicians situated the cause of the disease in the kidneys, liver or brain before the significance of the pancreas was discovered in 1889, when Oskar Minkowski² removed the pancreas of a dog – “since a spare dog was available” (Tattersall 2009: 36-37) – discovering a few days later that the dog could not stop urinating and that its urine contained sugar. Minkowski’s findings later gave credence to the hotly debated internal secretion theory, which posited that a hormone was secreted from within the pancreas that acts upon sugar metabolism. It was then proposed that this internal secretion came from the Islets of Langerhans (named after Paul Langerhans who discovered them in 1869³), microscopic cells that lie within the pancreas. A low number of islets in the pancreas is now known to be the cause of type 1 diabetes and such knowledge led to Dr Frederick Banting, assisted by, then medical student, Charles Best, discovering insulin in 1921.

Prior to the 1920s, a diagnosis of diabetes would be the most terrible news that a patient and their family could hear. Affecting mostly (but certainly not exclusively) young children, it was all but a death sentence. In the early-twentieth century the only advance in treating diabetes was a ‘starvation diet’ as advocated by two of the few

‘pissing evil’, in reference to the unrelenting frequent urination that is a symptom of hyperglycaemia (Feudtner 2003).

² Oscar Minkowski (1858-1931) was a Lithuanian scientist who is credited with discovering the pancreatic origins of diabetes, but stopped short of developing insulin (Luft 1989).

³ Paul Langerhans (1847-1888) was a German physician who is best remembered for discovering microscopic cells in the pancreas, although their significance in insulin production was not realised until later (Jolles 2002).

diabetes specialists of the time, Dr Frederick M. Allen⁴ and Dr Elliot Proctor Joslin⁵ (Westman et al 2006). Through seriously limiting carbohydrate intake along with fasting days when nothing at all was consumed, Allen and Joslin believed they could extend the life of people with diabetes (henceforth PWD), however briefly and, given the diet, miserably. Indeed, Joslin (1943: 491) reflected that this was a desperate measure in the face of what was a seemingly unstoppable disease: “the aspect [vitality] of these children was truly dreadful. We literally starved child and adult with the faint hope that something new in treatment would appear ... It was no fun to starve a child to let him [sic] live”. Thankfully Joslin’s “faint hope” was realised with the discovery of insulin in 1921, in Toronto, by Banting and Best. Frank N. Allen (1972: 267) was a medical student in Toronto at the time and recalls witnessing the first patient treated with insulin:

On 11 January 1922, the almost moribund patient was given 15 cc. of the brownish fluid that had been prepared by Dr Best with painstaking care. A drop in the blood sugar followed, but more extract had to be prepared for a decisive trial. Beginning twelve days later, on 23 January, daily injections were given until 4 February. Now the results were certain. The condition of the dying boy was dramatically changed; in fact, he came back to life ... effective treatment of the severest diabetes was now at hand.

Dr Joslin (1943: 491) waxed more lyrical, imputing an almost messianic quality to Banting and Best’s achievement as he quoted from what he came to call the “Banting chapter in the Bible” to express his awe:

To me the only description that fits the diabetic scene at that time was written years before by the Prophet Ezekiel and if you will only put into Dr Banting’s mouth the words the Prophet wrote centuries ago [he quotes the Bible at length is his lecture⁶] you will realise what diabetics were like in 1922 and what he did for them. No words of mine can equal this description.

⁴ Frederick Madison Allen (1876-1964) was an American doctor who researched diabetes at Harvard University and the Rockefeller Institute in New York before opening the *The Physiatric Institute for Diabetes and Metabolic Disorders* in April 1921 (Tattersall 2009).

⁵ Elliot Proctor Joslin (1869-1962) was a leading diabetes specialist doctor. His practice was based in Boston, where his legacy continues through the Joslin Diabetes Centre. Reading Feudtner’s (2003) history on Joslin’s patients, it is clear he was incredibly well respected by his patients and colleagues.

⁶ An excerpt of this description: “so I prophesied as he commanded me, and the breath came into them, and they lived, and stood up upon their feet, an exceeding great army” (quote of the Prophet Ezekial from the Bible, quoted in Joslin 1943: 492).

Insulin did not cure diabetes, though, but rather, as Dr Chris Feudtner (2003) points out, ‘transmuted’ the disease from acute and fatal to chronic, one to which a PWD must always be vigilant. Hence, a whole new set of problems became apparent: as PWD no longer died quickly, clinicians started to see the long-term effects of diabetes for the first time. Keenly aware of this new reality, Joslin and colleagues did not become complacent in their care of PWD following the discovery of insulin. As Feudtner (ibid: 144) notes, Joslin was a stickler for control:

The Joslin group structured their diabetic management around the ideal of seizing control of the disease, preventing all complications, and extending life at virtually any cost. Their collective commitments to this ideal of complete control was entrenched so deeply that it became a sacred ideal, beyond criticism, connected to other fundamental dichotomies, natural and moral: control versus laxity; healthy versus sickness; life versus death; virtue versus sin.

It was quickly clear to Joslin and his colleagues that insulin was not a cure for diabetes, but a treatment for improving control and so extending life and increasing vitality. For Joslin (1943: 497 *my italics*), not taking responsibility for one’s self-management in the wake of insulin was tantamount to sin:

The creation of an individual responsibility in the diabetic has been and remains the keynote of treatment. If the diabetic is not imbued with the necessity, the desire, and the duty to maintain his health, there is little that a doctor can do for him. To a certain degree, I welcome this fact, *because it will mean that the diabetics who live are the desirable diabetics, the good citizens.*

Self-management of diabetes quickly became tied to ideas of good citizenship, and Joslin (ibid) continued to say that he had little tolerance for PWD who seek special privileges because of their condition: “I know I demand a good deal of a diabetic, but I have always felt and said that diabetics as a whole were superior people, and I believe this is the time for them to prove it”. I do not mean to present Joslin as some cold-hearted disciplinarian: as while he certainly had firm beliefs about how PWD should conduct themselves, Feudtner (2003) tells how he often charged patients only as much as they could afford and, at times, he and his colleagues would treat poorer patients for free. Nevertheless, the emerging themes of ‘complete control’, self-discipline and critique of ‘lax’ lifestyles were to frame thinking and practice around diabetes for years to follow. They also came to shape the everyday geographies of diabetes, as this thesis will show.

The discovery of insulin enabled PWD to live longer and throughout the years it has been refined and other technologies such as mobile blood sugar testing kits, insulin pens and insulin pumps have enabled PWD to gain even more exacting control of the disease. Though these tools enable control, they do not cure diabetes. Feudtner (2003: 91) makes this point clear in his book:

Each and every day of the twentieth century, diabetics and their families have had to manage the many challenges that the disease presents, from physiological abnormalities to social stigma. At a practical level, diabetics simply have to take care of themselves. Their lives have been marked by repetitious ritual: test the urine, inject the insulin, eat according to a prescribed schedule. To these necessities were added the intimate tasks that attend to the annoying or painful or dangerous complications of the disease: clip the toenails, inspect the feet, bath in warm water for a flare of neuritis.

Feudtner's aim is to bring attention to the ongoing realities of life with diabetes, an existence which, despite being 'manageable', is ever and always complicated by the disease. Feudtner (ibid: 208-209) does reflect on what he feels could be perceived as his cynical methodological approach, writing that:

Occasionally, I have wondered whether my interpretation reflects a poverty of imagination, whether in this era of multi-organ transplants and bold plans for gene therapy I have failed to exercise sufficient imagination regarding what the future might bring ... Yet the untrammelled pursuit of cure also suffers from an impoverished imagination, one lacking dedicated and constant awareness of the person who is the patient.

Feudtner does not discredit searches for cure, but warns against a tunnel vision in which the PWD and their immediate everyday life can be neglected.

Prior to insulin, most PWD would have been admitted to hospital so that their condition could be closely monitored. Allen opened, *The Physiatrie Institute for Diabetes and Metabolic Disorders* in April 1921 in Morristown, New Jersey (New York Times article 1921)⁷, intending it to become a renowned centre for diabetes treatment. Michael Bliss (2000: 39), in his book charting *The Discovery of Insulin*, notes that in the early-twentieth century, before insulin:

⁷ The New York Times article describes the institute:

The site of the institute comprises about 200 acres of lawns, woodland, gardens and farm lands. Laboratories, a diet kitchen and other scientific provisions occupy the main building. The institute specialises in the treatment of diabetes, obesity, Bright's disease and high blood pressure. One of its most important functions is scientific research. Treatment is offered to patients in all degrees of financial circumstances.

The thorough treatment of diabetes was expensive and complicated, involving prolonged hospital stay, careful preparation and weighing of individually tailored diets, elaborate daily tests, and special nursing for children. In prosperous North America diabetes was becoming something of a specialist's disease, with special diabetes wards being set up at hospitals and physicians building whole practices on nothing but the treatment of diabetes.

Once insulin came onto the scene, however, the need for a residential facility with concentrated services, such as Allen's, soon evaporated. Bliss (2000: 239) writes of Allen, who in the early-twentieth century was considered one of the leading experts in the care of PWD, that: "after insulin, Allen was just another diabetologist, the proprietor of a high-cost institute many of whose patients no longer needed its services". Before insulin, because of the need for close surveillance of diabetic bodies, PWD were to an extent spatially bounded to hospital wards and specialist centres. PWD would also have been spatially restricted due to their poor health, limiting a great deal activity and employment. Insulin changed all this: PWD quickly went from death's door to comparatively healthy and could look forward to a much extended life. Bliss (2000: 242) notes that, while many contemporaries at the time of insulin's discovery, including, no less, Banting and Best, the discoverers themselves, thought that "insulin had licked diabetes ... by contrast, Elliot Joslin had devoted his life to the treatment of diabetes. He also realised that the disease was far from solved by insulin", and he continued to advocate ideals of self-management as vital for PWD to ensure as long and as healthy a life as possible. Joslin's practice in Boston grew as a hub for diabetes treatment and today it exists as the *Joslin Diabetes Centre*, pioneering research into the prevention, cure and treatment of diabetes.

Joslin's focus on self-management continues today and diabetes is mostly an out-patient condition. Stays in hospital still occur, often at diagnosis, when a PWD's blood sugar is so high that it is advisable to keep them under close observation, and also to initiate them into practices of self-management. Complications from diabetes can also result in hospital stays, but diabetes is now primarily managed in the day-to-day spaces of PWD's lives. Technology has had no small part to play in this: Mol (1998: 277) writes that, "since the 1980s there have ... been miniaturised laboratories for patients with diabetes", referring to blood sugar testing meters (Figures 1 and 2). Prior to these meters, PWD could still test their sugar levels away from the clinic but

only through the more cumbersome method of urine tests⁸. As Lupton (2013: 266) writes: “not only has the clinic moved into the home, it has dispersed to every possible spatial and temporal location. Not only are medical and health-related data now mobile, but so are the bodies/devices that produce these data”. With this ‘de-centering’, PWD are not only located in everyday spaces, but also embody new spaces through creating “a clinic in the corner” (Patton 2010: 131), as they actively measure and support their bodies (Figures 3 and 4).



Figure 1. This picture shows myself using my blood test meter in a café. I have pricked my finger using a small lancet device and I am preparing to spread the blood onto the end of a test strip which has been inserted into the meter. After the blood has been smeared on the strip, the meter will take five seconds to display a number which will represent the amount of sugar in my blood at that moment in time (author’s own photograph).

⁸ Stanley Benedict developed a way to test for sugar in the urine in 1911. The test involved taking a sample of fresh urine, adding a set amount of a solution that Benedict had created, boiling the mixture and then comparing the resulting colour of the mixture to a chart to determine sugar content. It was the only way for PWD to self-test until the 1950s, at which time it was replaced by a test strip which could be submerged in a urine sample and would change colour quickly to indicate sugar content. Electronic meters become common in the late-1970s. These descriptions are according to Feudtner (2003).

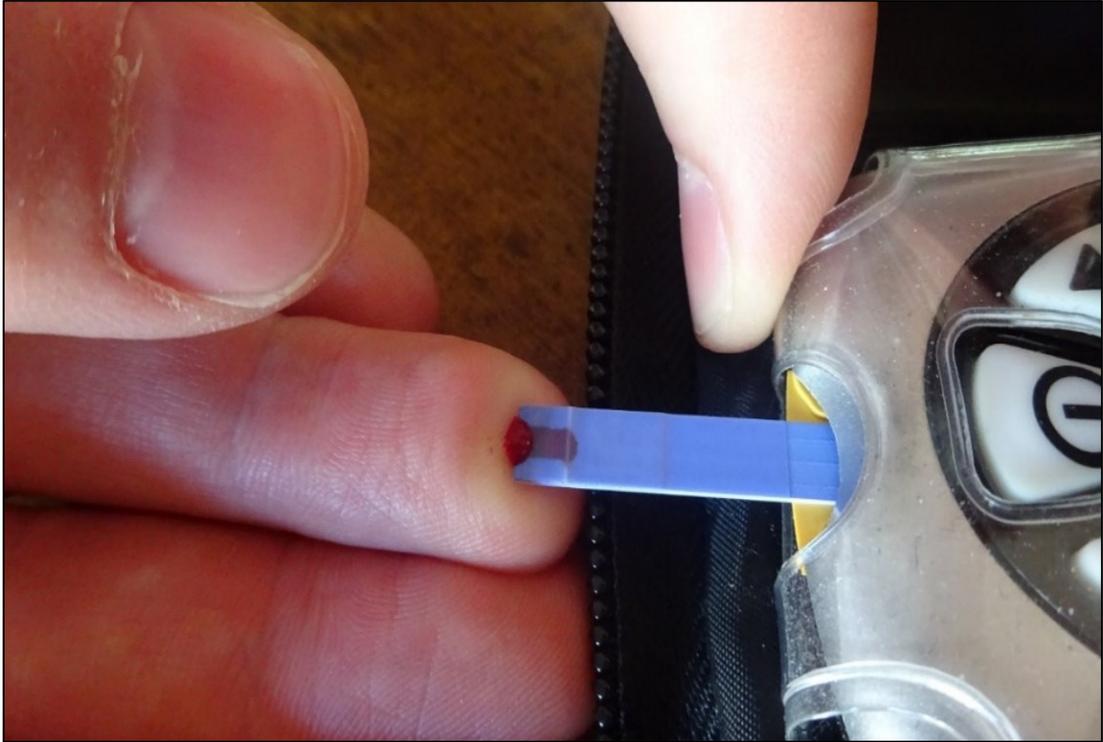


Figure 2. This is a further close up picture of the blood test meter in use. I have chosen this picture to demonstrate the 'bloody' aspect of this practice (author's own photograph).



Figure 3. A close up of myself injecting insulin into my arm (author's own photograph).



Figure 4. Preparing my insulin pen for an injection. This photograph demonstrates that the act of injecting insulin (and testing blood), when done in public, often takes place in restaurants, cafés, bars and similar places where food and drink is served and consumed. Hence it often happens in front of other people, in sometimes tight spaces (author’s own photograph).

Diabetes is now a geographically dispersed condition and this is where my thesis intervenes, exploring the spatial implications of leading a contemporary life with diabetes. Atkinson et al (2011) note that a wider de-centering of healthcare from clinical spaces is produced not only by advances in technology, but also neo-liberal ideologies of taking responsibility for one’s health. As Atkinson (2011: 625) surmises, “self-care captures the contemporary responsabilisation of the self for its own actualisation and wellbeing, a self-monitoring and disciplining of the body, conduct and being, and an obligation to make use of the available technologies and resources to do so”. While Feudtner (2003) stresses that insulin changed diabetes from a ‘natural’ disease (usually endured through a ‘starving’ life and a relatively quick death) to a lifestyle of mundane routine, I wish to stress that, as medical science has pushed even further forward, so too have notions of overcoming disease and illness. In this context, I want to suggest, in what follows, that ‘minor’ illnesses such as diabetes have possibly become concealed as somehow ‘private’ rather than ‘public’

endeavours of management. Moreover, I argue that diabetes has *receded* – a crucial concept for my thesis – from public view despite its mundane existence being an acute presence in many PWD's lives. My aim is not only to interrogate this continual clandestine presence, but to unravel the many ways in which diabetes is concealed in everyday life.

Moreover, my initial interest in studying diabetes comes from my own diagnosis in 2008. Throughout my six and a bit years (at time of writing) of living with diabetes, I have admittedly felt it recede into habit and routine, so that on many days I am *unaware* of its impact on my life. As my research participants will demonstrate, this 'recession' was not an uncommon response to questions about living with diabetes. In some ways this casts doubt on the need for my research, as it suggests that living with diabetes is not a significant enough 'biographical disruption' (Bury 1982) to merit such in-depth academic attention. But then there are periods of my life when I start to worry: I might realise, for example, that my blood sugar readings for the last month have been consistently high, but due to my failure to detect this as a pattern, I did not act to change. So I worry about the damage that this period of high blood sugar might have precipitated. Is that ephemeral shadow in my vision the beginning of retinopathy? Is the slight pain in my foot the beginning of an ulcer that could lead to amputation? Or are these embodied sensations nothing, merely the lingering effect of staring at a computer screen all day or the result of a bout of five-a-side football the previous morning? And then, of course, hypoglycaemia reminds me of my precarious body: working on a chapter, I feel myself lose concentration, I start muttering to myself, start to fidget and suddenly typing seems a most awkward chore. I check my blood sugar and discover a low reading – 3.6mmol/l – time for some jelly babies! Of course I *should* eat four jelly babies and wait ten minutes, but I frantically eat until the feeling goes away, thereby significantly raising my blood sugar in the aftermath. Unsurprisingly, I then feel sick and a little exhausted; I need to lie down for a while before I can resume work on both my chapter and balancing out my blood sugar. I found similar reflections among my participants as they often told of their diabetic body receding from everyday life and interactions, only then to tell of problems and dilemmas, both material and social, that occur in their everyday lives because of diabetes.

My suggestion here is that diabetes is something of a subtle condition, possibly even an insidious one. While the tools of self-management allow greater

control, this control is never complete, and diabetes can perhaps lull a PWD into a regime that may well be ‘controlled’ but with this control not set within ‘safe’ parameters. Indeed, Tattersall (2009), in the prologue to his book, compares living with diabetes to living with a tiger: so long as it is fed and you remain vigilant of the tiger it will leave you alone, but as soon as you turn your back, it will pounce. Likewise one of my participants, Kyle – incidentally a diabetes specialist nurse (DSN) and a PWD – often tells his patients and audiences (he speaks at many diabetes related events) that PWD have two full-time jobs: the first is their normal job, a nurse, PhD student or lecturer, and the second is managing their diabetes.

SOME FACTS

Realising that I have not yet explained what diabetes is, I now provide some facts and figures to contextualise the condition. There are over 3.2 million people in the UK diagnosed with diabetes mellitus, and an estimated 630,000 with the disease who are undiagnosed (Diabetes UK website A). Of these 3.2 million, 90% have type 2 diabetes (Diabetes UK website B). According to the 2013 Scottish Diabetes Survey (SDS), in Scotland, there were 268,154 PWD registered with health boards at the end of 2013, of whom 88.2% (236,605) have type 2 diabetes (SDS 2013). Diabetes mellitus is a disease caused by an inability of the body to turn glucose into energy because of a lack of insulin, a hormone developed in the pancreas. Diabetes mellitus is often simply referred to as diabetes, as it will be for this thesis, but there are numerous ‘types’. In type 1 diabetes the body produces no insulin at all and regular injections (Figures 3 and 4), or a continuous pumping of insulin into the body, are required to compensate. Regular injections are referred to as multiple daily injections (MDI), while the use of insulin pumps is referred to as a continuous sub-cutaneous insulin infusion (CSII). Type 1 often occurs in childhood and, in the past, has been referred to as childhood-onset diabetes; while type 2, more common in older people, was referred to as adult-onset diabetes, but this terminology has, today, largely been dropped as either type can occur in anyone at any time. Type 1 is often referred to as insulin-dependent diabetes mellitus (IDDM), and by extension type 2 as non-insulin-dependent diabetes mellitus (NIDDM), although these terms are not fixed to type as people with type 2 may still be insulin dependent. As the above figures show, type 2 is the most common form of diabetes and its onset is often linked to lifestyle factors,

such as poor diet and insufficient exercise, although genetic predisposition also plays its part. In type 2 the pancreas produces some insulin but not enough to maintain healthy blood sugar levels and is often controlled through diet regulation and oral medication. Other types of diabetes exist such as gestational diabetes, which occurs during pregnancy and often persists after, but my thesis mainly focusses on these two main types, partly because my participants only reported having type 1, type 2 or late autoimmune diabetes of adulthood (LADA⁹).

The two main dangers of any type of diabetes are developing *hypoglycaemia* or *hyperglycaemia*. Hypoglycaemia (commonly referred to as a *hypo*) occurs when one's blood glucose level is too low, which can occur from not eating, too much heat, illness, too much exercise or physical activity or taking too much insulin. Symptoms include shaking, sweating, loss of inhibitions, light-headedness and ultimately coma. Symptoms are usually acute, and treatment should be carried out immediately by consuming glucose (sugar), usually available via glucose or energy tabs but eating any carbohydrate foodstuffs is also effective. If a PWD is unable to treat the hypoglycaemia themselves, a glucose injection can be given which raises blood sugars. Hyperglycaemia (commonly referred to as a *hyper*) occurs when blood glucose levels are too high, caused by not taking enough insulin or eating too much carbohydrate – hyperglycaemia usually leads to the initial diagnosis of diabetes. Symptoms of hyperglycaemia include excessive thirst, excessive urination, weight loss, lethargy and blurred vision. It is usually treated by taking insulin. Unchecked hyperglycaemia can lead to diabetic ketoacidosis (DKA), which can cause extreme vomiting and ultimately coma. DKA is an extreme outcome of hyperglycaemia as it needs a very high blood sugar level to occur. The more insidious symptoms of hyperglycaemia are the long-term ones that develop due to frequently and/or consistently higher (rather than highest for DKA) blood sugar levels and are usually quite slow to present, but can result in serious complications such as amputation, loss of sight or heart attack.

Blood sugar (or glucose) is a measure of the amount of sugar in one's blood and is usually measured in millimoles per litre (mmol/l). Most PWD will self-test by using a small electronic meter. The lower limit is usually set at 4.0mmol/l with

⁹ LADA is perhaps best described as a liminal form of diabetes bearing indicators of both type 1 (for example, insulin injections) and type 2 (for example, being adult-onset) but not quite definable as either.

anything less being hypoglycaemia territory; the upper limit is usually set at 8.0mmol/l with anything more being considered hyperglycaemia territory. HbA1c is another measure of blood sugar levels and PWD have this measurement taken every three to six months to indicate average blood sugar levels over the previous three months (it is commonly measured as a percentage with 6.5% indicating ideal levels). For many clinicians, the care of diabetes today is a ‘gluco-centric’ endeavour, in which the priority is to minimise deviations in blood sugar control.

GETTING TO THE POINT

As the chapters unfold, I keep in mind four central research objectives to explore the *everyday geography of living with diabetes*, designed to illuminate many of the spatial contingencies that the condition presses down on and into a PWD’s everyday life. These objectives are:

- To examine how diabetes influences a person’s everyday negotiation of diverse spaces, from the private home to the public street.
- To bring more sensitivity to the social and emotional aspects of living with diabetes, as linked across the spaces inhabited, used and maybe avoided.
- To examine to what extent PWD feel their bodies and their actions are influenced by ideals of what a PWD *should* be like.
- To explore notions of care of the self and examine, given the aforementioned dispersal of diabetes care from the clinic, the sense of personal responsibility that comes with diabetes.

These objectives will be addressed throughout the chapters and I briefly outline the content of each:

In **Chapter 2**, I introduce the literature from myriad disciplines that concern the lived experience of diabetes. With further reference to geographies of health and geographies of disability, I chart a path for my own research to build upon this literature using a geographical compass.

In **Chapter 3** I discuss the diabetic body as a recessive body. I trace this recession to two main roots. The first root I examine involves discursive forces, such as diabetes being considered an ‘easy’ to manage condition. This can prompt PWD to remain quiet about their diabetes thus leading to a recession of talking about diabetes in the public domain. The second root concerns everyday diabetes related practices and processes that can become so routine for PWD that they recede from a PWD’s everyday thoughts. Using insights from selective published autobiographies written by PWD, I suggest that this recession is not entirely unproblematic and that it does not occur easily. In the empirical chapters that follow I continually refer to these recessions, complicating them and disputing their easy occurrence. I do this with reference to four conceptual pivots, which I outline in Chapter 3. These pivots are phenomenology; emotion and affect; performance and performativity; and PWD as biological citizens. I take these coordinates in turn and explain how each helps me bring attention to the clandestine geographies of PWD in order to challenge notions of an easy recession.

In **Chapter 4**, I briefly discuss the rise of qualitative methods within human and health geography. I then present a rationale for my chosen methods, namely an online questionnaire and face-to-face interviews with PWD. Many of the interviews were carried out with participation of specialist diabetes clinicians working within the NHS. These clinicians assisted in the recruiting of participants through diabetes education courses, called Dose Adjustment For Normal Eating (DAFNE). The courses from which I recruited were exclusively for people with type 1 diabetes who practice MDI. However through other recruitment methods, such as Glasgow-based diabetes support groups, I also recruited participants with type 2 diabetes. I reflect on some of the challenges faced when implementing these methods, and explain why I have chosen to keep my own ‘diabetic voice’ quiet, but not entirely silent, throughout my analysis. Additionally I describe the other research avenues that I took, particularly the use of blog material in Chapter 5.

In **Chapter 5**, I support the notions of a discursive and routine recession of the diabetic body in public space, by arguing that PWD have little room to express the difficulties or stresses that come with the condition due to diabetes being configured as ‘easy’ and unimposing on one’s life. Following this discussion, I critique an

‘externally’ spatial way of analysing the experience of health and impairment in geography for missing out on the “geography closest in” (Rich, quoted in Longhurst 1994: 214). While numerous geographers have advocated for health geography to pay greater attention to the immediate and embodied ‘blood, brains and bones’ (Hall 2000), few delve into this internal geography to look at the network of affective sites that exist within. I discuss how my research participants have come to know their (diabetic) bodies, inside and out, and suggest that a ‘space-in-body’ approach could provide new insights. This is advanced further with an in-depth case study of two cartoonists/bloggers, drawing from their cartoons, blogs and personal communications with myself.

In **Chapter 6**, I continue to discuss how diabetes is a far from ‘easy’ condition, showing how, although it is possible to manage the condition with little medical complications, it is still so entangled with one’s everyday life that spaces, places and activities are often experienced problematically. I take a series of everyday spaces in turn – home, work, public and clinical, as well considering the less bounded places of mobility – thereby fleshing out the spatial dispersion, or ‘bodies-in-space’, of diabetes. I effectively contradict some of the results from my online questionnaire data that configure these spaces by various degrees of safety, demonstrating that PWD often experience their bodies with a hidden and quiet sense of anxiety. This raises questions about how the treatment and care of PWD should be approached by clinicians, as spatially diverse. I thereby continue to address oversights in current research on care, pointed out by Atkinson et al (2011: 567), which “help make invisible the multiple sites through which our practices are shaped”.

In **Chapter 7**, I present a narrowed down example of how diabetes affects one’s everyday geography. I consider, with reference to Judith Butler, how the management practices – of testing blood sugar levels and injecting insulin (what I call testing and injecting management or, for the sake of easy reading, TIM) – are performed in space (particularly the spaces of restaurants and cafés which represent the most frequented spaces where the visibility of diabetes is obvious). Through this discussion a fully fleshed out, intricate geography of the diabetic body emerges, one that is full of conflicts, tensions, connotations and fears. In considering the visibility of diabetes, I appeal to the idea of ‘coming out’ as a diabetic, I thus explore some of the associated

geographical literature on ‘coming out’ in order to understand the social pressures that people feel to disclose or conceal their condition and its self-management signifiers (as displayed in Figure 5, and seen in practice throughout the other figures in this chapter).

In **Chapter 8**, with reference to the idea of ‘biological citizens’ as introduced by Nikolas Rose (2007), I consider the moral and ethical imperative of being a PWD, as revealed by my participants. PWD often feel under surveillance and subject to disciplinary forces that attempt to determine what they can eat, whether their blood sugar control is good or bad and how much ‘kit’ is reasonable for them to be using. My aim with this chapter is to complete the empirical sections of my thesis, by asking readers to ‘travel in parallel’ (Davidson and Henderson 2010) with the PWD in my analysis so as to enable an empathetic understanding of the condition.



Figure 5. Assorted pieces of my own diabetes ‘kit’. This is my own personal kit and other PWD may have different brands and manufacturers of items. Further possible items may include tissues (to stop fingers bleeding after a blood test), sharps bins (for safe disposal of used needles and lancets), bottled water, sweets/fast acting carbohydrates (to use in the event of hypo), some form of identifier in the case of emergency (such as a bracelet, necklace or wallet card) and even cool bags to keep insulin at a reasonable temperature. While travelling, especially through airport security, it is advised to have a signed and/or NHS letterhead letter, from a hospital clinic or GP practice, explaining that you have diabetes and need to carry these items at all times.

Finally, in **Chapter 9** I summarise the key findings of the preceding chapters and make some suggestions on how to make space, chiefly everyday social space, more accommodating for PWD. I conclude by highlighting a contradiction of life with diabetes, that becomes apparent throughout my thesis, and suggest something of a theoretical compromise for understanding diabetic bodies.

CHAPTER 2

LITERATURE REVIEW: THINKING ABOUT A ‘GEOGRAPHY OF DIABETES’

INTRODUCTION

In this chapter, I will argue that there is a lack of sustained geographical scrutiny into life with diabetes and that such a scrutiny, with guiding principles from health geography, can reveal the importance that space and place has on the everyday life of PWD. To begin this literature review, I will therefore summarise how diabetes and PWD have been treated from a series of disciplinary viewpoints. I will commence by discussing biomedical perspectives, in which diabetes is something to be cured or prevented, with PWD rarely mentioned other than as research participants for clinical trials. Moving on to social science perspectives, I will show how anthropological studies critique biomedical and epidemiological approaches, unveiling the power structures that exist within the creation of this knowledge which often neglects the experience, knowledge and opinions of PWD. Sociological perspectives continue this critical scrutiny as they consider intersecting identities of gender, race and sex, among many others, as influences upon the experience and treatment of PWD. Psychological perspectives uncover the effect that diabetes can have on a person’s identity and mental health, often to the detriment of their ability to manage the condition effectively. Nursing studies also concern themselves with diabetes, focussing on how better to treat PWD, and advocating a more recursive relationship between PWD and clinicians¹⁰. Following this brief overview I will collate certain aspects of the

¹⁰ In this disciplinary review, I do, admittedly, present quite simplistic definitions of academic disciplines. This rudimentary classification reflects the extensive range of social science research and literature that concerns diabetes, which, I believe, is rather amorphous (reflected in the many interdisciplinary journals in which research is published, for example *Social Science & Medicine*). Distinct disciplinary trends are therefore difficult to determine (although a larger, exhaustive and systematic literature review may uncover such distinctness). For example, Mol (2008) provides an extensive ethnographic study of how diabetes is cared for within a Dutch hospital. Her current ‘institutional’ disciplinary affiliation is anthropology but previously it has been social theory or political philosophy. Her 2008 book *The Logic of Care*, which will be referred to many times throughout my thesis, reflects her inter-disciplinary interests as well as the amorphous inter-disciplinarity of diabetes. Therefore, in the following disciplinary review, I do not ‘place’ Mol within any perspective, instead I consider her work – as a general social science perspective on diabetes – after I complete this disciplinary review. Indeed, Mol’s book has been the subject of an AREA book review forum, where reviewers have evaluated its relevance to human geography. The three reviewers

literature on diabetes, from various disciplines, to give an impression of how diabetes is often represented in various media; as a less than serious condition which is to be given little sympathy due to misunderstandings of the relationship between type 1 diabetes and type 2 diabetes.

I will then introduce what could be understood as an existing ‘geography of diabetes’, including some contributions by professional geographers along with inputs from other disciplines. For the most part this geography is epidemiological and concerned with mapping the prevalence of diabetes against various sociological attributes. However, a body of work from social scientist Myles Balfe (beginning with his 2005 human geography PhD on student life with type 1 diabetes), together with various inter-disciplinary co-authors, opens diabetes up to issues of space and place, providing a parallel and partial foundation for my own contributions. There is little in addition to this work from Balfe and colleagues that could be termed a ‘human geography of diabetes’, however, and so I will briefly review three concerns of health geography to demonstrate the suitability for diabetes to be given more exposure in this sub-discipline. Firstly, and representing a broad description of the sub-discipline, health geography provides a series of conceptual references to consider how health and illness affect a person’s experience of place. Secondly, the provision of healthcare brings to light the, sometimes obscured, spatially *relational* aspects of diabetes *self*-management. Thirdly, operating under a health geography umbrella, geographical studies of disability provide further insights into how to develop a geography of diabetes, even if the marrying of diabetes and disability can at times be problematic. I will then conclude by discussing how the geographies of diabetes will be further explored in the following chapters of the thesis.

DIABETES IN THE DISCIPLINARY LANDSCAPE

BIOMEDICAL PERSPECTIVES

The exact pathology of diabetes is still unknown. With type 2 diabetes, lifestyle factors have been found to contribute to onset but are not necessarily the only factor

all highlight Mol’s points about relational care and her discussions on the use of technology which could be useful in elaborating non-representational geographies (Bowlby 2010; Greenhough 2010; Clarke 2010). My intention, with the upcoming section, is to give a (selective) flavour of the range of disciplines and approaches that study diabetes, while highlighting their geographical ‘hints’.

and theories of genetic hereditariness are much discussed and debated. In the early 1960s, Neel (1962) introduced the ‘thrifty gene theory’, proposing that in feast-or-famine eras a ‘thrifty gene’ would allow people to store large amounts of fat during a feast period so they could survive the subsequent famine period. Thereby, the thrifty gene was reproduced through natural selection. However, since industrialisation and urbanisation of human environments, the thrifty gene has become a disadvantage as, in the Western world at least, widespread famine is no longer an issue. This means that people, in the Western world, are more likely to be overweight because the thrifty gene makes them store excess food for a famine that does not happen, hence making them susceptible to the onset of type 2 diabetes. With regards to type 1 diabetes, Daneman (2006) summarises the Eisenbarth¹¹ model, noting that, although this model is somewhat dated (having been established in the 1980s), it still offers the most relevant explanation. The model proposes that every person has some degree of susceptibility to type 1 diabetes and that this susceptibility interacts with an environmental trigger, such as a virus, which initiates the destruction of the Islets of Langerhans. Other theories include the ‘hygiene hypothesis’, which proposes that the higher rate of prevalence of diabetes (and asthma) in children in modern times can be explained by the lack of stimulus of the immune system from a dearth, due to modern vaccinations and medicine, of early life infections (Gale 2007).

The classification of diabetes ‘types’ is debated by clinical researchers. Wilkin (2001) sets forth the ‘accelerator hypothesis’, arguing that type 1 and type 2 diabetes share a common aetiology: that is, they are essentially the same disease, sharing the same accelerators of weight gain (obesity) and insulin resistance, but that they progress at a different ‘tempo’. Wilkin (2007) contends that a reclassification of diabetes to a single type would encourage a lifestyle approach for prevention of type 1 diabetes. However, his theory is unproven and much contested, for instance by Gale (2007), who argues that Wilkin places too much importance on weight gain affecting both type 1 and type 2, thereby obscuring other factors that affect the rate and development of both types of diabetes, such as genetics and metabolism. The exact pathology, of all types of diabetes, however, remains unknown and contested.

¹¹ Referring to George S. Eisenbarth M.D, a US medical researcher who passed away in 2012, and who had devoted his career to researching diabetes.
(<http://www.ucdenver.edu/academics/colleges/medicalschoo/centers/BarbaraDavis/Pages/George-Eisenbarth.aspx>)

Hall (2004) discusses how competing discourses emerge when explaining the cause of heart disease, between a genetic inheritance and behavioural factors. Hall discusses the dilemma that many clinicians ponder, that is to explain to a patient that he or she has a genetic predisposition to heart disease may result in them adopting an unhealthy lifestyle due to the development of a fatalistic ethos. In fact, through this reluctance, the clinicians may be reinforcing a ‘good’ and ‘bad’ dichotomy – good patients who develop heart disease (or type 2 diabetes) have bad luck, while bad patients bring it on themselves. The reluctance of clinicians to use genetic factors to explain type 2 diabetes will be evident in Chapter 8 where I discuss how people with type 1 diabetes enjoy something of a ‘genetic privilege’. Adopting a genetic and lifestyle dichotomy, type 1 diabetes causality is understood as genetic, while type 2 causality is moral. Perhaps this distinction is why Wilton’s accelerator hypothesis is resisted, as his theory melds the two types into one, troubling distinctions of genetics, morality (mainly body weight), causality and type. These troubling theories of causality are reflected in media representations of diabetes, which will be discussed later in this chapter. Concluding his paper, Hall (2004) suggest that providing patients with greater understanding of the genetic factors of heart disease does not necessarily result in fatalism but can create a pragmatic self-care approach.

From a biomedical perspective, diabetes is a disease to be cured and/or prevented. Of course treatment and cure of diabetes are essential research aims, and, like Feudtner (2003), who I discussed in the introductory chapter, my aim is not to criticise this research but to argue that it often treats diabetes purely as a disease to be cured and PWD solely as subjects to be cured¹². Research into cure/prevention can be summarised in two major categories. The first involves transplantation of the Islets of Langerhans (from healthy pancreata or through stem cell methods) or transplantation of whole a whole pancreas, and is considered a real possibility for future treatment of PWD (especially type 1). The major downside, and the reason that this method is not currently in widespread use, is that such treatment requires a strong and constant regime of immunosuppressive drugs, in order for the new cells to be accepted by the

¹² Medical philosopher, Marcum (2011) writes that biomedical research into type 1 diabetes is often branded a ‘failure’ because a cure has not yet been developed, despite the fact that knowledge into managing and treating the condition is ever advancing. Indeed, Marcum raises questions about the definition of ‘cure’ with regards to type 1 diabetes, musing that ‘cure’, meaning the eradication of disease entailing no ongoing interventions, excludes possible definitions of ‘cure’ as eradicating symptoms (such as effective self-management).

host body. This regime makes the receiving person vulnerable to myriad other infections, so much so that the advantages of transplantation are, most often, fewer than the disadvantages of not having the procedure. There nevertheless remains hope that transplantation will become a viable potential cure for diabetes as medical technologies advance (see Tavakoli and Liong 2013 for a summary of this approach). The second approach is to prevent diabetes through vaccination. Biomedical researchers argue that a vaccine could prevent or reduce the impact of the immune system attacking and destroying the Islets of Langerhans. Currently human trials of vaccination have shown little success, but researchers are excited about the potential for developing this method in the future (Boettler and von Herrath 2011).

ANTHROPOLOGICAL PERSPECTIVES

Turning to the social sciences, anthropological studies report aboriginal or developing world populations as experiencing higher rates of type 2 diabetes prevalence. This is often understood as a result of a switch to a ‘modern’ lifestyle, in which the built urban environment itself is sometimes considered by aboriginal people as contributing to diabetes prevalence (Lang 1989; Akhter et al 2011; Eaton 1977; Faisal 2010). Various researchers (Fee 2006; Poudrier 2007; Everett 2011) have noted that the ‘thrifty gene theory’ is often used as an explanation of why many aboriginal and indigenous populations have higher prevalence of type 2 diabetes. The explanation goes that aboriginal people often have the thrifty gene due to their difficult living circumstances where food is not plentiful, but now, with recent ‘Westernisation’, they are exposed to, and consume, plentiful food opportunities. Fee (2006) writes that this racial explanation can lead to a ‘geneticisation’ of people, as they are defined by genes rather than other aspects of individual or collective identity, thereby hindering attempts to understand the condition more completely. Fee (2006: 2988) argues that the thrifty gene theory has been used, perhaps unwittingly, by researchers as a “crude proxy” reflecting racist discourse, and thereby obscuring the fact that diabetes, regardless of race, is the same disease in all people. Among aboriginal populations, Weiner (1999: 178) reports that the increased prevalence of diabetes is often understood as an issue of “power imbalance” born out of “socio-political roots” that restricts access to greater knowledge and potential treatment practices. Weiner argues

that there is a neglect of aboriginal and indigenous perspectives on diabetes causation and so social, cultural and historical reasons are underexplored.

Glasgow is a culturally, ethnically and racially diverse city, and such diversity does impact on the experience of living with diabetes. For example, Lawton et al (2007), carrying out a survey of both Asian immigrants to Scotland and white Scottish people, found that Pakistani and Indian immigrants to Scotland ‘externalised’ causation for type 2 diabetes on to factors related to their immigration experience, such as increased stress, to such an extent that development of type 2 diabetes becomes considered as inevitable. White Scottish respondents to their survey, however, most often considered type 2 diabetes to be caused by a personal failing. Lawton et al (2008a) note that British Pakistanis and Indians are aware that their risk of type 2 diabetes is high because of Asian foods, which are high in carbohydrates; but that, unlike white PWD, they are reluctant to cut *out* such foodstuffs to be replaced by healthier alternatives, but instead prefer to cut *down* because the eating of such food is important for maintaining cultural connections. Baradaran and Knill-Jones (2003) come to similar conclusions in their own research, finding that PWD from ethnic minority groups in Glasgow have less knowledge about diabetes and regard the condition less seriously than do white PWD. This research argues that approaches to understanding PWD’s perspectives need to be more culturally and context sensitive. Hand-in-hand with this sensitivity, there also needs to be an avoidance of essentialist assumptions about race and diabetes causality. As discussed in the previous paragraph Fee (2006) is wary of diabetes, especially type 2, becoming known as a disease that has racial causality, thereby obscuring social factors. There are thus ethnic and racial intersections in diabetes experience and self-management in Glasgow which, building from the aforementioned researchers, represent an interesting field for future study, albeit one not touched upon in my own research.

SOCIOLOGICAL PERSPECTIVES

Sociological perspectives on diabetes are abundant. Exploring issues of gender among children with diabetes, Williams (1999, 2000) finds that girls are more likely to be forthcoming when talking about their diabetes and incorporate it into their lifestyle, while boys are more likely to remain quiet in order to maintain a ‘masculine’ identity. For older PWD, Sardaki and Rosenqvist (2002) note that deep-rooted gendered

expectations of wives and mothers to assume the responsibility of ‘health’ in families can lead to the neglect of diabetes self-management among women. With regards to men, Liburd et al (2004) find that they can have a sense of diminished masculinity, for attending to diabetes self-management – such as acknowledging the potential for hypos – impacts on everyday activities that could otherwise be carried out with a ‘recklessness’. Social factors can also effect life with diabetes and Mendenhall et al (2010) find that it is often those with lower socio-economic status that suffer most from diabetes-related complications. Spirituality is also a factor in diabetes experience, and Polzer and Miles (2007: 179) describe how belief in “God Is Healer” leads to some people relinquishing control of their type 2 diabetes self-management altogether and trusting God to heal their diabetes. As the previous paragraphs have shown, race and ethnicity are also considered to affect experiences of diabetes. Although Sedgewick et al (2003) note that, while many US studies identify a lack of access to health services for ethnic minority groups, their own (quantitative) questionnaire survey finds that black African and black Caribbean people with type 2 diabetes in the UK do not experience a similar lack.

The aim of my research is not to focus on any one of these identities or intersections, as others have done, but instead to unfold some of the more cross-cutting and common experiences of living with diabetes. My research thus runs a risk of presenting an ‘unmarked’ diabetic subject, but I attempt to counter the risk by nuanced attention to the peculiar subjectivities of being a PWD, which can arguable transcend identity categories. Nevertheless, identity intersections do occasionally surface in my analysis, (for instance when discussing pregnancy and motherhood in Chapter 8, but I intend my research to be relevant to all PWD regardless of intersecting identities (including type of diabetes).

PSYCHOLOGICAL PERSPECTIVES

Psychological perspectives on diabetes have considered the impact of the condition with regards to ‘diabetic’ identity¹³. Johansson et al (2009) consider how a phenomenological approach to researching life with diabetes reveals fears among

¹³ Indeed, the accepted term in the NHS is now ‘person (or people) with diabetes’ (PWD) rather than ‘diabetic’, in order not to suggest that having diabetes is central to a person’s identity.

PWD of diabetes becoming an all-consuming facet of their life. Tilden et al (2005) consider how a PWD can reject a diabetic identity, neglecting self-management to the detriment of their health, while Zoffman and Kirkevold (2005: 763) argue that poor glycaemic control can, in part, be explained by PWD's desire to "keep life and disease apart". Adolescent years are a particular focus of research, as it is often during this period of life that PWD diagnosed as children start to take over responsibility for self-management from their parents or guardians (Karlsson et al 2008; Piana et al 2010). Such a changeover can cause problems through a denial of diabetes as it clashes with the usual teenage rites of passage such as rebellion against authority, alcohol, smoking and sex (Rankin et al 2011b). Many of these studies can be considered as adopting a broadly phenomenological methodology, privileging the personal accounts of PWD (Tilden et al 2005 and Johansson et al 2009 explicitly state that they consider their approach phenomenological).

A key area of psychological research is the relationship between diabetes and depression, it long being thought that there is significant co-morbidity between the two (Rubin et al 2004; Gonzalez et al 2011). Gonzalez et al (2011) note that the dominant thinking has been that PWD are two to three times more likely to have depression than people without the condition, but they also note recent studies that suggest PWD are 'only' 60% more likely to have depression. Reviewing literature covering the connection between diabetes and depression, Gonzalez et al argue that, due to poorly constructed research designs, 'depression' among PWD is often only understood as a major depressive disorder (MDD) and thereby other emotional issues, not necessarily due to MDD, are overlooked. They write (ibid: 237) that "this symptom-based and context neutral approach to conceptualising and assessing MDD is particularly problematic for patients with diabetes, leading to both an over-pathologising of patients and an under-appreciation of the role of chronic illness in explaining emotional symptoms". The neglected level of emotional problems is often referred to as 'diabetes distress', which Gonzalez et al define as typified by those emotional and psychological issues affecting PWD who are not necessarily clinically depressed. This 'over-pathologising', Gonzalez et al (ibid: 238) argue, subsequently leads to many care interventions focussing on anti-depressant drugs and psychotherapy, which do not address the issues of diabetes distress, and instead they call for "a new treatment model to understand and address the

emotional concomitants of diabetes”. Methodologically, such a new treatment model would focus on qualitative methods rather than quantitative. Much of the data concerning diabetes and depression is collected through self-reporting quantitative questionnaires, and there are concerns about the non-reporting or under-reporting of depressive symptoms due to the stigma of being ‘depressed’ (Rubin et al 2004).

NURSING STUDIES PERSPECTIVES

Ethnographic methods are used in nursing studies to understand the lived experience of PWD – in social and emotional terms rather than exclusively biomedical ones – and as such attempt to narrow the gap of understanding between practitioners and patients (Haidet et al 2006). Without these methods there is an unbalanced understanding of experience between PWD and clinicians, which can create moral imperatives of ‘good’ or ‘bad’ PWD (Broom and Whittaker 2004; Rasmussen et al 2007; Minet et al 2011). PWD can thereby feel subject to a medical and disciplinary gaze, and drawing from Foucault’s concepts (of a disciplining gaze) is not entirely new in the diabetes literature (Ferzacca 2000, Balfe 2005 and Lawton and Rankin 2010). Rasmussen et al (2001: 631) discover the advantages of a more ‘relational’ approach, writing that: “health professionals’ recognition of the experiences and feelings of participants led to their feeling motivated and able to talk about the ‘trivial’ aspects of their diabetes management as well as the ‘big item’ concerns”. The ‘trivial’ refers to the everyday, mundane items that may play on PWD’s minds. Kumagai et al (2009: 317) discuss their study where medical students visited PWD in their homes, which proved successful as the students reported learning more of the “emotional side” of living with diabetes as opposed to the “statistical”, and so they subsequently reconsidered their assumptions about life with diabetes. Haidet et al (2006) stress the importance of establishing a ‘partnership’ with health care professionals in order to negotiate a plan for effective self-management, while Karlsson et al (2008: 562) suggest that teenagers find themselves “hovering between individual actions and support of others”. Without this type of research, the lived experience of diabetes is understood only in biomedical terms, such that, as Ramanathan (2010: 70) summarises, experiences of diabetes gather “hues of permanence and weight” and cannot be talked about without recourse to established medical and social terms.

Ferzacca (2000: 44 my emphasis), writing from an anthropological viewpoint, argues for more consideration of hybrid medical practices which “suggests something other than the medical practices of patients as either *resistant to* or *accommodating of* medical discourse”. The literature concerning DAFNE courses in the UK represents an example of this hybridity. DAFNE is a five-day long outpatient course which aims to teach a PWD to adopt a flexible insulin regime allowing greater freedom in calculating insulin doses in relation to what the PWD does during the day, rather than calculating what they do in relation to a set insulin and injection routine. Engaging with Foucault, Balfe (2005) considers the DAFNE course to be a technology of the self, as for some of his participants it liberated them from subjective disciplinary practices¹⁴. The course is arguably also a form of biopower, which attempts to train self-disciplining citizens who will drain less resources from the state in the future due to improved levels of glycaemic control meaning fewer future complications (Shearer et al 2004). Rankin et al (2011a) and Lawton et al (2011) represent multiple authors who have carried out research on the effectiveness of DAFNE courses as part of a larger project¹⁵. They consider DAFNE to have generally improved the self-management routines of PWD, but they also note that some participants feel burdened by the increased work and scrutiny that they need to apply to their bodies. For this reason, Lawton et al (2011) found that embedded pre-DAFNE lifestyle choices such as having meal routines often persisted even after a DAFNE intervention, part of which involves encouraging flexible meal times.

REPRESENTING DIABETES

A key theme which weaves throughout the diabetes literature is how the condition is represented to, and subsequently understood by, people who do not have diabetes. Diabetes can be written out of everyday life and space as a serious medical condition. Mol (2008) considers a Dutch advertisement for a blood sugar monitor which represents diabetes as overcome, enabled by this excellent technology. The people in

¹⁴ Balfe did not recruit participants from DAFNE courses, like I did, but some of his participants had attended the course.

¹⁵ This project was funded by the NHS National Institute for Health Research (NIHR) and was titled: *Improving management of Type 1 diabetes in the UK: the DAFNE programme as a research test-bed*. The project funding period spanned October 2007 - May 2013 (<http://www.nihr.ac.uk/funded-research/improving-management-of-type-1-diabetes-in-the-uk-the-dafne-programme-as-a-research-test-bed/2168>).

the advertisement, presumably PWD, are hiking in the hills, apparently not restricted by their diabetes, while the monitor displays an ideal blood sugar level. As will be discussed by my participants in later chapters (particularly Chapter 6), isolated spaces can also cause anxiety among PWD since physical activity and exercise can have unpredictable effects on blood sugar levels, which even the most advanced blood test meter does not negate easily.

Conversely, representations of diabetes can exist at the other end of this ‘seriousness’ spectrum. Ferguson (2010) notes that, in cinema, diabetes is commonly represented as a severe illness. He posits that this is because, to filmmakers, diabetes management is “characterised by boredom”, and so “it necessitates a dramatic presentation to be made legible” (ibid: 184); and so the representation of diabetes in film is “filled more with gangrene, amputation, kidney failure, sweat, and comas than it is with glucometers, insulin, healthy eating, or exercise routines” (ibid: 189). Ferguson (ibid: 186) argues that:

Sick or disabled characters are not more present in today’s visual culture since this more accurately resembles real world diversity, but rather they appear in order to allow healthy viewers the opportunity to conceptualise distant cultural lessons and, likewise for ill spectators to internalise representations of their marginalising characteristic.

Ferguson laments that the routine realities of diabetes are rarely portrayed, and hence these realities are *imagined* by people *without* diabetes as far removed from the everyday public domain. Such representations also portray PWD as having precarious bodies, with the condition usually a “plot point ... to introduce a sense of crisis or narrative action” (ibid: 189). These arguments show how representations of diabetes are confused. Is it a minor condition, easily overcome by responsible PWD (as the Dutch advertisement suggests); or is it a serious condition, which needs greater understanding and levels of empathy from others? This is the tightrope that I frequently walk in my subsequent analysis, and which I hope to traverse throughout by extrapolating a series of conceptual coordinates to be introduced in the following chapter.

Western media often represents type 2 diabetes as primarily caused by obesity and poor diet/lifestyle, while neglecting social, economic and environmental determinants (Rock 2005; Gollust and Lantz 2009; Hellyer and Haddock-Fraser 2011). For example, Gollust and Lantz’s (2009) examine 698 news articles from 19

US papers, finding that 69.6% of the articles suggest that obesity is the main cause of type 2 diabetes and only 11.6% suggest socio-economic reasons. In other research, Gollust et al (2009: 2165) study the resulting opinions of a randomly selected cohort of US adults, when confronted with a news article suggesting social determinants as the cause of type 2 diabetes. The authors discover that there is a significant split between “people who hold strong values of personal responsibility [who] would likely disagree with a social determinants message that suggests social or governmental responsibility for improving population health” and those who look to societal and governmental sources to take responsibility through public health programmes. The same authors (Gollust et al 2010) further propose that people *without* diabetes¹⁶ are more likely to support increased government spending on diabetes research when they were exposed to media items suggesting genetic and socio-economic factors for type 2 diabetes, as compared to when they were exposed to media items suggesting behavioural causes. Popular reporting of diabetes often serves to stigmatise type 2 diabetes by implying that the responsibility for maintaining a ‘healthy’ diabetic body, or even avoiding type 2 diabetes altogether, is dependent on an individual’s own choices, rather than on any social, economic, cultural or other factors.

Type 2 diabetes is much more widespread than type 1, and in Chapter 8 I will discuss how some PWD with type 1 wish to make explicit their distinction from PWD with type 2. That said, moral values and expectations of personal responsibility are still placed on *all* PWD (Balfe et al 2013c). Anderson-Lister and Treharne (2014: 1377) present interesting research which examines what people *without* diabetes think about PWD, finding that “perceptions of irresponsibility [of PWD], especially in terms of management of their diabetes, would sometimes decrease feelings of pity, sympathy or concern, increase feelings of anger, irritation or aggravation and decrease willingness to help”. While type 2 diabetes dominates popular representations of the condition, type 1 is also implicated in discourses of moral failing and personal irresponsibility. Type 1 needs to be managed, and if this management is not done well then short-term losses of bodily control (hypo) and long-term medical complications become more likely (Chapter 5 will discuss these embodied changes in more detail).

¹⁶ Their participants were members of an online survey sampling group of US adults. They ultimately surveyed 2,490 people and so it is possible that some may have had diabetes.

There are also myriad choices about ‘right’ and ‘wrong’ eating practices, drinking habits and exercise routines which affect all PWD, regardless of type.

Feeling this sense of personal responsibility, Broom and Whittaker (2004: 2378) note that some PWD enact a “child parody” in which they position themselves as children, in part to mock how they experience their treatment by clinicians as patronising but also acknowledging that they are not being as responsible as they could with regards to self-management. Following this ‘child parody’, it is useful to draw on Colls and Evans (2008: 628), who discuss how responsibility for the healthy eating of children is dispersed among various actors (state, parents, supermarkets, children) and argue that, “in this respect, the focus of the analysis becomes the relations of responsibility that exist between actors, rather than the responsibility that is placed upon them”. Colls and Evans insist that responsibility (or care) for the self is not an individual endeavour, but instead is a shared responsibility (or care). They also acknowledge that the socially produced imperative to eat (and otherwise live) well is not necessarily an idea that should be disrupted, but rather at issue is the dissemination of the responsibility for realising this goal among the various actors, rather than the responsibility being concentrated on the individual. Pause et al (2011: 88) bring this notion into stark relief as they challenge assumptions that obesity is the main cause in the rise of type 2 diabetes among New Zealand school children: “past projects in schools in New Zealand have not necessarily contributed to children’s health and well-being, but rather suggest an acceptance of discourses that are associated with guilt and the self-monitoring of the body”. The impact of this guilt on individuals is well discussed by Longhurst (2011), who talks candidly about jeopardising some of her feminist principles in order to achieve a slimmer body so as to appear more disciplined and in control of her body; in other words, to enjoy “thin privilege” (van Amsterdam 2013: 155). Evans and Colls (2009) demonstrate that even a regulatory (population level) approach to challenging obesity among UK children, specifically intended not to breach into a disciplinary (individual level) approach, may upset children about their bodies and so is not always successful. The mere idea of being under surveillance, especially through what Evans and Colls (ibid: 1073) call an “unverifiable gaze”, serves to create anxiety and unease among children. They quote another author to argue that it “is not just the particular body a particular child *has* but the particular body a child *is* among other bodies” (James quoted in Evans and Colls 2009: 1072 italics original). In turn, having diabetes is not the problem, it

is the opinions, reaction and conduct of others – both PWD and people without diabetes – that creates many of the social problems that PWD experience. There are immediate and material embodied anxieties about living with diabetes that also can serve to affect social lifeworlds, and my aim is to consider these social and embodied anxieties in tandem throughout my thesis.

AN EXISTING GEOGRAPHY OF DIABETES

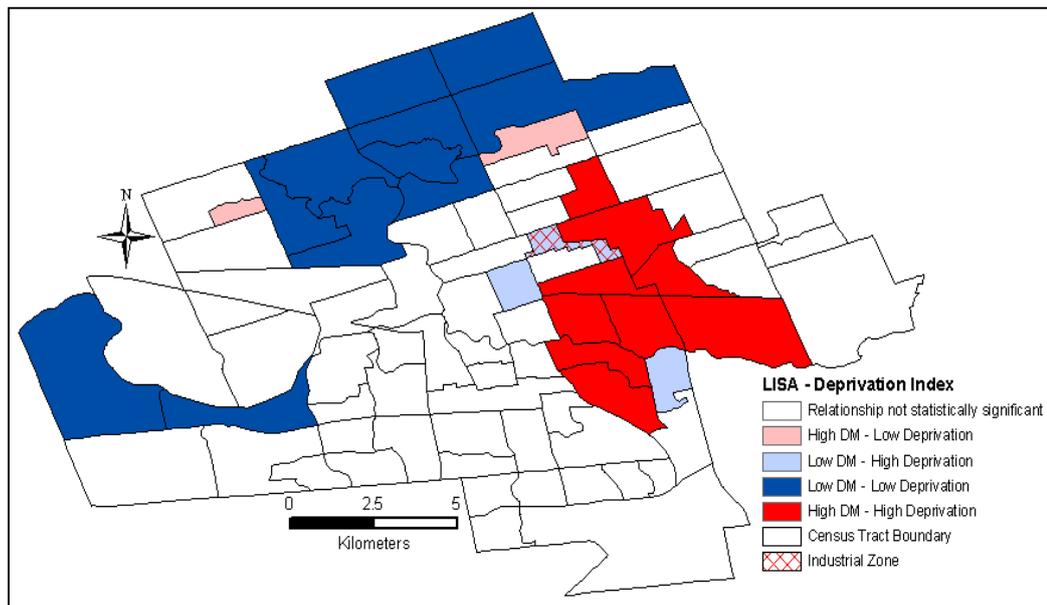


Figure 6. The map (Tompkins et al 2010: 2415) shows the prevalence of diabetes by area in the city of London, Ontario, against levels of ‘deprivation’. In the associated legend ‘DM’ refers to diabetes mellitus and ‘deprivation’ refers to a deprivation index (representing levels of income, education and family status). The map suggests that in the areas of low deprivation diabetes prevalence is low, while in areas of high deprivation prevalence is high. Thereby, a correlation between deprivation and diabetes prevalence is suggested. Tompkins et al are unclear about whether they have distinguished between type 1 and type 2 diabetes.

There is a ‘geography of diabetes’ that focuses on epidemiological mapping of incidence and prevalence rates, although this research is not necessarily carried out by professional academic geographers. Mayer (2010) notes that the epidemiological approaches and use of methods such as GIS fall under the remit of medical geography, even if the work is not published within geographical journals. Such studies have found that, in Western countries, high levels of type 2 diabetes prevalence are more likely to be found in areas of low-income and social deprivation (Kelly et al 1994; Congdon 2006; Tompkins et al 2010; SDRN 2011). Figure 6, taken from Tompkins et al (2010) – who do, in part, title their paper *The Geography of Diabetes* –

exemplifies this mapping of diabetes. Research also suggests that type 1 can be related to socio-economic factors (Congdon 2006), although the exact cause of both types is still subject to debate. Socio-economic variations in diabetes prevalence may reflect, or be reflected in, unequal access to healthcare services (Hunt et al 1998; Leese et al 2008; Mendenhall et al 2010), and Rock (2005) even argues for type 2 to be classified as a ‘communicable’ disease due to the social inequalities that have been found to underlie its geographical spread. With specific focus on the UK and type 1, it has been argued that in Northern Ireland there is a higher rate of prevalence in rural areas than in areas more densely populated (Cardwell et al 2006; Cardwell et al 2007). The authors use the hygiene theory to explain their findings: proposing that, because of rural children’s lack of exposure to infection at a young age, their immune systems have not developed as much as urban children, who are more likely to be exposed to infections and thereby develop more effective resistance. However, they also acknowledge that this finding is unusual and contradictory to findings from other countries, and so reflect Miller et al (2011: 248) in noting that such mapping projects are not always entirely reliable as:

The geographical variation in type 1 diabetes incidence is one of the largest observed for any non-communicable disease. The incidence has been found to vary geographically by world region, different countries within world regions, and by areas within countries.

Further reflecting a medical geography, diabetes is the focus of epidemiological studies. In Scotland, the Scottish Diabetes Research Network (SDRN)¹⁷ take a primarily epidemiological approach to studying diabetes, as they outline the various contributions of their members. Population level approaches explore the link between socio-economic status and mortality; use of insulin and development of cancer; likelihood of hospital admission related to HbA1C levels and ethnic difference in blood sugar control among other topics (see SDRN Annual Report 2012 for a research summary)¹⁸. Nonetheless, Rock (2003: 140) warns of prioritising such population level approaches in explanations of diabetes and PWD: “with the proliferation of statistics about disease, it has become more acceptable – even ethically imperative –

¹⁷ The SDRN was formed in 2006 with the objective of creating a collaborative research group among various clinical centres in Scotland (<http://www.sdrn.org.uk/>).

¹⁸ The most recent annual report available on the SDRN website.

to predict individual experience by situating the person in question in relation to statistically defined populations”.

Another specifically geographical approach to ‘map’ diabetes has been undertaken in rural North Carolina (Cravey et al 2001; Gesler et al 2004; Arcury et al 2004; Arcury et al 2005; Gesler et al 2006; Skelly et al 2006¹⁹). The researchers here introduced the concept of *socio-spatial knowledge networks* (SSKNs) in order to uncover the most effective sites for disseminating health care information about diabetes, later refined into *diabetes knowledge network nodes* (DKNNs). These networks map people’s everyday movement in a specific area of North Carolina, seeking to establish a hierarchy of the most visited places. The aim of the research is to use this information, alongside local culturally and ethnically diverse understandings of type 2 diabetes, in order to establish an optimal location to disseminate knowledge about diabetes to the community. The healthcare advantages of this research have been discussed as follows: “this geographic approach, assessing knowledge space, is an important and useful technique for nurses because it expands our ability to understand how people use the environment to learn about health and disease and access health care” (Skelly et al 2002: 160). This research shows how diabetes is implicated in many different everyday spaces and places, such as barbers, churches and supermarkets, and how understandings of diabetes can differ along, spatially inflected, racial and cultural lines.

Epidemiological research is not the only ‘geography of diabetes’ in existence, though, and a body of work predominantly by Myles Balfe (beginning with his 2005 thesis and continuing through Balfe and Jackson 2007; Balfe 2007a; Balfe 2007b; Balfe 2009a; Balfe 2009b; Balfe 2011) on university students with type 1 diabetes represents a qualitative enquiry into the socio-cultural geographies of living with the condition. Broadly speaking, Balfe’s research concerns the balance of maintaining the identity of an ‘unfettered’ university student while also successfully managing type 1 diabetes. He explores this conflict by exposing how the consumption practices (mainly alcohol), gender perceptions and social expectations of university life affect a student with diabetes, influencing their physical and social movements throughout the space of a university. He uses Foucault’s ideas of disciplinary practices and

¹⁹ Wilbert Gesler, the cultural/medical geographer, is a contributing author to all of these papers and certainly references to his explicitly geographical endeavours are referenced in the papers, although they are not a key focus.

technologies of the self to envisage how the body and practices of a student in the space of the university are subjected to various expectations. Self-disciplinary practices are conducted by the students in order to conform and fit in, while technologies of the self, such as insulin pumps, allow some students, as far as possible, to present an ideal (student) body type. Balfe considers how these expectations lead to students often adopting risky strategies as they seek to negotiate and compromise among different body ideals, often resulting in one body ideal indeed being prioritised at the expense of others.

More recently, Balfe has been part of a group of researchers conducting studies into the experience of young adults with type 1 diabetes in Ireland²⁰. This research involves interviews with PWD as well as healthcare professionals, and the researchers span the disciplines of public health (in which Balfe himself now specialises), including sociology, psychology and medicine. Balfe's leaning towards health geography is clear though, particularly through an article published in the journal *Health and Place* about the experience of young adults managing diabetes in the workplace (Balfe et al 2014). The authors argue that, even though young adulthood (early-twenties to thirty) is typified by endeavours to improve self-management (as compared to the risky approaches of university students in Balfe's previous research), there still exist difficulties for sustaining effective self-management in the workplace. This is mainly because of time pressures which influence availability, timing and diversity of meals, as well as limiting opportunities for exercise. Other publications from this group contain a geographical flavour, such as Balfe et al (2013a), where the authors discuss the unequal distribution and availability of health services throughout Ireland in the wake of austerity measures. Taking a more psychological view, Balfe et al (2013b) report on young women with type 1 diabetes who engage in deliberate insulin omission in order to lose weight, but often then lose overall control of their diabetes management. Most pertinent for my own research, Balfe et al (2013c) cover aspects of 'diabetes distress' among PWD, presenting a synthesis of issues that are reflected in my own findings and analysis. These overlapping issues between my own and Balfe et al (2013c) are: feelings of self-consciousness about how others perceive diabetes; PWD (type 1) being mistaken

²⁰ This research is funded by the Irish Health Research Board (HRB) for the period September 2012 – January 2014. The project is titled: What factors influence the self-care practices of young adults with type 1 diabetes in Ireland?

as having type 2 diabetes; the day-to-day management of diabetes being burdensome and underappreciated by others; difficulties with healthcare services and healthcare professionals; concern about potential future complications; perceptions of diabetes in the media; pregnancy; and support from friends and family. The similarity between what Balfe et al and I find in our research demonstrates the rich understandings of life with diabetes that qualitative research may uncover. While the geographical focus in Balfe et al's body of work is somewhat diluted by the range of disciplines associated with the authors²¹ and the clinical journals in which they are published, in what follows I unpack the over-lapping issues from a more distinctively geographical perspective.

King (2008: 239), although not a geographer²², examines adolescents' lived experience of diabetes, referring to a PWD's journey through life as a "trek" so as to emphasize the extra difficulties:

It is possible to consider the 'pathway through life' for an individual as a journey along a hypothetical path, which leads from 'now' to the end of life. For an adolescent without a chronic disease, such as diabetes, this pathway may be construed as being almost level with, occasionally, upward gradients coinciding with occasional crises in their lives, which may be either physical or psychological, or both. However, for adolescents with type 1 diabetes, their 'pathway through life' is not represented by this gradual gradient model, but is strewn with major gradients representing serious problems in their lives, ranging from the initial diagnosis, through fears of hypoglycaemia and/or hyperglycaemia, to diabetes-related complications and early death.

King's use of the term 'trek' is itself suggestive of a geographical exploration of space and environment. Balfe's work also illuminates significant periods in this trek: firstly, through the experiences of university life in his earlier work; and, secondly, later, through the experiences of young adulthood. While Balfe and his multiple co-authors' work is important because it exposes, in detail, the myriad and often mundane problems that plague PWD on a day-to-day basis, my own intention is to expand this analysis to more varied spaces and periods of life, beyond the figure of the student and young adult (but not necessarily excluding either), and so seeking an expanded social and cultural geography of everyday life with this chronic condition²³.

²¹ Balfe is listed as the first author in each of these publications (Balfe et al 2013a; 2013b; 2013c; 2014), but all publications state that each author is an equal contributor.

²² King writes from a Health Sciences perspective.

²³ As mentioned in the previous chapter, as I outlined the foci of each of my empirical chapters, I am additionally positing an *internal* bodily geography of diabetes.

ADVANCING A GEOGRAPHY OF DIABETES: THREE TRAJECTORIES

Broadly speaking, my research contributes to medical geography and health geography. It has been noted that that these terms can be somewhat arbitrary, with the distinction unclear (Kearns and Collins 2010). That said, ‘medical geography’ is most often understood as epidemiological (Mayer 2010), considering issues of disease ecology, and concerned with biomedical service provision. Thus, a medical geography orientation is reflected in much of the existing geography on diabetes just discussed. In the mid-1990s Kearns (1993; 1995) called for the insights of geography’s ‘cultural turn’ to reform medical geography by involving aspects of social and cultural geographies in understanding a person’s experience of place with regards to their health. ‘Health geography’ has since emerged as a concurrent line of research and analysis to medical geography, in which geographers consider the social and cultural aspects of health, in particular challenging a biomedical reductionism to the body. It is important to note that this ‘separation’ of medical geography and health geography is far from simple. Through her three progress reports, Parr demonstrates that medical geography and health geography are both bound together by issues of the body (Parr 2002a); healthcare (Parr 2003) and debates as to whether the introduction of ‘theory’ to medical/health geography has affected its critical contributions (Parr 2004). What emerges from her reports is a sense that there is an inherent and complimentary connection between medical geography and health geography, rather than as sub-disciplines in opposition (empirically and theoretically) to each other. The complimentary foci of health geography have been approached through the adoption of ethnographic methods: a shift to qualitative methods from the quantitative methods of GIS and spatial science of medical geography (my own ethnographic methods will be discussed in detail in Chapter 4). This shift reflects changing ethical imperatives: to treat people “as *persons* rather than *patients*” (Kearns 1995: 252 italics original) and keeping pace with a more general “peopling of human geography” (Cloke et al 1991: 58).

I will now outline three facets of health geography that inspire my own research into life with diabetes: space/place; healthcare; and disability. Firstly, while

medical geography is concerned with space²⁴, health geography is concerned with a person's social, cultural and emotional experience of place²⁵. While a particular *space* may have an overarching meaning, for instance home space as safe and comfortable, the same *place* is experienced differently by different people. For some, the home is not safe and comfortable, but rather a place of work, isolation or abuse (Blunt and Dowling 2006). Often geographers uncover these divergent meanings with regards to health. For instance Milligan (2009) finds that elderly people, confined to their homes and dependent on carers, experience their home as an 'insititutionalised' place. For women with fibromyalgia syndrome (FMS), Crooks (2010: 59) writes that, far from being a safe retreat for recovery, home is experienced as a "routinely unpredictable" place of work due to their fatigue and expectation to complete household chores. The spatial isolation that illness creates for people has been discussed by Myers (2010; 2012), who notes that home can become a place of despair for men with HIV/AIDS. The restriction to home can also serve to obscure the experience of illness to others, as Moss (1997) notes that older women with arthritis are often hidden in their homes, with much of their action in dealing with their illness being concealed.

Work space is also experienced differently. The issue of disclosing illness or disability is often anxious and confusing for people. For some, obvious impairments mean their disclosure is necessary for certain accommodations to be made, while for others, with less 'obvious' impairments, there are concerns that disclosure may jeopardise their current and future employment (Wilton 2006). Crooks et al (2008) consider that for women with FMS, their experience of space is affected by their illness and their identification with 'disabled' categories. Such identification is related to the idea of disclosure of illness, as some women say they prefer to reject a categorisation of disability while others prefer to acknowledge it in order to obtain accommodations to make their work lives easier.

Clinical spaces are also a focus of health geography. Pooley et al (2001), contributing one of the few explicitly human geography papers regarding diabetes²⁶, acknowledge the importance of clinical settings as conducive to good care. The

²⁴ Primarily, as large-scale backgrounds upon which distributions and locations can be identified and mapped.

²⁵ Referring to nameable sites that can be the focus of personal meaning.

²⁶ Although this is not published in a human geography journal, but rather the inter-disciplinary *Health and Social Care in the Community*, lead author Pooley is a human geographer by practice. It should be noted that, unlike Balfe, diabetes is not a focus of Pooley's overall research interests.

authors find that PWD are upset by the lack of time they can spend with health care professionals, seeing different clinicians at each visit, and not being asked relevant questions about their problems with diabetes. Pooley et al thus parallel more explicitly geographical work by Crooks and Agarwal (2009), who examine the importance of the clinical setting for women with clinical depression. These authors found an ‘impersonal’ clinical setting, involving stressed staff and reliance on computer data, to aggravate the women rather than put them at ease. Particularly for diabetes, Munt and Hutton (2012), writing from a nursing studies perspective, bring attention to the problems of maintaining control over one’s own diabetes management when hospitalised, thereby again flagging the relationship dynamics between clinicians and PWD. Nevertheless, clinical space is not always experienced negatively, as Kearns and Barnett (2000) note that the introduction of a *MacDonald’s* restaurant in a New Zealand hospital, while possibly being critiqued as a ‘commodification’ of clinical spaces, may also lead to hospitalisation being a less dreadful experience for children.

The importance of a diabetes-related experience of place is inferred throughout the non-geographical diabetes literature. Stuckey (2007; 2009) and Stuckey and Tisdell (2010) note how the built urban environment may be experienced differently by PWD as, for their participants, satellite dishes and large outside clocks in city spaces hold certain meanings and reminders for PWD about self-management and surveillance of their bodies²⁷. Likewise Shiu and Wong (2002) note that fear of hypoglycaemia can be exacerbated depending on location; in their case noting a participant who is anxious while travelling alone on a minibus stuck in traffic. Additionally, Nagelkerk et al (2006) discuss the barriers to effective self-management for PWD in rural settings. Rankin et al (2011a) and Lawton et al (2011) have both noted that participants in their studies will make decisions on injecting insulin or testing blood sugar levels with regards to their immediate geographies: “if I’m out and about and I’ll see something that I fancy [eating], I won’t bother ... it’s just a pain to try and find somewhere to do my injection” (participant in Rankin et al 2011a: 536). Lawton and Rankin (2010) further detail an ethnographic investigation of DAFNE, discussing how the space of a DAFNE course can help to alleviate feelings

²⁷ For one of Stuckey and Tisdell’s (2010) participants, satellite dishes were a reminder of potential surveillance. Even if not necessarily a surveillance device, they were understood as part of various surveillance apparatus. Large outside clocks were understood as a reminder of routine but also of one’s mortality, possibly shortened by diabetes.

of isolation due to the interaction and shared experiences. They also draw on Foucault's writings to discuss the panoptical effect of the DAFNE course, where participants' blood sugar levels and adherence to the regime are routinely inspected by the other participants on the course, the aim being to encourage personal problem solving and less dependence on clinicians. This approach leads to an analysis, in my own research, of how these panoptical pressures are experienced in life outside of the DAFNE space, especially with the common (mis)perception that diabetes is easy to control and so PWD may feel the need to front an image of control, regardless of what they are really experiencing. Extrapolating *all* of the spatial resonances from the various diabetes literatures is not a practical aim for this literature review, however, and so instead I will continue to refer to the relevant connections as I unfold and analyse my data in the empirical chapters.

The second facet of health geography I wish to discuss is the issue of healthcare. Parr (2003) outlines some future directions for possible research on geographies of care and caring. First, she considers the increasing commodification of care alongside the rise of telemedicine, which means that care can be practised in diverse locations (for example, the clinic, but also the home or even the workplace) by myriad actors (for example, healthcare professionals, but also informal carers and self-administered care). In the previous chapter I mentioned a 'deinstitutionalisation' of diabetes care predicated by the discovery of insulin. This shift has now developed into a 'telecare' of the self. Such developments are very important for my thesis as care for diabetes is now spatially distributed, at the same time as, to an extent, being 'devolved' to PWD (with biopolitical implications). PWD care for themselves in every location of their lives (home, work other social space, as we shall see in Chapter 6), but some care still remains in 'institutions': the GP offices and hospital clinics (problems with which we shall see in Chapter 8). There are also the more 'informal' spaces of care, such as support groups, which, as Hall and McGarrol (2013) point out, can be important for people when 'formal' routes of care are less accessible.

Writing about the politics and ethics of care and caring, Parr (2003) considers whether health geographers should engage more critically with systems of healthcare. In terms of critiquing systems of diabetes healthcare, Annemarie Mol (2008) provides a detailed thesis as she posits 'the logic of care' over the 'logic of choice'. Mol takes issue with the idea of a fully-informed neo-liberal citizen, for whom responsibility of diabetes care is completely devolved into personal choices. She argues instead that

myriad other factors contribute to the care that a PWD receives; for instance, private biotechnology companies that treat PWD as consumers rather than patients (remember her critique of the Dutch advertisement discussed earlier in this chapter), but also the whole web of life circumstances such as employment and relationships. While Mol argues that, while many think individual choice (the ‘logic of choice’) is the morally correct route for a person-centred healthcare, it is not always the most informed and myriad other factors and relationships in a person’s life must be considered to ensure that a suitable approach to care is reached. Essentially, Mol is arguing that a person cannot make a decision on care entirely by themselves; any attempts to untangle from other relationships (with family, friends, work colleagues and medical professionals) are futile. The ‘logic of care’, on the other hand, represents a pragmatic approach that suggests more realistic aims for self-management within the particular parameters of a PWD’s life. Mol’s text is littered with geographical hints as she conveys the structural factors that impede an idealised logic of choice. For example, she talks of diabetic bodies needing to be controlled and ‘tamed’ in office/work spaces in order to adhere to societal norms about working/public bodies, and she considers the intricacies of blood sugar management, such as deliberately running blood sugar levels high in order to avoid hypos in precarious situations/places. As with the collected works of Balfe et al (2013a; 2013b; 2013c; 2014), my research often corroborates Mol’s and builds upon them further in a geographical direction.

Recent publications from the Scottish Government reflect Mol’s ‘choice’ dichotomy. *The Diabetes Action Plan* (DAP 2010) – the latest in the series of plans produced by the Scottish Government – outlines a broad strategy for improvement in diabetes care in Scotland, with a recurring emphasis on a more ‘patient-centred’ approach. The overall aim is to empower PWD to manage their diabetes on a more individual basis (the ‘logic of choice’). *Gaun Yersel*’ (2008)²⁸ is a document produced by the Long-Term Conditions Alliance Scotland (LTCAS)²⁹ which sets out plans for the self-management of people with long-term conditions. Although the document situates the responsibility for self-management with the individual, it also proposes models of self-management involving a partnership with various other organisations

²⁸ *Gaun Yersel*’ is Scottish vernacular meaning ‘go on yourself’ or ‘do it yourself’.

²⁹ The document is endorsed by the Scottish Government (it includes a foreword from Nicola Sturgeon, then minister for health and well-being, now Scottish first minister) and is drawn upon in the DAP.

and individuals such as the NHS, charities or unpaid carers. In doing so, these documents represent a state-government acknowledgement that living with a long-term condition is not an easy thing, and that care and self-management are relational (the ‘logic of care’). Nonetheless, they also acknowledge that self-management is itself being promoted by and through state intervention, thereby suggesting that there does exist some degree of expectation on individuals to adhere to self-care norms³⁰.

Parr (2003) also calls for more attention to be paid to the *practices* of caring. In human geography, as Parr suggests, Milligan (2009) focusses on this ‘doing’ and ‘receiving’ of care in the home, particularly for older people, and highlights that ‘care’ in much of the geographical literature is figured as relational. However, with diabetes it is most often a care of the self. The everyday intimate practices, of testing and injecting – intimate as they involve penetration of the flesh and ‘gathering’ of blood – are carried out by the PWD themselves³¹. This ‘personalisation’ of diabetes care, I would argue, is part of why diabetes is often regarded within such a neoliberal framework, as previously discussed. Diabetes care is hence seen as entirely in a PWD’s own hands (both metaphorically and materially), and not as a relational activity. Of course, as Mol (2008) contends, this is not the case; the self-care of diabetes is relational, as my own research repeatedly underscores.

A key tenet of healthcare, in human geography, has been the issue of global inequality (Parr 2003). Kearns and Reid-Henry (2009) highlight a tendency for some scholars to limit their focus to the Western world. Certainly, this is a concern for a geography of diabetes, as there is less availability of diabetes medical technology in many countries. For instance, in sub-saharan Africa, diabetes is a growing health problem, but what little resources are available are directed towards the treatment of acute rather than chronic illness (Levitt 2008; Kengne et al 2013). My focus, however, is in a Western/UK context where, for the most part, access to medical care and technology is widespread. There are inequalities within Western countries as well,

³⁰ Somewhat contrary to my argument, Hall and McGarrol (2013), writing about people with learning disabilities, argue that healthcare in Scotland is *less* likely to be dominated by neoliberal ideas of personal healthcare responsibility than other parts of the UK. For instance, the authors note that in some recent Scottish Government documents terms such as ‘personalisation’ have been purposefully avoided. Instead, they argue, that care in Scotland is more likely to be characterised by ‘progressive localism’, involving community based approaches.

³¹ This is not true for all PWD of course. Children with diabetes may have most of their care conducted by parents or guardians. PWD with mental or physical disabilities may have carers carry out parts of their self-management. Also, PWD who are in prison may not be allowed manage their own condition. In my research, all the participants conducted their own self-management.

with research suggesting that national healthcare systems such as the NHS enable better management of diabetes, compared with countries such as the USA that do not have such a system (Mainous et al 2006).

Geographies of disability entail the third facet of health geography that I find integral to my research. The shift from medical to health geography has been tempered by acknowledgement that the introduction of social and cultural aspects and an intentional neglect of the biomedical – for fear of slipping into biological reductionism – has meant that the body has been marginalised in health geography (Dyck 2010). Hall (2000) has highlighted this neglect and suggested a focus on the ‘neglected blood, brains and bones’, while Parr (2002a: 243) has called for more “sociobiological” approaches, which take seriously bodily realities in relation to socio-spatial contexts. Perhaps the area of health geography that has most refocused attention on the body is the geography of disability. Geography of disability, in large part, is influenced by the social model of illness and disability which posits that it is the environment, with all its social, cultural and structural facets, which ‘disables’ a person, rather than by the medical model where it is a person’s impairment which disables. This model has been considered in human geography, particularly by Imrie (2001) and Gleeson (2001), who write about structural barriers in the built environment. Other research, by Crooks et al (2008), shows that in the workplace there is an expectation for bodies to be healthy and able, so that impaired bodies are more noticeable.

Of course this dichotomy of models (social vs medical) is also in danger of letting the body fall through the cracks, as a staunch defending of the social model would claim that impairment (whether it be physical – including unseen aspects such as fatigue – or mental), should not disable. Bodies then are almost irrelevant in this view, with all the problems existing instead in the built and social environment. As anticipated by Hall (2000) and Parr (2002a) this emphasis was not satisfactory to many scholars and a cultural model, as Wilton and Evans (2009) describe, emerged. This model, while not neglecting the advances of the social model, considers the embodied experiences of pain, fatigue and discomfort that impact on a person’s everyday life and geographies.

Wilton and Evans (2009) also note the minority group model which involves groups of people considered disabled, by others, rejecting the term and instead positing themselves as a minority group with distinct social and cultural identities.

With regards to hearing impairment, Skelton and Valentine (2003) find that ‘Deaf’ is adopted as an identity category by those who consider their Deafness as a difference – as part of a cultural/linguistic community – rather than as an impairment and disability. Meanwhile ‘deaf’ is adopted by those consider themselves as having an impairment and wish to be more easily understood on ‘normal’ terms. This model is also evident in much of Davidson’s (2008, 2009) work with people on the autistic spectrum, who challenge labels of disablement and stress that their ways of communicating are merely different rather than wrong. Likewise, Paterson (2014) argues that the richness of environmental experiences, of blind or near blind people, is doubted due to assumptions that their lifeworld is somehow lacking. Hansen and Philo (2007) also note people wishing their impairment to be considered their own ‘normality’ rather than something wrong in comparison to ‘normal’ others. For instance, they write of one woman whose ‘crab-like’ way of walking is most comfortable for her, but she feels pressure to adhere, as far as possible, to a ‘normal’ way of walking by using crutches.

Chouinard et al (2010: 3) signify a growing interest in the geographies of disability and they note that “the focus on the disabled body, on the experiences of impairment within particular spaces, was a central theme of the first wave [of disability studies in geography]” and subsequently outline a manifesto for a second wave, focussing on the themes of:

First, a broadening of the meaning of ‘disability’ to encompass other bodies and experiences; second, a deepening concern with the embodied experiences of disability and chronic illness; third, the possibilities and challenges of the increasing interaction between disabled people and technology; and fourth, an interest in shaping policy agendas and the ‘place’ of disabled people in contemporary society (ibid: 3-4).

My research contributes to this second wave, by considering how embodied experiences of diabetes are always relationally constituted as well as by showing how the material and social environment can be disabling for PWD through restricting movement, constraining social participation and influencing identity formations. Moss and Dyck (2003) complicate considering disability and chronic illness in similar ways, noting that, while many impairments to bodily function are physically obvious and therefore easy to understand as disabilities, chronic illness is often less physically obvious and presents less predictable problems, therefore confounding the

configuration of chronic illness as a disability (see also Charmaz 2008; Wendell 2013). This complication, which situates diabetes as a ‘contested illness’ (Moss and Teghtsoonian 2008), will be addressed in the following chapter as I discuss the discursive formation of diabetic bodies. I have already mentioned the dilemma of diabetes being considered by PWD as either inconsequential or serious, and the terminology that they use to describe diabetes duly varies. For some, it is a *condition*, for others a *disease*, for others still it is a *disability*, and for others it is not. The use of literature from disciplines cognate to human geography, such as disability studies, throughout my thesis reflects the liminal status of diabetes. I am not arguing for diabetes to be considered a disability, but I am arguing that in particular space/times it can be disabling. While I will attempt to use the term ‘condition’ throughout the thesis to refer to diabetes (as it is the most neutral term), at times I may refer to diabetes differently with regards to the contexts of a participant’s feelings and experiences.

CONCLUSION

This chapter has not offered an exhaustive review of the myriad literatures from various disciplines concerning diabetes, but, by touching upon how diabetes and PWD have been approached from biomedical, epidemiological, anthropological, sociological and clinical (nursing studies) perspectives, I have provided a relevant review of literature that leads up to a geography of diabetes. Such a geography already exists but is primarily concerned with epidemiological perspectives where space and place are areas on maps where diabetes ‘occurs’. A human geography of diabetes, inspired by Balfe’s (and his co-author’s) contributions can be distilled from the various disciplinary perspectives of diabetes. I do not mean to discredit the importance of large-scale, quantitative, spatial science approaches to studying diabetes. These studies, as demonstrated above, reveal crucial patterns of access to diabetes-related healthcare, along the lines of socio-economic status, race, ethnicity, urban/rural and so on. My smaller sample size and qualitative methodology (to be discussed in Chapter 4) limits the possibility for my research to uncover similar inequalities. Instead, I mean to uncover particular ‘geographies of diabetes’, inspired by facets of health geography, and thereby following on from the qualitative approaches evident in many social science studies.

Three facets of health geography are most relevant to my research into diabetes. Attention to the experience of space and place is the first, and reflects broader trends in human geography since the ‘cultural turn’ in the 1990s. Healthcare is the second, and is particularly relevant to me due to my collaboration with clinicians working on the DAFNE projects. My interest is also in contributing to the acknowledgement and understanding that care is not just practised by care-givers, but is also informally given and received in everyday relations and interactions in everyday spaces (Milligan 2014). In order to care for PWD, there needs to be a level of understanding of what it is like to live with the condition, which, due to the aforementioned representations, is often obscured. I believe that, through attention to a PWD’s geographies, this care can be given more ‘space’ to develop between people. Geographies of disability provide references to consider the embodied difference that PWD experience and how this impacts on their experience of space and relations with others. Considering diabetes as a disability is perhaps problematic, but, as I will demonstrate throughout my empirical chapters, the condition in its wider contexts can be disabling for some people. Using these reference points of health geography, I hope to argue, throughout my empirical chapters, for more supportive environments for PWD, acknowledging on the one hand that there are social-structural barriers but on the other that there are embodied experiences whose character is such that, to some extent, a ‘reduction’ to the biological cannot be ignored. Nonetheless, the ‘reduction’ to the biological in what follows (social and relational) is never straightforwardly equivalent to what a *biomedical* geography of diabetes might imply.

CHAPTER 3**CONCEPTUAL LITERATURE REVIEW: COORDINATES FOR APPROACHING A GEOGRAPHY OF DIABETES****INTRODUCTION**

In this chapter I will bring together various conceptual strands of human geography and philosophy to assemble my own orientations for studying the everyday geographies of diabetes. I will begin by discussing how diabetes can both ‘appear’ and ‘recede’ in a PWD’s everyday life. I take the concept of a ‘recessive body’ from Drew Leder’s (1990a) text, *The Absent Body* and consider two ways a diabetic body can recede. The first is a *discursive* recession, in which the diabetic body recedes from the public domain, under pressures to conform to socially accepted expectations of PWD and a fear of punitive consequences should one’s body and/or behaviour deviate from these expectations. I will draw from some autobiographies written by PWD in order to help illustrate this recession. The second is a *routine* recession: many PWD remark on the ease with which they have come to manage their diabetes over time, so that the daily management becomes something unreflected upon and incorporated into day-to-day life. These recessions reflect the position that diabetes often occupies in everyday life, as an invisible condition which is unseen, unknown and unappreciated by others. Following the discussion on recessive bodies, I extrapolate a series of four conceptually informed coordinates – namely phenomenology, emotion and affect, performance and performativity and biological citizenship – which inform my geographical analysis of everyday life with diabetes. These coordinates serve as pivots, laying a brief conceptual groundwork for the four empirical chapters which follow after Chapter 4. Each coordinate does not neatly apply to only one chapter but informs them all, although it may be obvious that in each chapter one coordinate is more to the forefront than the others.

DYS-APPEARING BODIES

Leder, a professor in philosophy, seeks to extend the thinking of Maurice Merleau-Ponty in his book, *The Absent Body* (1990a). To do so, he first considers the “ecstatic

body” (ibid: 11), which he regards as the body with which Merleau-Ponty deals, a body that perceives the world using its various perceptive organs: eyes, ears, skin, tongue and so on. Leder contends that Merleau-Ponty had little consideration of the body’s interior, nor the autonomic functions of which we are mostly unaware of and over which we have little control. Leder (ibid: 36) calls this body the “recessive body” and argues that, because there is a lack of sensory receptors within the bodily interior, corresponding to a lack of language to describe inner sensations, there has been a lack of interest in this realm in phenomenological studies of the body. He calls instead for an engagement with the bodily interior, the visceral organs that function autonomically, below the level of our consciousness, in a state of what he calls “depth disappearance” (Leder 1990a: 53). Leder (1990b: 212, 217) describes these internal processes:

A deeper magic takes hold of the viscera: digestion simply is accomplished within me, without my intervention, guidance or will ... The liver secretes its bile, processes its toxins, performs a myriad of metabolic functions. Yet I am neither the observer nor the director of such occurrences. They unfold according to an anonymous logic, concealed from the egoic self.

By exploring the distinctive concepts of “I can” and “it can”, Leder (1990a: 47-48) starts to demonstrate this complex phenomenology of the bodily interior. While ‘I can’ decide to eat a certain type and amount of food, I cannot choose how I digest it. Rather, ‘it can’, my body with its various autonomic functions. Yet, when autonomic functions are disrupted by the experience of pain and disease, Leder (1990a: 69) identifies the “dys-appearing” body, a previously taken-for-granted body now thrust into one’s awareness: in other words, it is a *re*-appearing body. Diabetes is one such disruption, and, given the unrelenting self-management that the condition requires, we are forced to think: what happens when the internal processes cease to unfold, when “anonymous logic” fails and the individual has to become both observer and director of his or her own body? A PWD’s relationship with his or her body is different because of this dys-appearance. The pancreas no longer functions and the person consciously has to take over this previously autonomic role, regulating food intake and insulin delivery rates. A “deeper magic” is hence replaced by a routine reality.

Shilling (2005) critiques Leder, arguing that his dys-appeared bodies are only ever considered as disrupted from a ‘healthy’ and able-bodied normality. Thereby,

Shilling questions the range of *The Absent Body* thesis, asking: what of those bodies that are rarely ‘normal’? He (ibid: 59 italics original) turns Leder’s thesis on its head, writing that “it might be more applicable to talk of the much rarer emergence of the healthy, fully functioning body as a process of *appearance* rather than disappearance”. Shilling (ibid: 59) is correct, of course, especially in the case of diabetes, where there is not a “healthy, fully functioning body”. Even the technological incorporations into everyday life, for some PWD considered the tools of managing a dys-appearing diabetic body, have, for some others, enabled a ‘normalising’ of life with diabetes so that it is no longer such a bothersome dys-appearance. Rather, diabetes has receded and the return of the healthy (non-diabetic) body could actually be a disruptive dys-appearance from their ‘diabetic reality’. However, my aim with this section is to discuss how diabetes can cause a break-down of a coherent body. Leder’s thesis offers a dense toolkit for this consideration, even if it is written from his own experience of the world, where his own body often seems to have a predictable ‘normal’ state (Shilling 2005) – one of his most salient examples of dys-appearance is of the digestive function of his body after eating an apple, hardly a relatable example for analysis of chronically ill bodies! It is still his ideas of a ‘recessive’ and ‘dys-appearing’ body that I take as useful for conveying the everyday experiences of diabetes. In the following section I will take the idea of a recessive body and discuss how the lived experience of diabetes has receded from everyday life both conceptually and materially, through, respectively, a discursive recession and a routine recession.

DISAPPEARING BODIES

DISCURSIVE RECESSION

It is not necessarily a novel idea to suggest that experiences of illness and disability can recede from the public domain. Referring to the ‘silencing’ of illness experiences, Charmaz (2002: 309) writes that:

Silence becomes a deliberate strategy when ill people reflect on possible actions. Ill people intentionally remain silent when they believe that (a) other people cannot comprehend their situations, (b) their views would hurt a

significant person, (c) voicing them would prove too costly, and/or (d) no one wants to hear their story.

Such strategies are evident among my participants and will be discussed throughout the four empirical chapters. Human geographers have also discovered “a culture of silence pervading rural (Highland) life when it comes to mental health issues” (Parr et al 2004: 410). This insightful body of work by Parr et al discovers that rural communities often suppress talk about mental health issues in subtle and sometimes stigmatising ways (such as avoiding those who are known to have mental health issues). In turn, as Davidson (2003a) finds, people with mental health differences (in Davidson’s research: agoraphobia), may attempt to hide their difference from others’ gazes, by, for instance, constructing masks or shields (of behaviour and appearance). In an even more material, rather than linguistic, silencing, many geographers have considered how people with illness or disability may feel they have to keep their dys-appearing body hidden, at work for instance, in order to keep their job safe (Moss and Dyck 2003; Crooks and Chouinard 2006).

Silencing and concealing the dys-appearing body is well covered then: it is something often perpetuated in society, and then, in turn, acquiesced to by people with impairment or illness. Instead, I want to focus on how this silencing not only conceals the embodied and emotional effects or symptoms of diabetes, but also the effort that goes into managing and living with the condition. Indeed, Moss and Teghtsoonian (2008: 11) consider ‘contested illnesses’ arguing that various legal and private sector authorities can control a person’s illness experience by generating truth claims, so that, “the bodily based expertise held by people who are ill has enjoyed a far less privileged status than any of these more conventionally accepted knowledges”. Essentially, they argue that there is a neglect of actually talking to and taking seriously the points of view and experiences of people who actually have a particular illness or impairment. The authors often consider conditions which are not always immediately visible, such as chronic fatigue syndrome, and I detect something similar happening with diabetes due to it often being considered an invisible or unseen condition. Such conditions can therefore become configured as something that can (and, in many cases, *should*) be overcome; and therefore struggling with these conditions exacerbates a sense of moral weakness and failure of an individual, when in fact many of the barriers to good self-management and self-care are social and institutional. A greater emotional sensitivity to the everyday issues faced by PWD is

needed so as to understand how to breach these barriers and ensure that PWD are not only able to achieve better glycaemic control but also better emotional well-being. This focus will be discussed in the remainder of this section with particular reference to Lisa Diedrich's (2007) text, *Treatments: Language, Politics and the Culture of Illness*, along with a brief review of some autobiographical texts written by PWD.

When critically reviewing a number of autobiographies of people with various illnesses, Diedrich (2007: 54 italics original) discusses how "socially sanctioned illness narratives dwell not on loss and failure but on the *overcoming of loss and failure*". She (ibid: 67) concludes for one source that:

In their [the authors'] need to focus on the good that cancer brings, the possibility to improve one's life and redeem oneself, they seem almost desperate to screen the real with a story of heroism – a story for the self – even as the self that this story is for disappears from the scene they have constructed.

The "real" of some sources therefore may be "screened" by a false telling of the story, told because of a culture where there is a "relentless brightsiding"³² and, "according to this brightsiding ideology, breast cancer is not a dreadful disease that we must find ways to prevent, rather it is a 'chance for creative self-transformation ... a makeover opportunity, in fact' " (Diedrich and Ehrenreich quoted in Diedrich 2007: 51). This claim is supported by Robinson (1990: 1177) who, considering written autobiographical accounts of people with multiple sclerosis, demonstrates the dominance of brightsiding narratives:

The nature of the narrative accounts of individuals can be seen to be framed and conditioned – by the audience to whom they are directed, and by whom they are seen and assessed. Although the stories are to a degree 'self-stories' ... in that they are in part addressed to the self and constitute a representation of the individual self, together they also constitute an accumulated and collective experience ... The social moulding of 'allowable' narratives appears to be a key factor in influencing their form and style.

Frank (1998: 331) notes, when discussing Foucault, that the telling of stories can be perceived as inextricably bound up with broader power relations, noting that "Foucault's middle-period work [referring to *Discipline and Punish*] leads us to ask

³² Diedrich borrows the term 'brightsiding' from Barbara Ehrenreich's essay *Welcome to Cancerland* published in Harper's magazine in 2001 and available online here <http://barbaraehreich.com/website/cancerland.htm>.

whether any evocation to tell the truth of one's self – including first person illness stories – is panopticism in a benign disguise". By this, Frank means that society's expectations (of illness experience) can shape the stories one tells of oneself. It is therefore hard to disambiguate any truly personal stories of living with chronic illness as there seems to be a guiding hand towards positive stories, a collective narrative and a social rejection of negative ones. Both Diedrich and Robinson make reference to a receding 'self', the individual experiences of which are overlaid by more dominant representations.

One such example of a brightsiding narrative is the autobiography of Nicole Johnson (2001), who writes of her heroic overcoming of diabetes. Johnson continually reflects that she regards herself as a role model to PWD, especially young people. Her role as a successful woman with diabetes can certainly be inspiring, but she presents a very extreme example, as Miss America³³, a role based on an idealised female body image (possibly an unrealistic example to set). Johnson also skirts over many of her actual life experiences with diabetes, for instance that of relationships, sex (an issue she regards very much as private and not suitable to discuss), depression (although Johnson does discuss being depressed at times due to diabetes, it is never a lingering thought throughout her book and is resolved ultimately by her own positive attitude) and the day-to-day grind of having diabetes. Johnson's life post-autobiography continues her brightsiding narrative; her website (www.nicolejohnson.com) is a testament to her raising awareness of diabetes and her successful publications³⁴ demonstrate her ever 'inspirational' way of living with the condition.

Diedrich (2007) argues that brightsiding potentially occludes more politically informed activism around the treatments of and for illnesses such as breast cancer. She (ibid: 53) writes that, "according to this rhetoric, the dead and dying have failed: failed to survive and so failed to have cancer improve their lives ... Via this rhetoric of survivorhood, those who did not survive are somehow responsible for their own deaths". Roney (2009: 239), herself a PWD, has also written an autobiography about

³³ She won the competition in 1999, and diabetes awareness was one of her campaign points.

³⁴ Along with her autobiography, she has published multiple diabetes cook books (see www.nicolejohnson.com). In a recent diabetes 'self-help' book: *Young Adult Type 1 Realities* (2014), Johnson has addressed issues of intimacy, sexual intercourse, drugs, alcohol and depression among many other life experiences with diabetes. However, while she does acknowledge these aspects more directly than she does in her autobiography, her advice does not go far beyond acknowledging that diabetes can exacerbate problems with such issues.

life with diabetes³⁵, and likewise vents her frustration at what she calls “the public patient”. She argues that media representations of people with illness and disability often focus only on the young, affluent, white and physically attractive, configuring these patients as heroic due to their positive approach to illness. She laments that this focus defines heroic narrowly and denies the more banal heroism of people continuing to work and struggle with medical bills, while also writing out of the picture those whose illness means they are less mobile and less able to display a positive image. Wendell (2013: 163) makes a similar claim, arguing that activism campaigns for people with disabilities are dominated by the “healthy disabled”, as the “unhealthy disabled” often do not have the time or energy to participate fully. The image of disability activism then becomes one of capable, energetic and ‘serious’ people, marginalising the experiences and input of those whose disabilities render them less able to participate. Diedrich’s analysis hence informs the idea of a discursive recession of diabetes. Through my own research I have found that this recession pervades much of day-to-day life with diabetes, so that people feel unable to express their feelings and concerns about the condition. Johnson’s book reflects a sense of a moral imperative to overcome diabetes: if people are suffering because of the condition, it is because they are not ‘doing’ their diabetes right. In my thesis, I want to critique this heroic narrative as contributing towards a silencing of talk about diabetes and also the various emotional states that can exist for PWD.

The autobiography of Norman Savage provides an example of this silencing in action. Savage, heavily contrasting to Johnson, writes as a self-confessed ‘uncontrolled diabetic’, his difficulties with diabetes often being exacerbated by drug and alcohol abuse, general neglect, misunderstanding and mismanagement. While Savage is not completely ‘silenced’, as he has written and published a book after all, he still comments on his frustration arising from a feeling that he cannot talk to people about his problems with diabetes:

I’d never had anyone in my family offer words or actions that showed empathy or understanding in regard to my diabetes while cancer, brain tumors, leukemia and the like were fawned over, loved, understood and respected. I’ve no idea if that fact alone shaped some of what I’d become [possibly referring here to being both an ‘uncontrolled diabetic’ and a ‘junkie’], but certainly I

³⁵ The paper from Roney quoted here is a published transcript of a conference paper. Roney is an English Literature academic from the United States. Her autobiography (Roney 1999) is a non-academic text.

am sure that diabetes was, at that time, too slow a death for me and not nearly romantic enough for me to appreciate (2010: Ch. VIII³⁶).

For Savage, there is little expectation of sympathy or empathy for diabetes-related problems, and instead he fears being labeled as lazy, indulgent, bad and wrong; and so he decides to let it go unacknowledged and silent. He struggles to gain legitimacy for his diabetes, stuck in the paradox described in the previous chapter, where diabetes is simultaneously serious (he believes diabetes is slowly killing him) but also not serious (or romantic) enough to expect empathy. Hence, for large periods of Savage's life he felt unable to acknowledge the impact of diabetes, although, he reflects that he did constantly think about his condition: "yet diabetes ... was a second class citizen to me, I had it, and that's all I'd admit. Put a gun to my head, you'd have to shoot me for me to say any different" (2010: Ch. VII).

Gorman-Murray (2007: 9) champions the use of autobiographies when examining the experiences of GLBT people, arguing that "gay men, lesbians and bisexuals ... need to speak and write about their difference, or it is silenced, rendered invisible by the assumption of 'natural' heterosexuality". Something similar seemingly happens with diabetes; and, unless research is undertaken to highlight the emotional experience of living with the condition, it becomes assumed as 'naturally easy'. In this way diabetes gets pushed towards the margin of acceptable conditions, not perceived by others as serious enough to be a legitimate problem in life or perceived by PWD themselves as minor enough that it can be completely ignored and expunged. 'Public patients' (Roney 2009) such as Johnson do little to help achieve a balance, portraying diabetes as merely a challenge that can be overcome if one adopts a responsible lifestyle. Throughout my thesis, I will discuss how the discursive recession that is evident in these autobiographies is also evident among the accounts of my participants.

ROUTINE RECESSION

Along with the discursive recession of diabetes, I argue that diabetes often recedes due to the development of everyday routines to manage the condition. Contributing to the first wave of phenomenological thinking in human geography, Seamon (1979)

³⁶ Savage's book is only available as an e-book. Unfortunately it does not have page numbers.

proposes the body-subject: the idea that the body itself is intelligent, in part, independent from the cognitive process of a person. In this analysis, the body-subject is able to handle the mundane tasks of the day as they have become habitual body movements, a habit of doing things reinforced by repetition and remembered by the body. The cognitive processes of the person can thereby be freed to concentrate on more difficult tasks, problems and obstacles that emerge throughout the day.

Seamon (1979: 54-55) describes what he calls “body ballets”, which are a “set of integrated gestures and movements which sustain a particular task or aim ... simple hand, leg and trunk movements become attuned to a particular line of work or action and direct themselves spontaneously to the need at hand”. Extending this idea, Seamon (ibid: 55) describes “place ballets” as “an interaction of many time-space routines and body ballets rooted in space” (ibid: 56). Seamon notes how these place and body ballets often go unnoticed by people and how it is not until they are disrupted, or even lost, that their significance is felt. PWD certainly establish body and place ballets due to the routine practices of day-to-day self-management. This is especially true for those PWD diagnosed at a very young age, as they go through life with the practices of self-management as a normal experience. For those diagnosed when older, however, such a routine recession is not necessarily achieved unproblematically. Conscious, effort is often initially and continually required, as for many PWD diagnosis is a ‘biographical disruption’ (Bury 1982) from a previous way of being. Balfe (2005: 251, 255) also writes about such routines developing for one of his participants: “testing was an ingrained habit, a disciplinary activity that Erin had internalised as part of her habitus”; while for another: “he represented it as a laborious, time-consuming process rather than a fluid integrated practice”.

Further to this, routine recessions are not always stable and can be disrupted by changing circumstances, such as a progression of the condition or a change in living or employment circumstances. Bissell (2015: 134), drawing from Ravaisson’s writing on habit, notes that he “emphasises how the efficacy of habit is irreducibly contingent on milieu”. Bissell uses the example of air travel, writing that at the start of the journey an experienced traveller draws from habit to pass through the various boarding processes and security checks with ease; but as the journey continues and as the traveller disembarks, he or she is exhausted and therefore less able to draw from habits and thus finds the processes of arrival difficult.

Whilst the world of this airport is known to this passenger conceptually, it is experienced through a very different quality of movement. The sleep that was so stubbornly distant on the plane has finally caught up with him [or her] and walking, which is usually such a to-hand pleasure, has become a chore fraught with difficulty (ibid: 139).

Of course, walking is not “such a to-hand pleasure” for many people with illnesses and impairments, and such a claim highlights one of the key critiques of a phenomenological (and post-phenomenological) approach in which the subject is assumed to be able-bodied, perhaps male and otherwise ‘unmarked’. Nonetheless, I use the quote to demonstrate that routine recessions can be disrupted, even in the well-frequented places of a person’s life along with fairly uniform places that may be “known ... conceptually” such as an airport. These twin recessions of diabetes – discursive and routine – recur as core concerns throughout my empirical analysis, but for now I turn to the four conceptually informed coordinates which help me to think through my geographical analysis of everyday life with diabetes.

COORDINATES FOR A GEOGRAPHY OF DIABETES

PHENOMENOLOGY

Phenomenology and geography crossed paths as part of a 1970s humanistic turn in the discipline which saw a fervent rejection of positivism and the ‘natural sciences’. Many geographers started to incorporate phenomenological ideas into their research by prioritising people’s personal experience of space and place. Among them were Buttimer and Seamon (1980), who recount their and their colleagues’ increasing interest in *The Human Experience of Space and Place*³⁷, although there are concerns that phenomenological approaches prioritise human experience and so only provide a

³⁷ Phenomenology as espoused by Edmund Husserl sought to ‘bracket out’ everyday experience in the search for a “pure” realm of meaningful encounter between person and world (Gregory 1978a: 163). Later, Alfred Schutz proposed a ‘constitutive phenomenology’ that focussed more on the material “bric-a-brac” of everyday life, rather than bracketing it out or transcending it as Husserl suggested (Gregory 1978b: 126). Pickles notes that humanistic geographers such as Buttimer advocated a more relaxed phenomenology, as Buttimer, for instance has, “paid less attention to the ‘letter of the phenomenological law’, as it were, than to recapturing something of its spirit” (Buttimer quoted in Pickles and Pickles 1985: 46). Buttimer’s phenomenological bent to humanistic geography attends to the everyday meaning-holding experiences of people, and best reflects my own interpretation of a phenomenological approach.

partial account of the world. Indeed, Bondi (2005) alerts geographers to a conceptual dilemma for the social sciences: that of creating a relational methodological approach which upholds neither individual subjective experience nor social contexts as the locus for considering emotions. Addressing this dilemma to some extent, the idea of post-phenomenology has emerged as a way of progressing beyond the perceived limitations of phenomenology focussing purely on a human subject, keeping the tenets of an experiential phenomenology but mixing in ideas of more relational geographies such as the non-human along with more focus on the intra- and trans-human (Lea 2009).

Simonsen (2013), likewise argues that phenomenology, particularly the contributions of Maurice Merleau-Ponty, pre-empts many of its later critiques. She proposes a ‘new humanism’, distilled through her re-reading of Merleau-Ponty’s works, which involves the experiential tenets of phenomenology but also addresses recent anti- and post-humanist concerns³⁸. In summary she identifies three main points. Firstly, she argues that a ‘new humanism’ prioritises the experiential understanding of everyday life, so that embedded structures of meaning can be challenged. Secondly, she proposes that, unlike the perceptions of ‘old’ humanism, new humanism involves an,

Openness towards the other (human or non-human). It is an understanding of others that, on the one hand, does not reduce them to the same, nor, on the other hand, sees their alterity as so radical that it precludes all mutual understanding (ibid: 23).

Thirdly, she proposed that there is a rethinking of ideas of agency, as emerging from the inter-corporeal world, rather than agency being a privilege only of the ‘human’ in ‘humanism’. Therefore, Simonsen (ibid: 23) continues, the subject is understood as emergent in this new humanism and, “it sees the political as an intersubjective field of forces where agents emerge and styles of co-existence are negotiated within the

³⁸ Simonsen’s (2013) advocacy of a ‘new humanism’ is borne out of increasing anti-humanism and posthumanism which often considers phenomenology or ‘old’ humanistic geography approaches as unsuitable for understanding issues of representation, difference and materiality. Simonsen’s idea is that the two approaches are not mutually exclusive, and there can be productive cross-overs and exchange of ideas. There are similar critiques of ‘closed-off’ theoretical approaches in human geography. Reflecting Simonsen’s points, Cresswell (2012), reviewing the edited collection *Taking Place: Non-Representational Theories and Geography*, suggests that much of what is non-representational theory (NRT) has already been considered by earlier humanist geographers. Likewise Colls (2012) considers the advantages of interweaving NRT and feminist geographies, which are often considered incompatible. Colls (ibid: 434) suggests adopting a “nomadic consciousness” to assist feminist geographers to explore NRT while remaining tethered to the core principles of feminism.

dense texture of everyday experience”. This ‘new humanism’ is reflected throughout the remaining conceptual coordinates outlined in this chapter, and, therefore, throughout the whole thesis. The mundane occurrences of everyday life are explored from a PWD’s perspective, prioritising their emotional and affectual experience along with their own (and my) considerations of their performative bodies. These experiences serve to disrupt the embedded understanding of PWD discussed in the ‘recessions’ section of this chapter, and, hopefully, present PWD as having both individual and collective specificities, that are not so “radical” as to “preclude all mutual understanding”. PWD *do* act in relation to the agency of both other individuals and collectives. The previous chapter discussed the work of Mol (2008) who flags a mistaken privileging of agency as residing only with the human agent (the logic of choice), and instead proposing, much as Simonsen does, an “intersubjective field” (the logic of care) where the ‘political’ is a product of emerging agents. This dynamic and fluid ‘political’ of life with diabetes is discussed through the lens of PWD as ‘biological citizens’, predominantly in Chapter 8.

My overall methodology can be considered phenomenological as my methods involve prioritising the written and verbal accounts of PWD as I attempt to uncover the details of PWD’s everyday lives, wherein “everyday practice is produced in and through an abundance of embodied skills, modes of enactment, and styles of habituation which can and do ‘go unnoticed in the background of our lives’ ” (Binnie et al and Thrift quoted in Binnie et al 2007: 517). Yet I do not see my methods and analysis as a stale study of life with diabetes, and I hope to prove, as Crang (2005) contests, that there is still life and value to such traditional methods as interviews and questionnaires (see also Hitchings 2012, who defends the use of interviews in eliciting mundane accounts of people’s lives. I will explain my methods in more detail in the following chapter).

I also take encouragement for a phenomenological approach from Butler (2004: 154), as she writes that:

Though phenomenology sometimes appears to assume the existence of a choosing and constituting agent prior to language (who poses as the sole source of its constituting acts), there is also a more radical use of the doctrine of constitution that takes the social agent as an object rather than the subject of constitutive acts.

As I continue to discuss the idea of the discursive recession of diabetes through performance and performativity later in this chapter and throughout others (especially Chapter 7), I will consider PWD as both agents who act and ‘objects’ who are acted upon, partly by discursive forces. In doing so, I attempt to address Butler’s (ibid: 159) claim that theories positing how embedded social practices and norms do not arise from pre-cognitive ‘natural’ subjects,

Still lack the critical resources for thinking radically about the historical sedimentation of sexuality and sex-related constructs if they do not delimit and describe the mundane manner in which these constructs are produced, reproduced, and maintained within the field of bodies.

It is these ‘mundane manners’, with regards to diabetes, that I wish to expose with my research, and I believe a phenomenological approach ideally suited to this task.

That said, my research also follows the path of post-phenomenology, as Lea (2009: 377) argues:

The methodological challenge [of post-phenomenology] is using methods that clearly and habitually situate the human at the centre, and adapt them so they allow access to the inhuman forces that are the subject of post-phenomenological geographies ... The first of these is the empirical focus upon spaces and practices in which the action of these forces is heightened, and thus more accessible.

A particular post-phenomenological twist will occur in Chapter 5 where I look at the internal geography of the diabetic body. Following philosopher Frederick Svenaeus (2011), I will show how, for some PWD, the diabetic body can become ‘unhomelike’³⁹, particularly through an imaginative process in which the pancreas is attributed a rebellious personality in conflict with the human host. In many ways this rebellious ‘bad’ pancreas is an inhuman force, affecting the PWD from inside the body.

In the vein of Svenaeus’ (2000a; 2000b) ‘phenomenology of illness’, many geographers such as Hall (2000) and Parr (2002a) encourage more focus on the body. Parr (ibid: 247) advocates the importance of a more embodied approach to medical geography, in which:

³⁹ Svenaeus (2011) develops the terms ‘homelike’ and ‘unhomelike’ to describe experiences of one’s own body during illness from Freud’s (2003) discussion of ‘unheimlich’, which translates as ‘unhomely’, and which Freud uses to consider the ‘uncanny’.

Attention to the social organisation which surrounds urination and bleeding, for example, may help us to understand how bodies which do this (in)correctly are categorised and managed by a medicalised society. If we are serious about fully understanding the relations between health and place, the environment and disease, spaces of healing and health care, can we afford not to focus a little more closely on the materiality and meaning of the body and its messy processes?

Although much of the work stemming from this embodied turn does not delve into the deeper recesses to capture the “internal geography ... of the body” that Hall (2000: 27) urges, and there remains a dominant focus on the *body-in-space*. Many authors have considered how one’s emotional relationship with space can change due to illness. For example, Myers (2010, 2012) with respect to the home and HIV/AIDS, Imrie (2010) with respect to the home and disability, Crooks et al (2008) with respect to clinic spaces, work spaces and FMS. While such research is an inspiration for studying the geographies of diabetes, it offers little guidance of the physical internalities of the ill body.

In a “geographical reading” (Philo 2000: 12) of Foucault’s *The Birth of the Clinic*, Philo remarks on Foucault’s tracing of “the emergence of medical practices that are now commonplace, involving not just intrusive surgery but all manner of techniques designed to see into the body (X-rays and related body scans)”. Philo’s paper provides insight for an alternative *space-in-body* conception. He describes Foucault’s three ‘spatialisations’ of disease: the first, a classificatory system of tables and charts where disease was abstracted from the body into learnable nosologies; and the second, a physical system of diseases tracked in/through the body itself:

They [diseases] began to be localised in their particular bodily ‘seat’, and in so doing became set within a thoroughly spatial system of bones, organs, blood vessels, fatty deposits and tissues. Attention duly shifted to this ‘geographical system’ that was the body itself, and here is the crux of Foucault’s narrative in *The Birth of the Clinic*: namely, a shift that prompted the notion that from now on a defining role of the doctor would be to subject suffering patients to the most rigorous and exacting of medical gazes, which in the majority of cases would look not just *at* the body but *into* it as well (ibid: 13).

Clinicians came to recognise the importance of seeing into a patient’s body in order to treat disease. Philo (ibid: 16) continues:

Foucault hence identifies the emergence of a dual structure that sought to install, on the one hand, ‘a continuous supervision of the social space’ ... a

diffuse, non-specialist medical gaze entering into every pore and fabric of regular social life ... but also allowed, on the other hand, the re-emergence of ‘discontinuous, exclusively medical spaces’ wherein a scientific medical gaze was sanctioned to keep on observing, probing and recording extraordinary cases.

This dual structure is what Foucault considers to be the tertiary spatialisation, involving both an institutional regulation but also a non-institutional one which serves to regulate people’s everyday lives (which I will consider in Chapter 8). While the secondary spatialisation is important to understand the space-in-body of PWD, the tertiary spatialisation involving a “non-specialist medical gaze” is important to understand how the image of a PWD is often configured as a personal failing. It is this gaze that, only seeing the surface inscriptions of bodies-in-space, overlooks the immediate affectual and emotional reality of living with diabetes. Simply peering into the “fabric of regular social life” will not uncover the hidden, invisible aspects of diabetes, but instead configure it continually as a contested illness (Moss and Teghtsoonian 2008). The “scientific medical gaze”, on the other hand, can also be problematic; through concentrating on material organs, a tenet of the medical model of illness, the emotional, affective and even imaginative qualities can then be written out by an objective science. The geographical system that Philo highlights is of course highly relevant for my argument, and I will discuss the pancreas as the central affecting interior site for PWD in Chapter 5.

EMOTION AND AFFECT

Introducing ‘geography’s emotional turn’, Bondi et al (2005) claim that human geography, to the mid-2000s, had shied away from involving emotions. They provide an overall statement for how they see emotions being more included in human geography: “an emotional geography ... attempts to understand emotion – experientially and conceptually – in terms of its socio-*spatial* mediation and articulation rather than as entirely interiorised subjective mental states” (ibid: 3 italics original). They insist that emotional geography should not be considered as just another strand for the disciplinary map, since emotion inevitably permeates throughout all aspects of the discipline, and they propose instead that geographers should try to be more attuned to the emotional value and processes of their research. Many geographers have shown the benefit of acknowledging emotional sensitivity in

their research for understanding the lifeworlds of others deemed different by mainstream society. As Bondi et al (2005) remark, it is perhaps at the intersection of work between the body and illness/impairment/disability that emotions in geography have been most apparent. Geographers have studied how a person's social participation in the world can be curbed by different life circumstances, considering the emotional toll that can result (examples include Moss and Dyck 2003; Davidson 2005; Parr 2008). Emotions are not something only to be observed and studied in our participants, though, for geographers such as Valentine (1998), Moss (2001) and Longhurst (2011) have considered their own emotions prompted by facing challenges in academic settings where difference (bodily and sexual) was not expected and even resisted. Moreover, it is not only when considering those bodies that 'differ' where emotion is relevant, and engagement with emotions has continued in human geography, with a broadening focus to include landscapes and everyday encounters (Smith et al 2009).

Emotion and affect are particularly tricky terms in human geography. Pile (2010a: 8 italics original) points out that some geographers feel emotional geography is "mesmerised by *expressed* accounts of emotional life", a critique which, he argues, is "hopelessly naïve and even misguided". Such geographers, Pile writes, prefer to draw on the concept of affect in order to delve below this assumed surface expression. Affects refers to intangible feelings and sensations (such as a vague sense of uneasiness) that are different from more tangible and nameable emotions (such as anger). Thien (2005: 450) is critical of such a distinction between emotion and affect, though, and argues that:

This model of affect discourages an engagement with everyday emotional subjectivities, falling into a familiar pattern of distancing emotion from 'reasonable' scholarship and simultaneously implying that the emotion of the individual, that is, the realm of 'personal' feelings, is distinct from wider (public) agendas and desirably so.

Thien fears that such writing on affect will turn geographical work back towards a masculine perspective where emotions become re-considered as personal and, by extension feminised, while affect goes "beyond humanity in all our diversity" (ibid: 453), in other words, a return to the unmarked masculine subject. Thien worries that such work on affect (specifically mentioning McCormack 2003) can ignore the relationality of space, including issues of power that exist in certain space with regards

to gender or disability. Meanwhile, geographers working with affect, such as McCormack (2003), believe that mere representation of emotion misses out on certain relations that humans have with the non-human, whether it be technological apparatus (particularly salient for studies of diabetes given the technology necessary for TIM) or relations with other non-humans such as animals⁴⁰.

My engagement with emotion is very much in line with Thien as I seek to study the relations of having diabetes in space. Diabetes is often considered in ‘gluco-centric’ terms: that is, one’s ‘success’ with diabetes is determined by achieving ‘good’ numbers in the sense of keeping a healthy balance of blood sugar levels. This ‘life in numbers’ reveals only one aspect of living with diabetes and ignores the emotional effort that goes into achieving these numbers, whether ‘good’ or ‘bad’. For instance, PWD can feel anxiety, foreboding, frustration and sadness when their numbers are bad, but also happiness, relief, satisfaction and contentment when their numbers are good. These emotions fluctuate as blood sugar control fluctuates, and the emotional experience of living with diabetes is never a stable one. Smith et al (2009) note how, in academic geography, “in some texts emotions are very deeply hidden indeed under tables of data and figures, maps, detached observation, third person or impersonal narratives, and so on”. It is a similar neglect of emotions that I find in much contemporary care for diabetes. PWD are asked to complete blood sugar diaries for clinicians and then often judged only on those results. Figure 7 is a week-long extract from my own blood sugar diary. It represents the absence of an emotional sensitivity in diabetes management and care, and the labour of living with diabetes is hidden. As Ferguson (2010: 192 my emphasis) writes, lamenting the representation of diabetes as mostly a body-in-space condition:

In using technology to transform blood into a number, *the body’s internal drama is easily displaced*; its actual functions or failures are experienced secondarily to the reading on the meter. For this reason, the drama of the post-insulin diabetic’s life is really only in his or her failure – blindness, amputation, renal dysfunction, coma.

⁴⁰ This is also a potentially interesting line of inquiry for studying diabetes. Experimentation on animals, specifically dogs and later rabbits, was essential in the discovery of insulin and its subsequent refinement. Until recently most types of insulin were synthesised from organic animal material (such as cows and pigs). Animals feature quite prominently in the history of insulin production and this relation is not always obvious. However, such relations are not within the remit of my research.

Evans (2006) considers a similar disregard of emotional and social factors with reference to obesity and the Body Mass Index (BMI) measurement, which often reduces people's 'health' only to manifestations of their body size and weight. As Evans (*ibid.*: 261) nonetheless clarifies for her own arguments, and which I believe also applies to my own research and relationship with participants:

In discussing morality and medical knowledge of obesity [read diabetes for my purposes], I am therefore not questioning the morals or intentions of those involved in producing or acting on medical knowledge, rather, I am questioning how ideas about 'right' and 'wrong', the association of guilt with some practices, are formed through, and rooted in, the discourse *surrounding* medical interpretations of obesity.

Likewise, with regards to diabetes, I do not mean to suggest that adhering to medical advice and controlling blood sugar levels as tightly as possible reflects a simplistic submission to a domineering biopower, as tighter control of blood sugars *is* shown to decrease the likelihood of severe complications in later life (The Diabetes Control and Complications Trial Research Group 1993⁴¹). Instead, like Evans, I want to question ideas of morality associated with diabetes self-management. For instance, raised blood sugar levels may not indicate 'bad' or neglectful control but a strategy to avoid the acute (and potentially temporarily debilitating) symptoms of low blood sugar in a particularly stressful situation, like a PhD viva! Such an instance of high blood sugar recorded in a diary might still appear to a clinician as a failure to control.

Canguilhem (1989: 42 *italics original*) describes the problem of a strict quantitative divide between the normal and the pathological:

According to which the pathological phenomena found in living organisms are nothing more than quantitative variations, greater or lesser according to corresponding physiological phenomena. Semantically, the pathological is designated as departing from the normal not so much by *a-* or *dys-* as by *hyper-* or *hypo-*.

Following Canguilhem, in a 'gluco-centric' quantitative approach to diabetes care, there is no 'dys'-appearing body, only a quantitative variation from a norm (*hypo-*, in

⁴¹ The Diabetes Control and Complications Trial Research Group's (1993) (often referred to as the DCCT) report is considered a watershed study in diabetes management. It was a clinical trial with 1,441 PWD which showed that multiple daily injections (MDI) of insulin are effective in reducing long-term complications. As such, it encouraged clinicians, the world over, to advocate closer control through MDI. The only drawback was the likelihood of more frequent hypos which were not considered too detrimental to health, although recent research (Jacobson 2011) has suggested that the effects of frequent hypos, particularly on cognitive performance, are unknown.

the case of diabetes meaning a *low* blood sugar and hyper- meaning a *high* blood sugar). In such an approach a normal life is attainable, so long as this quantitative variation, between low and high, is minimised. Indeed, this is the root of frustration for many PWD: a normative assumption that diabetes should not be a troubling condition, that one's body should not dys-appear because the technological advancements of insulin and portable testing meters enable control over these variations. This control is not devoid of an emotional scale, however, and such diaries often obscure the impact that everyday emotional fluctuations and relations with space can have on blood sugar levels.

Date	Time	CP	BG	QA	BI	Comments
20/07	0800	13	9.3	15		
		11.6	7.1	9.6	10.6	
		12-1	9	15-1		
					13	
21/07	0800	13	9	17	15	
		10.7	?	6.6	14.1	FORGET LUNCH BG 2.0 min walk before dinner
		15	9	17	2-2	
					13	
22	0750	18	16	12.5	7	
		10.8	12.2	7.0	10.7	
		10-1	16-2	18	2.1	
					13	
23	0800	15	17	15	0	
		10.5	16.8	?	12.9	
		15-1	17.4	15	0	
					13	
24	0800	16	14	16		
		10.8	14.1	12.1	4.2	
		16-1	14+2	16-1		
					13	
25	0715	12	15	10		
		12.7	19.2	8.2	16.7	
		12-1	13-6	10-1		
					13	
26	0800	16	13	x	6	
		14.2	10.6	10.6	11.1	5.1
		16-3	13	x-1	6	
					13	

ACCOM PANI . . .
/ for exercise, during exercise

Legend:

CP – Carbohydrate Portion – estimated amount of carbohydrates in impending meal. 1 CP = 10g of carbohydrate.
BG – Blood Glucose (sugar) level immediately before meal.
QA – Amount of Quick Acting Insulin taken to cover meal. The + 1,2,3... are correction doses to compensate for high BG levels prior to meals.
BI – Amount of Background Insulin taken.

Figure 7. An extract from my blood glucose diary dated 20th July – 26th July 2012, with a separate 'legend' to initialled terms.

An affective register is not absent from my thesis. Much of one's experience with diabetes revolves around self-management (TIM), in which objects and the practices to which they are put are at best a routine chore and at worst loathed and hated. Trans-human relations, with these self-management devices, are evident through my chapters, if not necessarily attuned to with the same level of scrutiny as by a scholar

such as McCormack (2003). I do not approach emotion and affect as two separate conceptual coordinates, as Pile (2010a) advances, but rather as two notions enmeshed, and will discuss them so when they emerge from my participants' accounts. Other geographers concur with this approach and resist a strict differentiation between emotion and affect. Bondi and Davidson (2011: 595) critique what they call Pile's "categorical violence" as he attempts to "pin down" the concepts of emotion and affect. I agree with Bondi and Davidson (*ibid*: 595), in that I also wish the terms to be "vague and fuzzy", as well as allowing the terms to mean what my participants appeared to want them to mean.

Affect is still an important concept for my analysis, even so, and Hardt (2007: ix) provides a concise description of how I understand the concept throughout my thesis, writing that: "affects require us, as the term suggests, to enter the realm of causality ... they illuminate ... both our power to affect the world around us and our power to be affected by it, along with the relationship between these two powers". Bissell (2010: 81) also writes about the affective forces pressing upon an individual suffering from chronic pain as he passes a hospital on the bus on his way to work:

First, there is the affective force of the physical painfulness of the pain itself impressing through the body: the sheer bite of pain through the body itself. Then there is the affective power of the materiality of the hospital that is significantly enhanced by the presence of the pain, demanding a bodily response through choosing to sit on a particular side of the bus ... But then there is the affect of the hospital that intensifies the embodied sensation of physical pain, the clenched fists, the thumping of the heart, through its proximity. Furthermore, there is also the affective power of the condition of uncertainty itself.

Space, place, bodies and objects exist in a swirling realm of emotion and affect, as skilfully relayed here by Bissell. I will represent the diabetic experience of this realm as best I can, borrowing from the accounts of my participants in my empirical chapters (and to a limited extent my own experiences). I therefore agree with Brown and Tucker (2010: 249), who want to 'eff the ineffable' and who write at the end of their chapter which concerns the clinical experience of psychiatric patients:

This is what we would like to see from affect theory – a turn from the necessary philosophical labour of understanding experience beyond subjectivity toward the forging and unleashing of a plurality of highly particular and individually tailored concepts that explicate the complexities of experience threaded through contemporary socio-cultural settings.

PERFORMANCE AND PERFORMATIVITY

The geographical literature on performance can be understood as cleaved between two main perspectives, as described by Nash (2000). The first sees performance in geography as turning our attention away from the textual representation of life and difference that emerged from the cultural turn, and instead towards more abstract, pre- or non-cognitive embodied practices such as dance (Thrift 2000). The second perspective is more in line with the influential work of Butler (2006) in *Gender Trouble*, where attempts are made to uncover and question how everyday behaviour and acts are discursively constituted rather than naturally given. Geographers have used Butler's work to challenge existing power relations in space; exemplified in earlier work by Bell et al (1994), who look at the performance of sexual identities, and McDowell and Court (1994) who look at gender performance in the workplace. More recently Holt (2004; 2008, 2010) considers how young people with mind-body-emotional differences in school spaces perform in accordance to societal norms and values so as to appear to fit in. Butler is not arguing for a radical abandoning of representation (of gender), but rather for representation to be constructed in different ways. This balance is well summarised by Kirby (1997: 106-107 italics original), who writes of Butler's work: "if language and discourse are constitutive of lived reality, then the possibility of change is discovered in the internal and interminable movement *within* language". This is not dissimilar to the ideas of Bondi and Davidson (2011: 595) and, like them, I acknowledge that I am "understanding and working within this performative nature of language" which, they suggest, is "crucial to the health and development of emotional and affectual geographies". Indeed, following Butler's (2006: xxviii) aims with *Gender Trouble*, one of my aims with this thesis is to realise ways of creating a more "liveable life" for those on the 'healthy' margins.

Thrift (2003: 2020) brings attention to how performance can help focus research on embodied aspects: "in particular, the understanding of performance is caught up with two realms which are too rarely considered: the many communicative registers of the body and the minutiae of spatial movement". These aspects of performance resound keenly with the experience of TIM, the most obvious way that diabetes is communicated to others apart, of course, from telling someone. TIM is an embodied practice where one announces through the reveal of the kit, the insulin pen, the insulin

pump, the testing meter, the testing strip, the needle, the lancet and so on (see Figure 5, Chapter 1) that one's body is different and sustained differently. The finger prick of the lancet and the blood spread on the testing strip, alongside the penetration of the flesh by the needle all convey the violent, visceral aspects of the diabetic body to any who may witness. TIM is then a communication of difference, managed by the "minutiae of spatial movement" of working the kit on the body. Further, Thrift (ibid) writes "performance can also show up all the different ways in which 'small' spaces can have 'large' effects". The body is a small space, injection only occurs on a small site, the 'flabby' parts of arms, thighs or stomach, by a needle, often only 6mm in length and 0.25mm in width; but this act can also create space. The doing of TIM is a performance which can impact upon the spaces in which it is conducted. Simonsen (2007) proposes a 'geography of practice' in which embodied acts impact on the production of space. She (ibid: 174 italics original) echoes Lefebvre, reiterating that "an important precondition of the production of space is ... that each living body *is* and *has* its space; it produces itself in space at the same time as it produces that space". In addition to creating space with bodies and practice, space itself can be performative, imbued with cultural, social and historical meanings that direct the type and manner of performances conducted. Gregson and Rose (2000: 441) have previously argued for more attention to this performativity of spaces:

We want to argue that it is not only social actors that are produced by power, but the spaces in which they perform ... we maintain that performances do not take place in already existing locations: the City, the bank, the franchise restaurant, the straight street. These 'stages' do not pre-exist their performances, waiting in some sense to be mapped out by performances; rather, specific performances bring these spaces into being. And, since these performances are themselves articulations of power, of particular subject positions, then we maintain that we need to think of spaces too as performative of power relations.

I will discuss the performative nature of spaces throughout the thesis, but particularly in Chapter 7 taking restaurant/café/pub toilets and tables as a small case study.

My take on performance comes primarily from Butler and, like Butler (2004: 155), "I will understand constituting acts not only as constituting the identity of the actor, but as constituting that identity as a compelling illusion, an object of belief". The constitutive act for diabetes is TIM, and I will show (especially in Chapter 7) that, when performed as secret and concealed, it constitutes diabetes as a secretive

condition. In turn, a condition that is absent from public view in everyday spaces reinforcing depictions of diabetes as an easy-to-handle, less than serious condition. Butler's main thesis is to contend that there exists no natural category of gender. For Butler (2006: 191), gender is created through a "stylised repetition of acts", and she writes that "this repetition is at once a re-enactment and re-experiencing of a set of meanings already socially established; it is the mundane and ritualised form of their legitimation". I would argue that the repetition of how TIM is performed reflects "a set of meanings already socially established" about what is acceptable when it comes to doing TIM in public. I contend that the performance of TIM is not dissimilar to the performance of gender as described by Butler (ibid), a performance that "is not a radical choice or project that reflects a merely individual choice, but neither is it imposed or inscribed upon the individual". I believe that PWD perform TIM the way they do because of a discursive pressure; whether they seek to hide it or whether they expect people to look away, they are always influenced by beliefs about what is acceptable in public space. I also argue that there is something of an individual choice, an agency, akin to Erving Goffman's (1971) conception of performance, where people can choose from different fronts to present to others, albeit this choosing takes place within an enveloping regulatory framework.

Simply transferring Butler's theories on sex and gender to impairment and disability is not so easy. Samuels (2002: 64) considers the difficulty, prompting disability scholars "to at least ask if there is a difference between disability/impairment and gender/sex – and, since there obviously is, how that difference operates in the present situation"? A main worry is that Butler's work is seen by some disability theorists to "presume able-bodiedness as a prerequisite of subjectivity" (ibid: 69). Similar critiques, of an assumed able-bodied starting point, as I have already mentioned, are made against Leder, and it seems that the theorists who I consider useful to explain life with diabetes are not overly attuned to the experiences of those with bodily difference. Nonetheless, I believe that Leder and Butler offer a theoretical tool kit from which I can select appropriate ideas to help explain life with diabetes, although this does not mean that I religiously adhere to their respective theoretical theses.

While I argue that diabetes *can* be a form of disability for some (as I touched upon towards the end of the previous chapter), I believe there is still some confusion in disability studies about the inclusion of chronic illnesses. Hirschmann (2013: 145)

identifies an incompatibility between ideas of queer performance and disabled performance:

When gay identity is ‘performed’ in a way that heightens and exaggerates gender difference – becomes hypervisible – it strongly diverges from disability, for the ‘performance’ is generally the effort expended in overcoming or dealing with a disabling impairment caused by a hostile environment. So again, the parallels are not perfect.

I do not entirely agree with Hirschmann. For instance, the ‘performance’ of queer identity can be – as Brown (2000) describes with an example at the start of his book, *Closet Space* – a performance that also must overcome the heteronormalising forces in the environment, such as the disciplining gazes and disparaging comments from others who witness the performance. Hirschmann’s argument seems based on a physical impairment such as someone with mobility impairment, a missing limb for example, rather than someone with a contested and often invisible illness, such as diabetes. Sherry (2004: 780) agrees and writes that some disability scholars:

Argue that Butler’s theory of performativity cannot be applied to disability because bodily difference is not performed wilfully. But this argument mistakes impairment for disability and performance (a willful act) from performativity (rituals and social processes which help constitute an identity).

PWD *do* have a bodily difference that *can* be performed wilfully (as hidden or flaunted) but is also subject to a performativity of the discursive recession, which can render its performance as ‘naturally hidden’. I do then consider the invisibility of queer identity to be somewhat comparable to the invisibility of diabetic identity. One cannot know someone is gay by simply looking at them, and the same is true for chronic illness, as Hirschmann (2013: 144) notes based on Wendell’s experience of chronic fatigue syndrome (CFS):

Wendell’s experience of CFS recounts numerous examples of people simply not believing that she was ill because she did not ‘look sick’ and thereby confounded the dominant stereotypes. She notes that her ‘appearance’ was defined by what seemed important to the able bodied (for instance, good colour in her face, mobility) rather than what is important to her (fatigue after mild exertion) ... Such denial obliterates the possibility that the disabled other really exists.

Diabetes is not inherently invisible. The act of TIM is a visible identifier of a PWD, but it can be performed secretly and out of sight, ‘in the closet’, and often is, due to

the discursive recession of diabetes. Throughout the thesis I will present some ‘disabling’ accounts of PWD, that are perhaps doubted by others, as disabling, due to the relative invisibility of symptoms such as an obvious physical impairment.

There is also a politics of passing for people with non-visible disabilities as discussed by Wendell (2013)⁴², in which aspects of ‘coming out’ as ill or disabled are complicated. For instance, some of my participants want a greater acknowledgement of the difficulties that living with diabetes can involve, while others are keen to keep in line with a discursive recession and downplay or even completely conceal signs of the condition. Samuels (2003) discusses how, for people with non-visible disabilities, and symptoms that often fluctuate, ‘passing’ is a contentious issue. Passing as ‘normal’ can be read as detrimental to others with the condition, potentially compromising their receipt of legitimation for or about the disability. Samuels does not entirely agree, thinking that “such condemnations of passing often conflate two dynamics: passing deliberately (as implied by the term hidden) and passing by default, as it were” (ibid: 240). She means that, just because someone does not declare their non-visible illness or disability, it does not mean that they are contributing to a denial of disabling social and environmental factors. In fact, Hirschmann (2013: 146) argues that passing can be a form of empowerment for people with invisible conditions:

Those who choose to make or keep their disabilities invisible can operate in the nondisabled world of privilege to destabilise common narratives of disability, social policies, and practices, thereby contributing to a collective unease about what we, as human beings, ‘truly are’.

These contracting perspectives on passing are particularly reflected in the experience of living with diabetes as discussed by my participants, especially discussed in Chapter 7.

PWD AS BIOLOGICAL CITIZENS

Foucault’s work has long inspired human geographers (and of course many others from varying disciplines) to understand how bodies, space and (bio)power are entwined, and his concepts are of considerable importance for my thesis as well. Foucault (1991: 209) discusses Bentham’s panopticon and his prediction of a

⁴² Goffman (1968) discusses the idea of ‘passing’ with a concealable ‘stigma’ in great detail.

diffusion of its effects from institutional places to “a network of mechanisms that would be everywhere and always alert, running through society without interruption in space or in time”. Such a diffusion is arguably realised today and, following the principles of the panopticon, such mechanisms have been internalised by individuals as self-discipline and enabled by mobile self-testing equipment. Rose (2007) and Mol (2008) have both considered how bodies are disciplined by self and others in order to “tame” or “transcend” (Mol 2008: 35) those ‘deviances’ that disrupt such ‘docile bodies’ (Foucault 1991). From such disciplining, ‘biological citizens’ (Rose 2007) emerge, which often represent – in the case of diabetes – the effect of the discursive and routine recessions of diabetes, as they create malleable ‘docile diabetic bodies’ upon (and inside which) are inscribed the ideals (or norms) of living with diabetes (which, as we will see as the chapters progress, includes self-management, attitudinal approach, diet, exercise, weight and many others). Rose (ibid: 147) defines different types of biological citizenship as stemming from self-reflecting on biological difference as well as being programmed by state-led interventions into the creation of conforming biological citizens. With regards to personal health, he writes that:

Such a citizen is obliged to inform him or herself not only about current illness, but also about susceptibilities and predispositions. Once so informed such an active biological citizen is obliged to take appropriate steps, such as adjusting diet, lifestyle, and habits in the name of the minimisation of illness and the maximisation of health. And he or she is obliged to conduct life responsibly in relation to others, to modulate decisions about jobs, marriage, and reproduction in the light of a knowledge of his or her present and future biomedical makeup. The enactment of such responsible behaviours has become routine and expected, built in to public health measures, producing new types of problematic persons – those who refuse to identify themselves with this responsible community of biological citizens.

Rose’s ideas have been incorporated into human geography under banners such as ‘vital geographies’ (Kearns and Reid-Henry 2009) and ‘geographies of health and bioscience’ (Greenhough 2010). These works build on Rose’s text in different ways, Kearns and Reid-Henry wishing to curtail Rose’s privileging of the individual subject in decision-making so that the impacts of states, governments and ‘geographical luck’ (that is the advantages one does or does not enjoy through the uneven distribution of technology and resources) are not overlooked. They argue for a vital geography which considers questions about the “vital limits and capacities” of human life (ibid: 556). Greenhough (2010: 156) writes that biological citizenship is increasingly pervasive

among Western societies due to government initiatives that put the incentive in individuals' own hands to manage their care, but at the same time direct such care towards an accepted norm: "biological citizenship therefore not only provides the basis for claiming new rights ... but also comes with new kinds of responsibilities articulated through new forms of biological governance". Drawing from Rose's concept of the biological citizen, this regulation, in part, is influenced by a form of biopower emanating from clinical sites and the geographical imagination of what it entails – in this project – to be 'diabetic'.

One's diabetic self becomes scrutinised by both self and other, as PWD come to realise the effects of the tertiary spatialisation of disease as described by Foucault (Philo 2000). Of course technological advances in diabetes care serve to internalise regulation. DAFNE encourages PWD to become their own regulators: to make decisions about their own diabetes management based on their desired lifestyle and their glycaemic control. The operators stress that the aim of the DAFNE course is to improve glycaemic control and not necessarily to direct participants towards other healthy lifestyle approaches. If PWD wish to eat lots of crisps – one DAFNE participant, on a course I observed, talked about his love for crisps and wanted the flexibility to eat as many he wanted, whenever he wanted – or have a piece of chocolate cake after dinner, then, using the DAFNE guidelines, they can make this choice and still maintain their desired glycaemic control. The role of DAFNE is to liberate PWD from rigid eating practices, not necessarily towards an end of healthy eating practices⁴³. However, the DAFNE course, as Lawton and Rankin (2010: 491) consider, does impose some panoptical pressure on participants as they are "shepherded" towards 'accepted' behaviours by the course operators and by other participants. As Rose and Miller (2010: 272) write, "power is not so much a matter of imposing constraints upon citizens as of 'making up' citizens capable of bearing a kind of regulated freedom".

PWD are a particular type of biological citizen. They are often defined by their condition along medical and financial lines. For example, Govan et al (2011) configure PWD as a quantifiable percentage of the population in Scotland, and calculate how much they 'cost' the NHS. They discover that, between 2005 and 2007,

⁴³ Indeed, this is apparent when reflecting on the name of the course: Dose Adjustment For *Normal* Eating; it is not for *Better* or *Healthy* eating. Indeed, *DAFBE* or *DAFHE* does not have quite the same ring to it as DAFNE.

PWD accounted for 12% of the total Scottish inpatient expenditure, despite accounting for only 4.3% of the population. They argue that sub-optimal HbA1c levels are responsible for much of this expenditure, and so strategies that promote better HbA1c should be given priority in health care. This is one reason why the ‘gluco-centric’ approach is so prevalent in diabetes care as clinicians treat PWD as a homogenous section of the population, rather than as individuals. Again, the DAFNE courses are a prime example: Shearer et al (2004)⁴⁴ predict that establishing courses such as DAFNE, as a routine treatment for PWD, will result not only in greater health benefits for PWD, in terms of increased life expectancy, improved quality of life and fewer complications, but also save the NHS money: “overall, it was estimated that the DAFNE programme would save the NHS £2,237 per patient over 10 years and would break even at approximately 4.5 years post intervention” (Shearer Lay Summary 2010).

So how do PWD resist this panopticism? According to a footnote in Balfe’s (2005: 263) thesis, they do not:

One point that my interviewees continually stressed was that they did not have a disability. Rather, they said that they had an individualised ‘condition’; none of them were really interested in meeting other diabetics to talk about what it was like to live with diabetes. As such, the idea that they could construct a political identity around their condition was something interviewees found strange. Stigma, when it was experienced, was not appropriated and reworked into a broader social project. No interviewee questioned, in our discussions, why they experienced stigma, and whether it was wrong that they experienced stigma; their primary concern lay in how best to deal with it.

It is understandable that, given Balfe’s sample of PWD, this was the case. His participants were university students who were trying to balance the life of student and PWD for social reasons. I do not mean to say that Balfe’s thesis was devoid of instances of resistance and, in fact, the often mundane resistances to diabetic ideals that I will discuss throughout my thesis were also a theme of Balfe’s. I do mean to say that, by drawing participants from various walks of life, my research can uncover ways in which PWD *do* develop something of a ‘political identity’, albeit mostly in mundane but still significant ways.

⁴⁴ Despite being ten years old at the time of writing the thesis, these predictions are still being used by DAFNE to demonstrate the course’s cost effectiveness.

It is not until Chapter 8 that I will explicitly consider the difference between type 1 and type 2 diabetes, although the distinction will appear at times before. I started my research, attempting to recruit all types of PWD, because I did not want to limit the responses from support groups and online forums for interviewees and questionnaire respondents. Neither did I want to imply that – given that these groups involve both types of PWD – one type was more worthy of social science research investigating emotions and impacts on everyday life, than was the other. I continued in this vein because I wanted to discuss the experience of living with diabetes as shaped, in part, by lay conceptions that often do not differentiate between types, meaning that the experience of both conditions is often interrelated. In fact, by including both type 1 and type 2 in my research, I found that many PWD (type 1)⁴⁵ are annoyed at potentially being mistaken as having type 2, due to the associations of type 2 as self-inflicted by poor lifestyle. These PWD (type 1) are keen to stress that they are ‘good’ biological citizens, their diabetes caused by purely genetic factors that are beyond their control. Likewise many PWD (type 2) are keen to stress the biological causes of their diabetes which are often little considered.

Hansen (2002: 72) wants to resist a ‘disabling’ capitalist employment structure, and in so doing seeks to avoid a “disease of the month” way of thinking. Therefore, she explicitly does *not* specify the individual disabilities of the women in her study. She avoids this convention in order to make more general points about the experience of illness, arguing that:

I do not wish to engage in the voyeuristic practices of many researchers in disability, focussing on type of impairment or what is ‘wrong’ with individual participants as a curiosity or titillation. People with disabilities are always being asked what is ‘wrong’ with them. I did not wish to reduce people to a manifestation of their impairment and for this reason I resist a profiling of disability ... For this reason, individual disability or impairment is not dealt with in detail [in her thesis] (Hansen 2002: 67).

Such reasoning is shared by Kearns (1997), who argues that increased attention to narratives that provide nuanced and individualistic accounts of space can perhaps compromise the larger geographical aim of contributing to social justice. A concern therefore exists that a detailed focus on one illness, disease or impairment can lead to

⁴⁵ When I refer to PWD, I am referring to all PWD as illustrated by my participants. The term PWD in my thesis does not differentiate between types. When I wish to differentiate I will make it explicit in the text.

deconstruction of the overall aims of advancing social justice for all people with illness, disease and disability. My own thesis conflicts with this concern by focussing specifically on PWD, essentially providing a detailed profile of what it is like to live with the condition. Like McDowell (1991), who is wary of losing the specificity of feminism as a politico-theoretical project advancing the social and political concerns of women, due to increasing engagement with post-structuralism, I am also wary that the notions of Hansen and Kearns can lead to losing the specificity of illness and impairment, specifically in my case of diabetes and its particular politics, culture and aspects of day-to-day life. At the same time, though, I feel that findings from empirical evidence in my focussed study can help to inform future, both general and specific, studies on diabetes, disability and chronic illness, just as previous studies have informed mine.

CONCLUSION

I have outlined a way to approach understanding diabetes as an emotionally, mentally, physically and socially impinging condition, and not as a ‘recessive’ condition. Throughout my four empirical chapters, I will explore these aspects of embodiment, emotion, performance and biological citizenship. In Chapter 5, I will explore a PWD’s phenomenological relationship with their own body – particularly their own pancreas, which involves an uncanny division of self – creating a subject that is no longer coherent and whole, meaning that routine recession is difficult to achieve and, when it is, may be precarious and/or fleeting. In Chapter 6, I will demonstrate that everyday spaces and places affect PWD and restrict mobility as well as creating anxiety. I establish the experience of diabetes as not solely bound to internal, personal emotions but recursively affected by the environment and social context. In Chapter 7, I will consider how TIM is performed and how this performance exists with recourse to performative spaces, arguing that the discursive recession of diabetes is reinforced as TIM is configured as ‘naturally’ hidden. Finally, in Chapter 8, I will explore some of the vital questions of living with diabetes, asking what it takes to be a good diabetic biological citizen and how such notions might be resisted or reconstructed.

CHAPTER 4

METHODS: UNCOVERING DISAPPEARING BODIES (OR COVERING UP DYS-APPEARING BODIES)?

“I would not discuss anything diabetes related with you or anyone else” (Elliot).

INTRODUCTION

I have chosen methods that reflect the need to gather individual experiences of PWD in order to establish a picture of everyday life with diabetes. My primary methods are qualitative online questionnaires and semi-structured interviews, but, at times, are supplemented by secondary data from published autobiographical texts, online bloggers and my own tentative participant observation. These methods are situated in a qualitative research framework that now permeates much of contemporary human geography (Davies and Dywer 2007). The methodology of the research is situated in a version of grounded theory, which is “iterative, or recursive ... meaning that the data collection and analysis proceed in tandem, repeatedly referring back to each other” (Bryman 2008: 541). Throughout my research the questions and aims were flexible, changing depending on the information gathered. As way of introduction to the project, however, I will give a brief review of changing research methods in medical/human geography that were inspired by Kearns’ (1993; 1995) calls for increased attention to place experience in medical geography. I also introduce the collaborative aspects of my research through a discussion of my NHS ethics approval process. Following the introduction, I will discuss my two primary methods in turn, beginning each discussion with a brief outline of the method, then detailing my design and implementation. For each method, I will discuss issues of anxiety and positionality that created specific challenges for me during my research. I will conclude each section with some particularities of my analysis. I will then discuss the secondary methods that I use, along with providing personal insight on my experience of being a PWD researching PWD.

Dyck (1999) charts a rising interest in the 1990s within medical/health geography of using qualitative methods rather than quantitative methods that focus on the spatial distribution of disease and illness. The previous neglect of qualitative

methods in medical/health geography is possibly explained by the view that “either qualitative methods are presented as soft and subjective, an anecdotal supplement to the ‘real’ science, or qualitative methods are argued to be just as objective as the quantitative” (Winchester 1999: 62). Winchester (ibid: 65) describes her experience of using both quantitative and qualitative methods in a study of lone fathers, lamenting the failure of “numbers from questionnaires” to reveal, “the causal structures and underlying mechanisms which produced a particular geography of combative masculinity ... It did not even reveal the discourses whereby such a geography was reproduced”. On the back of this diversification of methods, study designs of purely qualitative methods – such as in-depth, semi-structured interviews – were no longer considered weak, for they did not need a “quantitative prop” (ibid: 66) and were more than just, “adding voices on” (Dyck 1999: 245).

Further to this, Cutchin (1999: 272) argues that qualitative methods allow research participants to be involved in the “problems of health and health care in their place; participants are encouraged to join the interactions that can remake the health dimensions of place”. With specific regards to PWD, Peel et al (2006) found a sense of altruism, where participants cited their interest in being part of the study as their responses could possibly be of help to other PWD. They also found that some people welcomed the opportunity to talk about their diabetes with people who were interested, because they felt that their time with healthcare professionals was limited and they found it difficult to talk to other people in their lives about their diabetes. Wilton (1999: 260) reflects on this issue, noting that “empowerment through education and shared experience constitutes a central component of participants’ efforts to make sense of and live with HIV/AIDS”. Hopefully, my participants will have seen some benefit, for both themselves and others, in taking part in my research.

Although funded entirely by the ESRC, my research is also, partially, a collaborative project with clinicians in Glasgow. The research has been assisted throughout by diabetes specialist clinicians working in the Greater Glasgow and Clyde NHS health board. Frequent liaisons with a diabetes specialist doctor who works in a Glasgow hospital, encouraged my scrutiny of the ‘gluco-centric’ approach, as he noted how, only recently in his practice, he had come to appreciate more fully the social and emotional dimensions of living with diabetes. This led to a larger collaboration with the operators of DAFNE courses held at three Glasgow hospitals: Stobhill Hospital, Victoria Infirmary and the Southern General Hospital. Together

with further help and input from contacts at each of these sites, my initial contact and I assembled a research strategy to recruit interview participants from DAFNE courses, along with possible methods to feedback my results to the DAFNE operators in Glasgow⁴⁶. Ethical approval from the University of Glasgow was obtained for the recruitment of participants through routes other than the NHS. Because the DAFNE courses are run on NHS premises and people undertake these courses due to their status as an NHS patient (i.e. one who receives regular care from a NHS diabetes clinic), both NHS Ethics and Research and Development (R&D) approval were also needed. Unfortunately, this process was fraught with difficulty, including limited and fragmented access to information about how exactly forms are to be completed and submitted, especially for someone working from a discipline such as human geography who has little understanding of the usual NHS procedures⁴⁷. The questions in the application forms are geared mainly towards clinical and medical trials, and expressing the ethical and scientific justification of a purely qualitative trial was often difficult.

Dyer and Demeritt (2009: 58) discuss the medical model of ethical approval that is being increasingly applied to social science by the ESRC, noting that “qualitative researchers have sometimes found it difficult to receive approval for proposals that do not include double blind experimental controls and other norms of positivist methodology that medically dominated RECs [Research and Ethics Councils] associate with ‘good science’”. They continue to note that human geography projects are often evaluated by people who are not human geographers, questioning, “whether these are the people we want to see deciding what kind of human geography gets done and by whom” (ibid: 58). My NHS ethics and R&D approvals were decided upon by a panel of non-geographers and, maybe more importantly, non-social scientists, to whom it is difficult to explain the purposes and advantages of qualitative social science research. In order to do so, I tried to be specific and succinct in the application forms, but this approach creates a catch-22 situation, as Dyer and Demeritt (ibid: 57) further discuss: “in the open-ended and exploratory traditions of hermeneutic social science, research purposes, methods, and

⁴⁶ As part of this strategy I intend to release a plain language summary of my research in the form of a short booklet. Potentially, this could be used by NHS, DAFNE and Diabetes UK as part of their distributed literature.

⁴⁷ Compared to researchers in clinical and medical disciplines.

intended outcomes are fluid and evolving. They cannot be specified in advance in a participant information sheet'. Trying to be specific on research that is based in grounded theory can be misrepresentative of how the research is ultimately conducted.

After a prolonged period, and with much assistance from my academic supervisors, as well as invaluable help and input from NHS collaborators, I eventually received NHS ethical and R&D approval. This approval permitted me to recruit participants directly from DAFNE courses and also supplied me with a 'research passport', a letter which confirmed that I was permitted on to NHS premises for the purposes of participant recruitment. It seems a shame that I encountered such difficulty and confusion when obtaining my NHS approvals, especially since Andrews (2002) argues that disciplines such as nursing studies and human geography could benefit greatly from an increased attunement to each other's theoretical and methodological practices. More streamlined access to NHS resources for qualitative researchers could improve care practices and enable a deeper understanding of divergent lifeworlds.

ONLINE QUESTIONNAIRES

OUTLINE OF METHOD

Literature concerning online qualitative methods has focussed on email interviews (Milligan 2005; Bjerke 2010), synchronous online interviews (Madge & O'Connor 2002) and surveys and questionnaires disseminated to online forums (Parr 2008; Davidson and Parr 2010), as well as online ethnographies (Parr 2002b; 2008) where researchers observe and/or participate in online conversations. As Parr (2002b) writes, people with illness may turn to virtual spaces in order to gain empathy and understanding of their illness experience, which may not be forthcoming in 'physical' spaces, along with seeking information and advice on their condition from lay experts (i.e. non-medical professionals). I chose to do an online questionnaire in order to access the multitude of diabetes forums on the internet. The questionnaire was chosen over other possible online methods because it satisfies certain ethical imperatives. For instance, respondents to an online questionnaire are well informed about the research whereas online ethnographies can be problematic as forum posts are often written

with an “illusion of privacy because correspondents do not see the numerous people reading their messages” (Madge 2007: 661). Although not geographically proximal to Glasgow, most of the online forums that I contacted were based in the UK and so the answers reflect a general UK perspective.

Online methods that do not involve the synchronous presence of both researcher and participant can be particularly revealing. Milligan (2005: 218) argues, with regards to narrative accounts written without the presence of the researcher that “the therapeutic benefit seems to unfold as, through their writing, respondents develop an understanding of their own actions, emotions and experiences”. Milligan also suggests that such a technique elicits personal feelings that participants may not reveal in a face-to-face interview. While PWD are not explicitly an online community, there is definitely evidence that significant communities of PWD exist online. The website, www.diabetes.co.uk, for example, has a sizeable forum, which reflects the usage of the internet as a method for communication and information sharing for people with illness and disability (Parr 2008). Greene et al (2010) have studied the posts from PWD on diabetes *Facebook* sites, suggesting that the posts indicate the existence of an online community where contributors shared stories, offered advice and even organised political activism by petitioning politicians and insurance companies about diabetes related issues. Further to this, Davidson and Parr (2010: 63) have argued that, for people on the autistic spectrum and people with mental health problems, the internet creates a space where community can thrive as opposed to what occurs in off-line environments that “can feel sensorially overwhelming, emotionally uncomfortable, socially stigmatising, and so, disabling”.

DESIGN AND IMPLEMENTATION

While the use of online methods is being given more attention for gathering qualitative data (Madge and O’Connor 2002; 2004, Parr 2002b; 2008, Crooks 2006, Davidson and Parr 2010), I believe that the ‘qualitative questionnaire’ is still somewhat underexplored. Most methodology ‘how to’ guides advise that questionnaires be short, simple and easy to answer to boost response and completion rates and suggest that longer questionnaires may suffer from ‘fatigue bias’ (see, for example, Parfitt 2005). Madge and O’Connor (2002) espouse the advantages of using an open-ended online questionnaire when studying the lives of mothers with young

children, but even they note the importance of making such questionnaires quick and simple as people generally have little patience for text-heavy web pages. Contrary to such advice, and with encouragement and guidance from my supervisors, I created a text-heavy questionnaire. The original version had thirty-six questions over six pages⁴⁸, almost all of which were open-ended in providing text boxes with unlimited word allowances for people to write answers, along with messages from me at the start of every section encouraging extended, detailed answers (see appendix 1). I did include some ‘closed’ questions, in the form of rating scale questions which asked how ‘safe’ people felt if they were to have a hypo in a variety of everyday spaces and how ‘comfortable’ they felt doing their self-management practices in such spaces.

The rating scale questions were intended to elicit descriptive statistics, and I discuss these results in more detail in Chapter 6. While closed questions with multiple choice may be easier to answer and provide a quantifiable data-set, McGuirk and O’Neill (2005: 149) note that “answers are limited to the range of categories designed by the researcher as an exhaustive list of possible answers ... Moreover, closed questions rest on the assumption that words, categories, and concepts carry the same meaning for all respondents and this may not always be the case”. The questionnaire was created using the *surveymonkey* service (www.surveymonkey.com) and would appear to respondents as a new webpage when a link was clicked. After completing it, respondents would click the submit button at the bottom of the final page which would send their answers to my *surveymonkey* account. The first page of the questionnaire served as an information page, and I made it clear that by submitting the questionnaire respondents were consenting for their responses to be used.

I found that, due to the length, many people only answered the first few questions, tending to drop off as the questions continued; others answered only select questions throughout the questionnaire and others still answered most questions but with very short, often one word answers. However there were also plenty of more detailed and lengthy responses, and it is evident that people who spent time answering the questions were often reflecting intimately and emotionally on their lives. I

⁴⁸ I made multiple versions of the questionnaire as my fieldwork progressed. Based on initial responses and feedback from respondents, I changed the wording of some questions, deleted others and added new ones. These changes were mostly in order to streamline the questionnaire: for instance, deleting a question that elicited very similar responses as a previous question – to the extent that many respondents simply wrote ‘see answer to question x’. The core themes of the questionnaires were unchanging. Likewise, the length of later versions of the questionnaire, while having fewer questions, was not significantly shorter.

received 127 responses to the questionnaire, 91 from female respondents, 35 from male respondents and 1 respondent who did not determine sex. The higher proportion of female respondents is in keeping with a similar study from Balfe et al (2013c) who found more female than male respondents when recruiting from a *Facebook* site (26 female to 6 male). In Parr's (2008) online questionnaire, posted on mental health discussion forums, she found the predominance of female respondents surprising considering that online environments are often dominated by men. Parr suspects that the predominance of female respondents is explained by women's use of the internet to challenge (or escape) male dominance in other 'physical' locations, and possibly this also explains my own spread of responses.

I split the questionnaire into seven main categories. The first category, *Introductory Questions*, establishes the attributes of the respondent, important in providing a context when reading, understanding and analysing the responses to the later questions. These questions, like all others, had text boxes supplied for answers⁴⁹. The second, third and fourth categories, *Diagnosis*, *Self-Management and Hypoglycaemia and Hyperglycaemia*, deal with people's behaviour and experiences. Enquiring about behaviour such as self-management practices and how these are adjusted in different spaces and places allows a geographical aspect of living with diabetes to be uncovered. I tried here to avoid using 'technical' geographical terms as far as possible and keep the questions simple, an especially important consideration for questionnaires in which the researcher is not present because the respondent cannot ask for clarification if they do not understand the question. In order to help prevent against the non-answering of questions by respondents because they dislike or do not understand the question, I explained in the information page that the

⁴⁹ Closed answering options such as multiple choice, for example asking the sex of the respondent and providing only two options male or female, may seem more effective for this section as they are much easier to answer for respondents (rather than writing 'male' or 'female'). However I have found with previous research, that when asking for feedback on online questionnaires, some respondents were dissatisfied with only two options of male and female when it can to describing their sex. Although that previous questionnaire was targeted at an online forum for gay, lesbian, bisexual and transsexual gamers, I still feel that providing open-ended options for responses for such 'attribute' questions can often reveal more detailed facets of a respondent's personality. For instance answering the age question, as 'a young 56' or 'I'd rather not say' rather than having only options of age ranges. Such responses, I feel, also engage respondents quicker with the questionnaire by giving them the chance to have a bit of fun or be creative when answering such routine, boring questions. For instance after changing the 'Sex?' question to an open ended text box many respondents chose to reply with the old joke 'yes please!', often before answering seriously. This possibility is enhanced by the fact that such online questionnaires are easily done anonymously and respondents may feel more comfortable when writing answers, instead of talking face-to-face (Madge & O'Connor 2004).

questions are just to be taken as guides and can be answered in any way. In encouraging respondents to do this, I sought to give them more control over what questions they wanted to answer and how they wanted to answer them. The lack of interviewer interference encourages respondents to share more, to go off topic and give a broader context. That said, this method may also suffer due to the absence of the interviewer to spur conversation in a particular direction, and this same freedom of the respondent can also result in a poor response rate for open questions. The final categories were *Stigma, Misunderstanding and Community*, so chosen as I attempted to elicit more ‘political’ experiences and opinions about living with diabetes. I ended with space for respondents to write whatever they wanted that might not have been asked by the questionnaire and also to provide feedback on the questionnaire itself. Respondents were not asked where they came from, but the majority of the responses derived from UK websites and spoke to UK issues (about the NHS for example). So, while these responses are not illustrative of Glasgow they are experientially close as they speak to the overall experience of PWD in the UK.

ANXIETIES AND FIRST CONTACTS

I must make a confession that I have often favoured online methods (at undergraduate and masters level) due to my fear of simply talking to people. I am anxious about talking to people I have never met before, especially people who I have asked through email or phone to talk to me in a café for a research interview, people who are therefore expecting me to lead the conversation, people who might critique my research, complain about my questions, sigh because I have wasted their time, or, worse, just leave during the interview. Online questionnaires seemed much easier: there is no talking required, in person or on the phone. Email and forum correspondence can be deliberated on, so my answers are measured; I do not have to leave my office; and I do not have to face the disappointment of bored participants. However, I fear that online questionnaires can be seen as a cop-out, an easy alternative to a more robust and detailed personal interview and so my adequacy as a researcher may be questioned. I do believe interviews to be a critical element in my research and, despite my fears, I have never had anything but a positive reaction from interviewees. Reflections on research processes are, of course, nothing new. Feminist geographers such as Rose (1997) have reflected on issues of positionality and power relationships

between researcher and researched, while Laurier and Parr (2000) have reflected on the emotional experience, particularly anxiety, of interviewing for the researcher. Although my research comes with interesting researcher/researched relationships and dynamics due to my also being a PWD⁵⁰ (see Valentine 2002, for a similar account with regards sexuality), these dynamics were not the most anxious aspects of conducting online questionnaires.

As part of a polite and ethical approach, I contacted the website moderators first with a sample of my questionnaire, asking for their approval to post it on their forums. While none rejected this request, there were many from whom there was no reply, which left me in limbo, wondering: is it rude to send a reminder? But maybe they never received the original message. Do I just send the original message again? But is this not also potentially rude? Or do I just write-off this website and lose a potential cohort of responses? My worst fears were not realised, and most of the ‘big’ forums – the ones that are well frequented by users – responded positively to my requests while the ones that did not respond were less frequented with infrequent moderation and upkeep. A tension still exists in establishing contact with a forum moderator for the first time: without my body to express gratitude as I would do in an interview, with smiles and eye contact and an interested pose, it is hard to know how to make a good first impression. In the first message to moderators (appendix 2), I tried to be formal and professional but at the same time relaxed in order to encourage a dialogue. With the questionnaire approved by the moderators, I moved on to contact the website users themselves through the first forum post (which contained a link to the questionnaire, see appendix 3). After posting this on the forums, I felt that my research and my questionnaire were now exposed to critique and judgement.

I myself felt vulnerable: I had not contacted an individual or even a few people or a small group, I had put myself out there where so many people could read my message, *google* my University profile and judge my legitimacy as a researcher. I felt the same sensations of butterflies in my stomach as I would were I about to conduct a face-to-face interview. To deal with this I simply turned away and started work on something else, hoping that, while I was working, the responses would roll in. When I went back to check, the very first response was a worst fear realised: a negative

⁵⁰ This is something I will reflect upon more, in the interview section, where the researcher/researched relationship is more embodied and close.

review of my research and questions. The answer to the final questions about what the respondent thought of the questionnaire were:

Far too long and pointless ... It's dreadful and a 5-year-old could have worded it better (Elliot)⁵¹.

This was disheartening and, although at the time I was able to put it into perspective and knew that not all responses would be like this (when I first read this message it was one of only two received at that point), I was now convinced that there was something wrong with the questionnaire, the wording of the questions, the sheer length or just the general topic, as this respondent also wrote the opening quote of this chapter in answer to a previous question⁵².

Fortunately of all the 127 responses to the questionnaire that I received, this is the only overtly negative feedback. Although many of the responses are only a few words, none are so openly critical. In fact, most of the responses are positive, with people reflecting on the usual surveys and questionnaires that are posted on forums that ask only closed questions and restrict answers:

Better questions than 99% of the people who try to do surveys about diabetic stuff (Annette).

I have filled in so many terribly designed diabetes questionnaires, that yours was a pleasure to fill in – didn't force me to select answers that were inappropriate, or ask questions that led me to respond in a particular way. I congratulate you on designing a proper questionnaire and hope you find the analysis interesting (Rachel).

There were many responses such as this, along with others, which suggested different questions I could ask, indicating that the questionnaire was thought provoking and legitimate. It was not all sunshine and daisies, of course, for, while there were no other negative responses, there were still some critiques:

Sometimes I feel the expectations were of negative responses (Shirley).

⁵¹ All names used for questionnaire respondents and interview participants are pseudonyms.

⁵² The following four empirical chapters all begin with quotes taken from Elliot's brief response. The quotes give a somewhat scathing review of my research but also, I feel, to an extent characterise the discussion and arguments in each chapter. Their usage also reflects my own co-opting of my first bad review, in a way repaying a bad review to Elliot by demonstrating how poignant his or her responses actually are.

It is a bit long and if, like me, other diabetics can't quite think what exactly to put in answer to the questions they will probably give up and you will miss out (Brian).

The benefit of such responses is that they help to inform future versions of the questionnaire and my interview guide. Such responses may not be achieved during the interview process as, while I fear that interviewees may be unhappy with the interview questions, they may not want to be rude or insult me, and so will not necessarily feedback any constructive criticism. The anonymity of online questionnaires makes truthful reflections more likely, allowing me to tinker with the questionnaire and also reconsider and improve the questions, which in turn permitted me to improve my interview questions, which in most cases are similar to the questionnaire.

The main drawback of the questionnaire method was having no opportunity to investigate further the answers of respondents. Many research projects will initially carry out questionnaires, whether online or through other means such as postal, and then take a sample of respondents as a source for follow-up interviews. I did not initially build such a mechanism into my questionnaire design. Admittedly, this was, in part, an oversight on my behalf. I also felt that for the questionnaire to be truly anonymous, people would feel uncomfortable if asked for real names or email addresses, essential for a follow-up. I knew that I would be doing interviews in the not too distant future, and already had in place strategies for recruiting interviewees, from support groups and DAFNE, so did not want to overwhelm myself with data. The questionnaire respondents also hail from around the UK (and potentially beyond) and so follow-up interviews may not have been suitable anyway. This said, some questionnaire respondents did identify themselves to me and in some cases I followed up with email questions⁵³. This all meant that many of my questionnaire responses hinted at interesting and sometimes profound experiences of living with diabetes, without necessarily revealing what these experiences entail. For instance, here is an excerpt from Edna's questionnaire 'transcript':

⁵³ I also attended a 'forum meet-up' – where members of one forum arrange to meet as a group periodically – in Glasgow early on in my fieldwork period, and there met many users from one of the forums. However, I did not attempt to identify anybody who may have responded to my questionnaire and neither did anyone identify themselves to me as a respondent. I was attending as an overt researcher but also as a local PWD. It had also been suggested to me by one of the forum moderators, who was also in attendance, that the attendees might not appreciate an overt researcher, so I did not attempt to recruit participants at this meeting.

Question 13: How do other people react to your use of diabetes management equipment such as needles and blood sugar testing equipment?

Answer: They don't see it ...

This is Edna's complete answer to this question, in which the ellipses are an original part. In a synchronous method or a method with a follow-up option, I would have been able to ask Edna what she meant by this fragmentary remark, since it suggests something of a hidden geography of diabetes which so interests me. Her ellipses imply that she does have more to say, and perhaps she was thinking of an example when she wrote this answer but could not write it down because of the aforementioned length of the questionnaire. Conversely, her use of ellipses might have been insignificant. My questionnaire responses are littered with such 'missed moments', as I call them, but fortunately many responses supplied more detail; and in the next section I will explain how I analysed and incorporated the questionnaire results into my arguments.

ANALYSIS

I manually coded all my questionnaire and interview data, according to a combination of 'etic' and 'emic' themes (Crang and Cook 2007) and, because I treated questionnaire and interview transcripts in the same way, I will discuss coding in the following section after explaining my use of interviews. That said, there are some specific points about the questionnaire analysis that I want to discuss. I mentioned before that the responses to the questionnaire varied in length and detail. Indeed, there were 18 of 127 total responses that I wrote-off for analysis because the respondents only answered the first few questions on age, sex and type of diabetes. There were also many people who wrote short, often one or two sentence answers to many of the questions⁵⁴. While these short answers initially seemed disheartening, when considered together short answers to the same question provide a good illustration of general themes. For instance, in response to the question: *Do you feel that having*

⁵⁴ Before coding my questionnaire responses I divided them into categories defined by length. I did this to gauge the amount of text to work through, as well as establishing a crude hierarchy based on the assumption that longer responses held more value than shorter ones. This proved not necessarily to be the case as long responses can go far off-topic while short responses can be succinctly insightful. Although this *was* the case for the exceptionally short responses that only answered age, sex and type of diabetes. My evaluation of length was based on a quick initial skim of a whole individual response. I classified 33 as 'long', 52 as 'medium', 24 as 'short' and 18 as 'no use'.

diabetes has impacted on your identity?, many responses indicated that diabetes has become a large part of their identity, overshadowing other aspects:

Yes, I'm a 'diabetic' first, then a person (Haylee).

Yes. I feel differently. I am asthmatic and that now takes second place to the diabetes (Laurel).

The other side was also evident in many of the responses, indicating that diabetes, while constitutive of identity, was not overpowering:

It doesn't define me, but it is part of me and my identity (Regina).

I refuse to let that happen, I won't be defined by a disease (Carly).

These answers have been edited by me, for spelling and grammar, but still represent the whole response given to this question. One sentence seems inadequate to take seriously as qualitative data, but, when considered alongside other responses of similar length, different categories relating to the role that diabetes plays in identities and senses of self emerge. Such varying degrees of self-identity as 'diabetic' are discussed throughout my empirical chapters, particularly with reference to the ideas of discursive and routine recessions. The answers to the questions were not intended to be subject to a quantitative analysis but, in Chapter 5, I have sought to categorise the answers to this question on identity. I did not make this question a closed question where respondents tick one category, and so I discerned four different categories of response: **Yes – positive** impacts; **No** – no impacts; **Inbetween** – mixed positive and negative impacts and **Yes – negative** impacts. In discerning these categories I had to make certain judgement calls about the content of people's responses, but I feel that all the responses fall within one of these four categories.

Even shorter responses were also helpful. I was initially dismayed at the amount of answers that were simply 'yes' or 'no', explained by the fact that my questions could simply be answered this way and the sheer length of my questionnaire, which understandably put off a few people. Even if just answering 'yes' or 'no' to the questions, the whole questionnaire would still take about ten minutes to complete, but these brief responses were certainly not to be discarded. Figure 8 shows how I would have seen a series of responses to a question asking if other people understand the management of the condition.

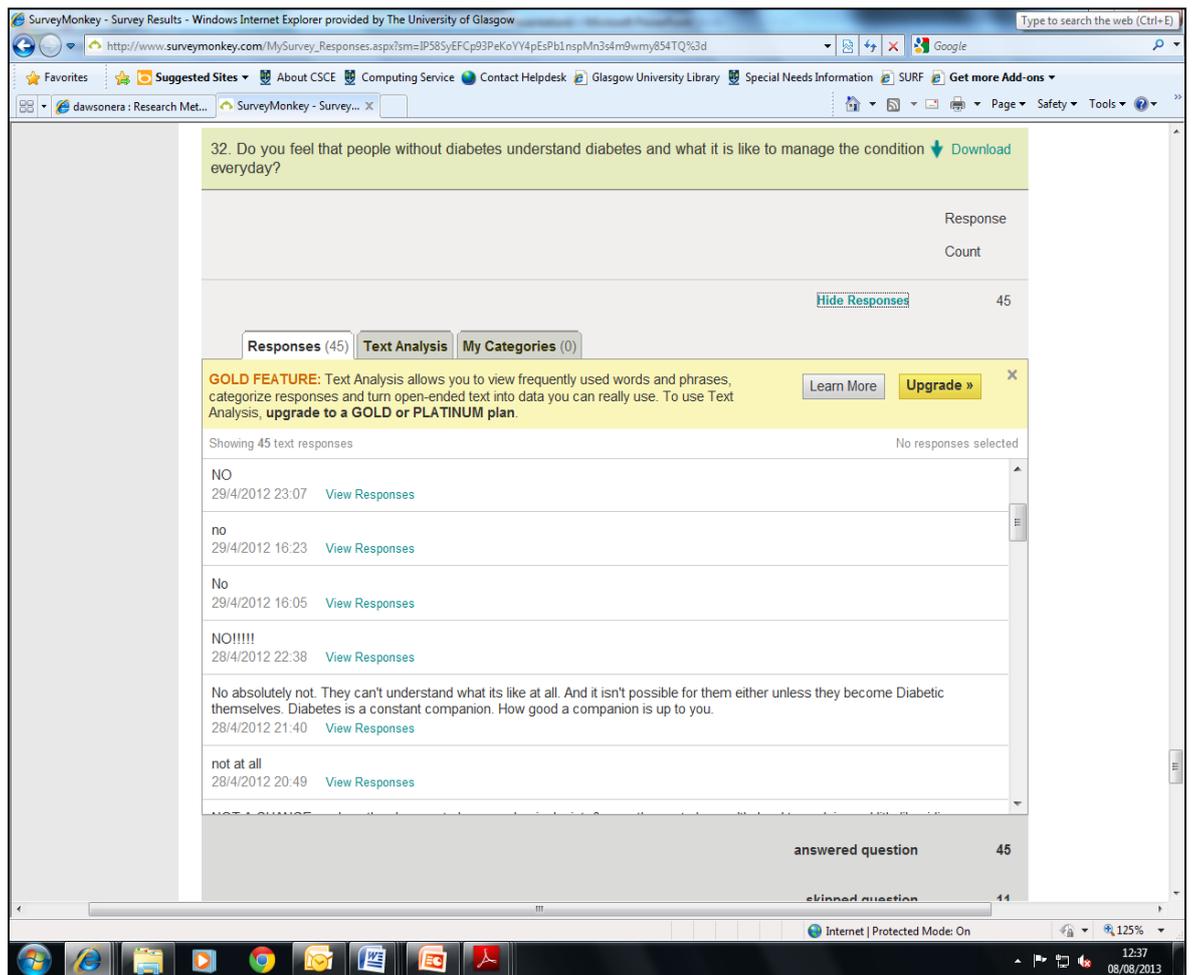


Figure 8. A screenshot from my *surveymonkey* account demonstrating a ‘citational effect’ of many of the questionnaire responses.

When first seeing these responses, it was as if four separate people had said ‘no’ to me in quick succession in different voices and tones, an affect provided by the different structure of all four ‘nos’. Curti (2009) writes that film subtitles can create an affective experience for the viewer, when they are presented in unconventional forms, such as varying fonts, fading, blurring and so on. The different formats of the ‘nos’ and the fact that they were the first four successive responses certainly stood out for me. This was even more resounding in that the fifth answer served to slow down the rapid ‘nos’ and provide some elaboration. This created a citational effect for me as I read through the answers, making me realise that, although I was initially disheartened, these short responses can be greater than the sum of their parts when considered together. Of course many responses were also considerably longer and detailed, and, as previously mentioned, many respondents took pleasure in completing

such an open-ended questionnaire. I believe, therefore, that my text-heavy questionnaire was a good choice for data collection. Throughout the thesis I will often use multiple short quotes from various questionnaire respondents to demonstrate this citational effect and reinforce certain points, providing a contextual framing to more detailed accounts from questionnaire respondents and interviewees.

SEMI-STRUCTURED INTERVIEWS

OUTLINE OF METHOD

Crang (2003: 496) observes that semi-structured interviews have become “de rigueur” for qualitative human geography. However, he also acknowledges the limitations of this method, arguing that: “the solid grounding of qualitative fieldwork in the engaged reality of people’s lived experience seems coupled to a focus upon verbal methods that paradoxically means qualitative work tends to produce very wordy worlds” (ibid: 501). He suggests a need to, “push further into the felt, touched and embodied constitution of knowledge”. Many geographers have effectively responded to this call. For instance Lea (2008) describes paying attention to bodies during interviews, including gestures, expressions and sighs. Meanwhile Longhurst et al (2008: 212-213) comment on the many ways the bodies of both researcher and researched is implicated in the research process with one author reflecting that her awareness of others’ bodies was heightened when others mixed sweet and non-sweet dishes on the same plate: “she became attuned to others’ reactions, such as a crinkling of the nose, a screwing up of the face and turning away from the plate”. Such approaches are attempting to move ‘outside the text’, as Crang (2005) would suggest, to move beyond the representational problems of *mere* quotations.

While I think there is much that is non-representational about life with diabetes – and at times in the thesis I touch on such aspects, maybe where participants found words unsuitable for their expression⁵⁵ – such a methodological approach does not serve well my aim of challenging the brightsiding and silencing of life with diabetes, thus I *do* wish to forefront the verbal and written accounts of PWD in my

⁵⁵ I take some insight from Lorimer (2008: 556), who writes that “NRT [non-representational theory] works best as a background hum, asking questions of style, form, technique and method, and ushering in experimental kinds of response”.

research and analysis. I prefer to follow Hitchings' (2012) lead where he argues that the traditional qualitative interview should not be considered inappropriate when researching everyday practices, even if such practices have become so ingrained in people's lives that they no longer think about or reflect upon them. Hitchings comments on two other studies previously conducted in which he and his co-authors had asked people about some of their mundane unreflected everyday practices. He found that people were indeed able to talk about subjects which initially seemed so unimportant or uninteresting to themselves. Many of my interviewees (and questionnaire respondents) told me that they rarely talk (or write) about diabetes as much as they did with me in the course of my research. As I will go on to discuss, my own diagnosis with diabetes gave me an 'in' with my participants, allowing an immediate rapport to be created in many instances, which tapped the ability of interviewees to talk about these mundane aspects of living with diabetes in a manner perhaps less likely had the interviewer not faced similar experiences him/herself. Even so, the same 'in' may, at times, have also obscured some aspects of living with diabetes that are taken for granted by *both* myself and my participants.

DESIGN AND IMPLEMENTATION

There were 41 individual interview participants. I conducted one double interview, during which two participants (mother and son) were interviewed at the same time. Therefore I consider this encounter as one interview, of two participants⁵⁶. I interviewed two participants (a married couple, Steven and Allison who we shall hear from later), separately, but during one continuous phone interview. Therefore I have considered this encounter as two separate interviews and two separate encounters. I originally intended to conduct follow-up interviews with participants to gauge any changing attitudes. I conducted three follow-up interviews which did not elicit any new data. For this reason, along with having already gathered a considerably large data-set (of both interviews and questionnaire responses), I decided not to pursue further follow-up interviews. Therefore there were 43 interview encounters (40 separate interviews of 41 participants and three follow-up interviews).

⁵⁶ I have not used data from this double interview in the thesis.

Face-to-face interviews and telephone interviews involve different embodied encounters. Face-to-face participants and myself as a researcher may have been put at ease with each other through non-verbal communication (such as smiling and making eye contact). Telephone discussions do not allow the same embodiment and perhaps this impacts on the data that emerges. This difference may explain why some telephone interviews were not as in-depth (for example: Maureen and Linda). However in other telephone interviews participants seemed more than happy to discuss intimate aspects of their life (for example: Arthur and Sheila). As I have concentrated on a thematic analysis of transcripts I have chosen not to distinguish between these two types of interview during the subsequent analysis.

The interviewees were recruited in one of three ways: through their attendance and encountering of my request for participants at a diabetes education course (DAFNE); through their involvement with one of two diabetes support groups in Glasgow; or through a third recruitment method that I call 'friends with diabetes'. I have found that, when discussing my research with the various people who I meet in life, friends, family, colleagues and acquaintances, many of them have some form of story about someone they know who has diabetes. In many instances, this has led to me obtaining contact details and arranging an interview. I believe that this three-pronged approach has left me with a suitably *illustrative* cohort of PWD living in Glasgow. Considering most interviewees are motivated to discuss their condition, given their interest in education courses and support groups, they are arguably not *representative* of PWD in Glasgow⁵⁷.

Potential interviewees were given an introductory letter (appendix 4) and information sheet (appendix 5) by myself, by gatekeepers within the support groups or by members of the DAFNE team. This information sheet explained what the research was about and why they were being invited to participate. Collaboration with the DAFNE operators meant that much of my research has been something of a co-production as interviews with DAFNE participants are, in part, intended to provide a critical evaluation of the course. The support groups also agreed to include a request for interviewees in their newsletters. It was then up to PWD to decide whether they

⁵⁷ There are just over 60,000 PWD (all types) registered with the Greater Glasgow and Clyde NHS board at the end of 2013 (SDS 2013). Therefore I cannot claim that my sample of 41 interview participants is representational of the overall population of PWD in Glasgow, the UK, or elsewhere (in terms of age, sex, gender, class and so on). The same holds true for my sample of 127 questionnaire respondents.

wanted to contact me for further details or to arrange an interview. Participants were asked to sign two copies of a consent form (appendix 6), one to be kept by me and the other given to the participant for their own records (although no participants chose to keep a copy). I indicated on the information sheets that the interviews could be conducted at a time and place of the participant's convenience, so that potential participants would feel comfortable wherever the interview took place. Many chose to invite me to their homes, while others suggested coffee shops or cafés that were convenient for them to meet. I also conducted one interview in a private room at the University of Glasgow. A number of other people were keen to participate, but for various reasons (location, work times, family responsibilities) it was difficult to arrange to meet for an interview. For most of these people, I was able to arrange a telephone interview. Ten interviews were done by telephone.

The sampling for my methods was not targeted at any specific group of PWD in Glasgow, in the same way that previous research into the lifeworlds of PWD has been (as Balfe 2005 focused on university students or Lawton et al 2007 on ethnicity). I have cast my net wider, intending to discover some of the common issues of living with diabetes regardless of age, sex, ethnicity and socio-economic status. My ethics approvals did not permit me to interview people under the age of eighteen, so my sample is restricted only to adults. As with the online questionnaire respondents the majority of interviewees are female: 23 female to 18 male (see appendix 8). This dominance of female responses may be because women feel more comfortable talking about personal illness. For instance, in her study of teenagers with asthma or diabetes, Williams (2000) found that girls incorporated illness into their everyday social lives and were more likely to talk about it, while the boys attempted to conceal illness as they found it threatening to their masculine identities. Most of my interviewees reflected a white, working/middle class cross section of the Glasgow population. This is quite a limited sample, due to the prevalence of diabetes in non-white populations in Glasgow and the differing beliefs in causation factors as rooted in cultural differences (Lawton et al 2007; Lawton et al 2008a). Recruiting interviewees from both the DAFNE courses and support groups also meant that most of my interviewees were already motivated to talk about diabetes in their day-to-day lives. This meant that I did not talk to PWD who were truly experiencing a routine recession, for such PWD would have been unlikely to attend DAFNE or the support groups and, even if they did, would be even more unlikely to want to talk to me. That said, I felt that some

of my interviewees, recruited from a DAFNE course agreed to the interview out of a sense of obligation as we had conversed during the course. These interviewees rarely elaborated on their short answers, and had little to say about diabetes when I prompted them to speak more. Also the aforementioned first response to my questionnaire, seems to come from someone who is experiencing a routine recession, and so reacted with annoyance and anger to my questions.

Although my interviews were intended to be open and to allow participants to speak about any aspects of diabetes of concern to them, the interviews were semi-structured and so I went into every interview with a question guide (see appendix 7). Like Peterson (2011), who reflects on her anxiety of carrying out interviews, these questions provided me with some safety: if the interview turned out to be difficult or awkward, I could fall back on my question list rather than be left fumbling for something to say. This list was useful for the interviewees who experienced their diabetes as a routine recession as they often answered questions brusquely, waiting for me to ask further questions rather than volunteering any information themselves. The interview guide consists of a list of specifically worded interview questions followed by a list of themes with multiple reminder words attached. Dunn (2005) remarks that this combination of a more structured schedule and a less structured guide allows a strong semi-structured interview technique where fully worded questions provide confidence, for the interviewer, and the themes provide prompts and suggestions for secondary questions to be composed on the spot.

POSITIONALITY

Stuckey (2007) describes how, like me, her own interest in researching the qualitative elements of living with diabetes stemmed from her own diagnosis. Her 2007 thesis, completed as part of a degree of doctor of education, provides a useful example of how to integrate one's own autobiography and experiences into academic work by treating yourself as researcher and participant simultaneously. Stuckey seeks to discover how creativity, such as drawing, photography, sculpting and crafting, can help PWD express their experiences and how diabetes educators may incorporate aspects of creativity into treatment practices. Specifically, she asked a focus group of women with type 1 diabetes to meditate and to think upon their condition before

drawing the first shape that came to mind. The series of images produced were then discussed by the group. Stuckey (2007: 223-224) reflects on this method:

Explaining how they felt about diabetes was difficult for all participants. It challenged them to think about how diabetes made them feel, after years of not being ‘allowed’ to feel or think about diabetes. It was hard for one woman to verbalise her feelings about her image, and the way diabetes caused problems in her life ... Another woman commented that it was challenging to put diabetes in words.

Stuckey effectively encounters the discursive recession of diabetes, supporting the idea that talking about diabetes honestly is somehow not “allowed”. It also supports those geographers who insist that conventional methods are increasingly unsuitable for researching everyday practices, for Stuckey’s participants indicate that there is something non-representational about living with diabetes. Stuckey’s thesis nonetheless suggests that it is not only the suppression of diabetes and its denial as a serious disease by wider society that leads to people’s inability to talk about it, but also how traditional biomedical treatment practices do not give enough focus to the affective and emotional experiences of PWD. In writing her own experiences into her thesis, Stuckey continually reflects on her role as both researcher and participant, insider and outsider. She (ibid: 341-342) discusses how she would, like her participants, bring her own specific understandings and interpretations of the drawings and photographs produced:

Each participant’s creative photographs felt like what diabetes is to me, and I bring my own sense of meaning to the images. Diabetes is a broken heart⁵⁸, filled with pieces of diabetes complications, hurt for the way in which I did not take care of myself when I was younger, feelings of being a little girl, afraid and alone. Diabetes is like Ms. Potato Head because my thyroid is not regulated, and there are times when I feel fat and irritable, but I put on a happy face and say, ‘everything is fine’. Diabetes is like a one-way ticket, not allowing me the freedom to escape from it, or to take a break. It is always there ... These images have added to my understanding of diabetes, and the process has strengthened my love for creativity.

Stuckey was never close to being an objective researcher; instead each of the images that her participants produced greatly affected her and allowed her to reflect deeper

⁵⁸ The things to which she compares diabetes are based on pictures drawn by her research participants.

on her own personal experiences with diabetes, as well as upon her experiences as an academic researcher (of diabetes).

In academic geography, Moss (2001: 3) describes why she uses her own experiences of chronic fatigue syndrome in her writing:

In much the same way that I have used the stories of the women I have talked to over the years, I have decided to use myself as a source of information. It was not so much to compare my life with theirs; rather, it was more to juxtapose mine with theirs, in a more collective sense, not point-by-point, oppression by oppression. I wanted to use my experiences the way I used theirs – to elaborate empirical links with concepts, to contribute to critically informed uses of the individual in political economy studies, and to shed light on the dearth of feminist analyses of materiality (both economy and matter-based) in geography.

Beginning my research, back in 2011, I thought that, by juxtaposing my own experiences of diabetes with others' testimonies, I would be able to relate to and empathise with my participants, allowing myself, the researcher, to become more personally involved. Remaining open to such introjection, as Bondi (2005: 71-72) writes, allows interviewers to be:

Emotionally present, and allows the interviewee's material to trigger feelings, whether of sadness, joy, anger, fear, protectiveness, disgust or whatever. At the same time, the interviewer sustains the capacity to think about these responses, and is not incapacitated by them ... The interviewer may identify with the interviewee in the sense of imaginatively taking the part of the interviewee within the incident, but without losing hold of the fact that this was the interviewee's experience rather than his or her own.

Pile (2010b: 488) issues a warning about establishing a close rapport while encouraging the co-production of knowledge, as such a rapport:

Raises familiar anxieties about how far the researcher might be unconsciously complicit in soliciting material from the researched that confirms the researcher's expectations and, more, that pleases them both – precisely because it seems intimate and rings true.

Pile (ibid: 493) proposes that human geographers should consider how to “manage the space between the researcher and the researched”, and, “to see the emotional dynamics underlying any research situation, you'll need appropriate distance: a (conditional) balance of intimacy and distance”. I certainly found achieving this balance difficult when conducting interviews, and my theory of being able to relate

instantly, empathise, be respected and even trusted was challenged at times during my interviews.

I first realised this difficulty after transcribing my first interview. As I listened through the audio, I began to question my effectiveness as a researcher: I cringed at my rapid, nervous speech, and I was displeased at my ‘missed moments’ for probing George’s (my first interviewee) answers further. I talked about myself a lot, a nervous attempt to establish this empathy and rapport, trying to relate to George and to demonstrate that I too live with diabetes every day. Parts of the transcript have me dominating the conversation. Much as when the first response to my online questionnaire seemed like a disheartening failure, my first interview proved also to unsettle me. While initially frustrated that the transcript emerging from this interview was not fitting my (misguided) ideals, I now realise that it highlights an important point regarding my methods. Rose (1997: 313) writes about the limitations of researchers seeking to be truly reflective, arguing that:

In the reflective landscape of power, the relationship between researcher and researched can only be mapped in one of two ways: either as a relationship of difference, articulated through an objectifying distance; or as a relationship of sameness, understood as the researcher and researched being in the same position. The contradiction is that the latter is impossible while the former is unacceptable.

I do not think that in this interview there was an unacceptable “relationship of difference”. It was clear that George and I could talk about our practices in a more conversational way than might occur in a more typical research interview, with greater contribution from the interviewee than from the interviewer. There was something of a “relationship of sameness” in that there was a lack, at times, of a clear researcher/researched power relation. Of course, as Rose would argue, and to which I agree, there can be no complete absence of a power relation: I still have a research agenda, and I still left the interview to transcribe and then analyse George’s responses. George meanwhile may have not given much further thought to the interview or my research⁵⁹.

Rose (ibid: 313) considers a sense of “betweenness” as a possible alternative to these extreme poles of difference and sameness, proposing that:

⁵⁹ Although, as it happens, I did conduct a follow-up interview with George, and he remains interested in my research through email contact.

The feminist task becomes less one of mapping difference – assuming a visible landscape of power with relations between positions ones of distance between distinctly separate agents – and more one of asking how difference is constituted, of tracing its destabilising emergence during the research process itself.

‘A sense of betweenness’ adequately describes my interview experience with George. While a difference will always remain, there is a clear sense of sameness between us that helps to produce the interview. England (1994) remarks that, due to polarities between herself and her research subjects on a particular project, she considered the research to be a failure, believing that the seeming reluctance of research participants to contact her was due to a problem of her not being able to relate. She considers a researcher’s own biography as inevitably influencing the research encounter, thereby influencing the information gathered. I do not share reservations similar to England’s for my own research. Instead, I enjoyed a particular positionality when conducting these interviews as both a researcher out to gather/analyse people’s experiences of diabetes, but never ceasing to be a PWD myself, able to slip between the researcher/PWD binary without ever abandoning or fully adopting either. An excerpt from my interview with Cheryl highlights how this positionality helped to establish rapport in interviews – especially in later interviews when I understood this positionality better – as we were able to joke about our shared experience of over-reacting to a sore foot and the subsequent panicky blood test to ensure that everything was really okay:

Mark: It [having diabetes] almost makes you a bit paranoid ... every time my feet hurt I’m like, oh my god!

Cheryl: I’m going to lose my toe!

Mark: I need to check my blood sugars!

Cheryl: Have I got ketones!?⁶⁰

I do not advocate that only a PWD can research PWD. This sense of familiarity that I experienced with some of my interviewees may also have led to me ‘missing moments’ to probe for deeper responses. While the ‘missed moments’ of my

⁶⁰ Ketones are an acid that occur in the body’s blood stream if blood sugar levels are high. Therefore detecting high levels of ketones signifies the possible onset of DKA.

questionnaires were a flaw in the execution of the method, those of my interviews were perhaps a ‘flaw’ of my positionality. For instance, during my interview with Steven, he talked about the advantage of his wife, Allison, also being a PWD, so that there is “a bit extra care ... if one or the other of us is in trouble the other can help out”. Although I did immediately ask further questions about being a PWD living with and married to another PWD, I footnoted this section in my transcript, reflecting that it would have been relevant to ask Steven how this extra care manifests, calling perhaps for an example. I muse in my transcript footnote that perhaps I did not ask such a good follow-up question because I assume I know, personally (and perhaps unconsciously), what types of extra care would benefit a PWD, so that at the time of the interview it did not cross my mind to ask. An interviewer without diabetes might have been more ‘switched on’ in the same situation, more aware of getting people to talk about the everyday practices that Hitchings (2012) argues are still accessible through interviews. Such an interviewer may have asked Steven to explain what he meant by ‘care’ or by the ‘trouble’ that he or his wife could experience. Such a minutiae of life with diabetes is not always evident in my data, then, and some mundane parts of being a PWD have maybe been lost because of the ‘relationship of sameness’ between myself and participants. That said, it was this same relationship that enabled me to arrange many interviews in the first place: many of my participants were intrigued about my research, precisely because I acknowledged on information sheets and introductory letters that I also have diabetes.

This ‘relationship of sameness’ presented other anxieties. Proudfoot (2010) notes that difficulty in eliciting ‘good’ (as in detailed and emotionally rich) responses from his interviewees may have stemmed from his lack of empathy with the soccer fans who were his potential participants. He reflects on an awkwardness which arose from his asking questions that were “naïve” and had “obvious” answers (ibid: 514). One theme emerging from the literature review of PWD studies is that the disease is often downplayed, made to seem easy and manageable, possibly so that markers of difference are not evident. By asking people direct questions about diabetes being difficult, affecting their work, family and social life, may have caused participants to respond with annoyance and discomfort, as people feel that I am leading my research to negative and cynical answers about life with diabetes (as Shirley’s earlier critique of my questionnaire suggests). Although I did not encounter any direct experience of this concern during the interviews, I did encounter a few examples at other times.

When I was visiting a friend's house I began talking with his father, and after telling him that I was studying diabetes, he told me that he has type 2 diabetes. He asked me what area of diabetes I was researching and I told him about my interest in the everyday, emotional, geographical experience. He seemed to dismiss the importance of this focus, telling me that he had never reflected on the emotional experience of diabetes and that it is something he simply 'gets on with'. He regarded his diabetes 'clinically', suggesting that the emotional experience of diabetes is excluded from such regard and he suggested that it would be more beneficial to look into the effectiveness of medications or matters of epidemiology. While none of my interviewees reacted in this way, as they would have been unlikely to agree to an interview in the first place, my experience with the first questionnaire respondent made me fear that it was possible. Elliot reacted to some of my questions in the same way that Proudfoot's respondents did, remarking on the question's naivety. For instance, in response to the question about what places are safe for hypos, Elliot responds: "plonker of a question again. All you do is eat a couple of sweets to solve the problem. What has safe got to do with it?"

The aggressiveness that Proudfoot encountered is echoed by the interview experience of Bjerke (2010), who noted that, when interviewing someone about approaches to participation in Alcoholics Anonymous (AA) programmes, his own personal experiences and opinions, of being a recovering alcoholic, conflicted sharply with those of his interviewee. The interviewee regarded frequent attendance as essential to staying sober, while Bjerke preferred to use his own personal methods rather than accept a regimented framework. He (ibid: 1721) notes that:

After some time ... the questions [asked to Bjerke by the interviewee] started to become more and more unpleasant. The whole focus of the interview was on me. I felt that I had to defend and legitimate my choices, and eventually it felt as though he had me 'nailed to the wall' with his arguments. I was really on the defensive.

As I started my fieldwork I was wary that such situations might occur: many PWD take different approaches to management – for instance some test blood sugars many times a day, before and after meals, while others may take a more relaxed approach, sometimes going several days without testing blood sugars. My self-management practices did sometimes differ from those of my participants. I was surprised, for instance, when one interviewee, Hayden, told me that, when he refers to 'carb

counting', he means his practice of taking a set amount of insulin for a meal and then eating a fixed amount of carbohydrates to match that amount. This contrasted with what I do, which is counting the carbohydrates in a meal and then taking a corresponding amount of insulin. To me, Hayden's routine seems restrictive and unenjoyable, compared to my own DAFNEesque⁶¹ regime. He also expressed his cynicism about the DAFNE courses (he had not attended one and is unlikely ever to do so), commenting that PWD he had known who, having completed a DAFNE course, had seemingly lost control of their diabetes, given that they could now eat what and when they wanted (and so had put on a lot of weight). Of course, gaining weight could be a sign of improving glycaemic control (weight loss is a symptom of consistent hyperglycaemia) and indeed of improving emotional health as PWD enjoy a more varied diet.

I was wary that, when talking with participants, I might inadvertently suggest that my practices are more relaxed or strict (possibly perceived as better or worse) than their own. While I predicted that my own experiences of having type 1 diabetes would benefit me in establishing a rapport with interviewees, I began to realise that it might also present possibilities for conflict and disagreement over the very personal issue of the self-management of one's health. I also became aware that my aim, to tease out the experiences of everyday life with diabetes, might also present possible conflict as people disagree upon the extent of interference that diabetes could and should cause in one's life. As it happened, no incidents of conflict occurred and I felt comfortable with all of my interviewees. There were times, with Hayden for example, where I could have attempted to explain the DAFNE course better, but felt that it could be interpreted by Hayden as me criticising his practices and knowledge of diabetes; and so I did not, thereby avoiding Bjerke's situation.

ANALYSIS

I analysed my questionnaire data and interview data through the same basic process. My questionnaire data was easier to analyse as the responses came written and so there was no transcription required, excepting spelling and grammatical correction,

⁶¹ I write 'DAFNEesque' as I do not rigidly follow DAFNE guidelines, but do adhere to their overall suggestion to develop a personalised approach to self-management within a framework of guidelines. Indeed, DAFNE operators rarely refer to 'rules' and instead say 'guidelines' to emphasise this point.

but I transcribed all 41 of my interviews verbatim. I conducted my analysis thematically, prioritising the content of my data ahead of other verbal moments, such as ‘ums’ and ‘ems’. The sheer amount of audio to be transcribed, solely by myself, in large part made this choice for me as it would have taken too long otherwise⁶². To attend closely to the ‘narrative’ and complete a conversation analysis (Wiles et al 2005) of each and every transcript would have taken even longer, if analysing the significance of every ‘um’, ‘err’, pause and stutter. While an analysis sensitive to this level of conversation might have revealed interesting results, I could not have given the same level of attention to every transcript and so chose to prioritise a thematic analysis. I also chose not to represent the different accents of my participants. Some of my interviewees had strong Glasgow/west coast of Scotland accents. These accents are often laden with cultural and social meanings, which, while significant, are not the focus of my thesis research. For the most part, the accents have been homogenised but there remains some Glasgow vernacular such as ‘wee’ for small or ‘jags’ for injections, which I feel serve to localise the research with a modicum of the local cultural and social connotation. Key biographical details of my participants can be found in appendix 8⁶³.

I started by coding both the questionnaire data and the interview transcripts together on paper, extracting themes and connections which I wrote up into a coding ‘guide’. I updated and reproduced this coding guide multiple times until clear themes such as TIM, everyday spaces, everyday anxieties, stigma, surveillance and so on started to emerge (appendix 9 provides an example of the first version of this coding guide). By the thirteenth iteration of this guide, produced after 24 interviews, the data had reached a saturation point, where no new significant themes were emerging as I continued to analyse and code the interviews. I then used this final version of the coding guide to analyse the questionnaire responses. The only significant new themes to emerge from the questionnaire responses concerned the particularities of online community. These themes formed the basis of my empirical chapters. Later in the analysis process, I used Nvivo. By entering my questionnaire data and interview transcripts, and using my final coding guide to code and sort data in Nvivo, I could see all the ‘raw text’ instance of one code on one page. It also provided a cumulative

⁶² I did attempt such a conversation analysis with some of my earlier interviews but it consumed far too much time.

⁶³ The table is too large to be included in the chapter.

record of the most coded ‘nodes’ (Nvivo’s terminology for themes or categories). Nvivo was used as a secondary analysis tool, my primary analysis occurred on paper (appendix 10 provides an example of my Nvivo coding).

ADDITIONAL RESEARCH

Although the questionnaire and interview data form the heart of my data collection, I used a variety of other methods for support. Before carrying out my own primary data collection, I conducted a review of some autobiographies and memoirs written by PWD, in which their lives with diabetes were the major topic. This review was important for giving me ideas about life with diabetes, and so helped to inform my questions for the questionnaire and interviews. Some of these publications have been discussed already in the previous chapter, and will be revisited in the following chapter. Their use is intended to be illustrative, with certain quotes chosen chiefly for their ‘literary’ impact. In Chapter 5, the data derives from a ‘mixed methods’ approach, as I refer to questionnaire and interview data alongside the autobiographical data. As the chapter progresses, I also introduce two online bloggers, whose blog entries, including sketches of the space-in-body of PWD, caught my interest early in the research process. I was able to contact these bloggers and conduct email interviews with them, as we sent questions and answers back and forth (I received their permission to use images from their websites and our correspondence in the thesis). In Chapter 5, I also use some data from an online diabetes publication called *diaTribe*. I did not carry out a full review of this publication, but was alerted to certain articles that helped to support my arguments in this chapter. Following Chapter 5, the other three empirical chapters prioritise my own primary data, almost exclusively, with any other sources being considered an illustrative assist.

At times during my research I also found myself doing something of a participant observation. For instance, during the summer 2012, I attended a DAFNE course, at a Glasgow hospital, in an official ‘observer’ capacity. My NHS collaborators encouraged me to attend so that I may be able to understand the day-to-day running of the course. I went to the course for all of the five days, and found it a surreal experience. It was made clear to me at the start of the course that I had a ‘non-participatory’ role in that I was not supposed to take part in any of the exercises and discussion. It was also made clear that I was not there to observe the participants but

rather the running, structure, delivery and content of the DAFNE course. Given these ethical parameters I choose not to record experiences, opinions, and stories of individual participants on the course when they shared these with each other. I did find this a little frustrating because some of the participants commented on very interesting, spatial/geographical topics. I also did not want to be seen scribbling down everything that people say in the corner of the room and so I withheld taking detailed notes about what people were saying and instead only took notes very intermittently so that I did not make people feel uncomfortable (a technique advocated by Cook and Crang 2007). The general chat of the participants helped me think about questions for my own interviews/questionnaires so I did take some generic, non-specific notes about their stories. I also regularly attended the meetings of the two diabetes support groups in Glasgow from which I gained many interview participants. The meetings took place, about once a month, in the evening and lasted for about ninety minutes each. They took the form of a guest speaker (a role I completed for both groups during the course of my research) followed by questions and discussion. I frequently chatted with others attendees and continue to keep in touch with a number of people from the groups.

One other method that I cannot avoid, as in effect already indicated in the ‘positionality’ section, is something of a constant auto-ethnography as I am a PWD myself. Crang (1994: 675-676) writes that he came to do an ethnographic study of his place of work, a themed restaurant, and reflects on his initial trepidation to use his employment as a source of research:

Somehow I refused to see working at Smoky’s as ‘real’ fieldwork, and felt others would feel much the same. I just had this sense that whatever going into the ‘field’ meant, it should involve going somewhere else, experiencing something new (and increasingly Smoky’s felt very routine), and starting when I was supposed to.

I can relate to these concerns from Crang, feeling that my own experience as a PWD is very routine, very mundane and does not involve me meeting other people or going anywhere specific: it just involves me ‘doing’ diabetes in my everyday life. Another concern about doing an auto-ethnography is that such reflections on fieldwork can be considered inappropriate and irrelevant. Punch (2012) writes, with some hint of frustration, about the way emotional reflections on the fieldwork experience can easily be suppressed in academic work due to fears of admitting to not being a

competent researcher. Yet, she argues that such revelations can lead to important support from colleagues, as well as allowing researchers to “achieve a more balanced sense of the ‘field’ ” (ibid: 92). Punch (ibid: 92) does insist that field diaries, to record personal experiences and emotions are not everyone’s ‘cup of tea’, and she argues that:

The degree of emotional investment in different research projects is likely to vary according to the researcher’s own baggage of emotions and feelings, their personality and emotional intelligence, their gender and stage in the lifecourse, the research topic, sensitivity of the research questions, vulnerability of the researched and the fieldwork location.

I have a large amount of “baggage of emotions and feelings” when it comes to diabetes; as it is a very personal subject. As I began my research then I thought it important for me to keep a field diary⁶⁴, to document how my own personal emotions and feelings were infiltrating any notions of ‘objectivity’ that I may have completing this research.

I hence had the good intentions of keeping a field diary/notebook of my own experiences with diabetes but I found such a task difficult. Firstly, much like Crang (1994) reflects, I am not going anywhere to observe myself, I just am. So where would my auto-ethnography start? Would it be from the moment I wake up in the morning? From when I start my work for the day? Do I only record those times when diabetes impacts on my life? Should I note my meal-times, when I must test, count and inject? Are the most important auto-ethnographic moments at clinic, GP, retinopathy, orthopaedic appointments? What about when I exercise, drink alcohol, stay up late, go to a wedding, go on holiday and alter insulin injections? Just by trying to design an auto-ethnography I began to appreciate how diabetes affects my life. It pervades all aspects of my life, not being something that necessarily ‘happens’ at specific times or places⁶⁵. At the beginning of my research I wanted to ask participants to complete their own diaries about life with diabetes, recording those times and spaces when and

⁶⁴ Punch (2012) makes something of a distinction between field notes and field diaries. Field notes she considers to be descriptive notes on emerging themes and ideas for analysis. Field diaries she considers to be personal reflections on how the researcher is feeling. For my ongoing ethnographical endeavour, I kept a notebook which constituted both my field ‘notes’ and field ‘diary’. This was practical because it kept all my notes in a loosely periodical archive, but also because I found it difficult to keep my ‘academic’ thoughts separate from my ‘personal’ thoughts.

⁶⁵ Although, of course, diabetes can be considered to ‘happen’ at specific times and places; for instance when someone objects to public injections or when someone has a hypo during a work meeting. Such events of dys-appearance are considered throughout my empirical chapters.

where the condition obviously interjected itself into their lives. Referring to my own instructions about writing this diary that I gave out to participants, I realised that completing it could be very difficult, which may explain why none of my initial interviewees seemed keen on the idea. In fact, one of my early participants, Samantha, said she did not want to do it because she already recorded her blood sugar test results every day and could not face recording even more of her diabetes. Balfe (2005) also found it difficult to persuade PWD to use this method.

Secondly, I found it hard to record all the times and spaces that diabetes makes an impact on my life. It seemed time-consuming and also pointless. So why should I write it down? I am not likely to forget it, but then, if I do not write it down I may overlook the importance of it in that it does happen every day. Also I find myself boring. I have never really experienced any major difficulty with diabetes (as in serious health complications, instances of serious stigma); it is a boring but frustrating, everyday necessity for me; not quite a routine recession though, as I do frequently acknowledge frustration, anxiety, sadness and many other emotions because of my diabetes. Even so, I do not want to write it all down every night as well. Surely, if I need it, the information is always there for me to be accessed? Am I not doing a proper auto-ethnography? I will not have the photocopied field notes that Crang and Cook (2007) and Laurier (2003) display in their ethnography ‘how to’ guides. A conclusion from Laurier (*ibid*: 146) helps to comfort me:

It is a mild hint of self-irony that my finishing words are: avoid reading books which claim to describe ‘how to do’ participant observation. If you must, read just the one and then throw it away afterwards ... Much like learning to play the piano or work out a mathematical proof or describe what a strawberry tastes like, you have to take a bite.

So, maybe I am not approaching ethnography⁶⁶ incorrectly at all. It is a personal thing, I can only do it my own way and not another. But Laurier (*ibid*: 146) continues: “participant observation is not difficult, nor obscure, though the topics, places, people, subjects and more to which you apply it may be. Since it acquires the shape and scale of its phenomena, in your first studies choose things you reckon you can handle”.

⁶⁶ I slip between using the terms ‘auto-ethnography’ and ‘ethnography’ because it was often unclear to me what I was doing. As I have tried to explain, I could never stop ‘researching’ my own life with diabetes as I talked to participants, therefore there was always an inevitable ‘auto-’ part to any ethnography I attempted.

Choose things you reckon you can handle? Living with diabetes! Phew! A massive subject, infiltrating every part of my day-to-day life, now record it, critically analyse it and write it up for a PhD thesis! Some may say ‘easy’, they may say, ‘I can write about myself for chapters. You already have your data, able to dip in and out of it at will, no tentative phone calls, no emails, no meeting participants at cafés and homes, no talks for support groups, no danger, no vulnerability’. However as the research progressed I became uncomfortable including too much of myself in the thesis. I feel that there is danger and vulnerability when using yourself as a research participant, and, as my research progressed, I became more uncomfortable with the idea of sharing too much of myself in my thesis. I felt a need to keep my personal ‘diabetic’ life and my work ‘diabetic’ life somewhat separate, so as not to be all-consumed. I was also fearful of writing out or writing over my participants’ accounts with my own experiences.

Despite choosing to only occasionally juxtapose my own experiences of living with diabetes with my participants’ my positionality still contributes to the knowledge created throughout the thesis. This project only began because of my own diagnosis and was sustained by my own continuing interest. Throughout the research process I have learned, both professionally and personally, about what it is like to live with diabetes. In many ways the thoughts and experiences of my participants reflect my own and so produce a thesis that is, by proxy, auto-ethnographic. Therefore, my own ‘diabetic voice’ is unnecessary, as I *am* centrally written throughout thesis, not loudly but nonetheless inevitably constant. This is most explicit when I have used photographs of myself to stand in for the embodied acts of my participants (see Chapters 1 and 7), which I did not capture with my audio and textual methods. For this photographic evidence, I *did* turn to my constant diabetic body, drawing on this resource, with the help of friends and colleagues who took the pictures.

CONCLUSION

With my chosen methods, I aim to discover some of the everyday realities of living with diabetes that are often obscured by discursive and routine recessions. I have argued that online questionnaires can elicit much deeper qualitative accounts, through both short and long answers, than might be first thought. Although I initially believed that my own diagnosis with diabetes would benefit my interview process, I began to

realise that actually it may have obscured some of the more mundane aspects of living with diabetes that Hitchings (2012) argues can still be uncovered with standard interviews. Nonetheless, I believe that my primary research methods, supported by a smattering of secondary methods, have more than adequately provided the tools for navigating through the various conceptual coordinates outlined in the previous chapter. The next four chapters will see the analysis of the data collected by these methods unfold.

CHAPTER 5

THE DIABETIC BODY, INSIDE OUT

“I don’t have a need to talk about MY diabetes” (Elliot).

INTRODUCTION

In this chapter I will explore the diabetic body, discussing its discursive and material presence in the everyday lives of PWD. This chapter focuses on “the geography closest in” (Rich, quoted in Longhurst 1994: 214): the geography of the body. I aim to debunk ideas of diabetes as a condition that is less than serious or even easy by exploring the constant state of awareness that a PWD experiences with regard to their body. Even though many participants noted the recession of the diabetic body in everyday life, episodes of “dys-appearance” (Leder 1990a: 69) persisted throughout their accounts. It is through a discussion of this attended-to body that I will express the hidden labours of diabetes that, due to preconceptions about the management and seriousness of the condition, are often difficult for PWD to express openly. I will attempt to redirect thinking of the geography closest in from either the miniscule levels of genes and molecules (Hall 2003; McCormack 2007) or the interpersonal realms of bodies-in-space, homing in instead on the often bypassed level of organs, interiors, blood and flows; what I call *space-in-body*. I am interested in how PWD come to know their diabetic bodies. Indeed, one of my main theoretical influences, Leder (1990a: 93) writes:

I have suggested that an explicit thematisation of the body can arise independently of the Other’s gaze. There are physical experiences such as pain, exhaustion, and illness that bring about the body as explicit object. Corporeal alienation does not come to be solely through the social confrontation but from within the body-for-me.

Bodies-in-space will feature prominently in later chapters. But for this chapter the focus shall remain on, as Leder describes, the “body-for-me”, to provide a foundation for these broader spatial discussions. The concept of Body-without-Organs (BwO), espoused by Deleuze and Guattari (2003), will provide a later conceptual reference and I will consider how my participants develop their own diabetic BwO to better

understand their bodies and diabetic identities. I found this a difficult topic to broach with my participants and so a case study of the sketches and personal correspondence with two bloggers/cartoonists, already attuned to imagining their diabetic interiors, will form an empirical base from which to discuss space-in-body. This case study will be pre-figured by a discussion about how my participants *do* consider their diabetic bodies. I will provide empirical evidence of the recessive bodies that I outlined in Chapter 3, and, through these materials, I will demonstrate the hidden anxieties of PWD.

THE RECESSIVE DIABETIC BODY

DISCURSIVE RECESSION

Brightsidings narratives are evident among my participants. Polly, for instance, writes that; “I just get on with it all [living with diabetes] in a normal everyday manner – some people on the forum I belong to really hate it. I cannot empathise with that. Get on with life is my motto”. Conversely, other participants, such as Sheila, express their frustration at brightsiding:

I think that you get happy-clappy [overly positive] diabetic people ... who say, ‘oh it’s not that bad we can do something about it, there’s going to be a cure for it’ ... let’s get out there and we can do marathon runs and we can do all this campaigning’ ... People are very ‘pro’ the illness and I’m like, ‘aghhhhh’! ... I just can’t stand the illness. I hate it with a passion.

As these contrasting accounts indicate, my participants’ overall attitudes to diabetes were varied. One of the questions in my questionnaire asks if diabetes impacts on a participant’s identity. Of 127 responses, 106 answered this question. Reviewing all the answers, I was able to discern the four different categories already described in Chapter 4. The spread of response can be seen in Chart 1. Although the chart shows that the single most common category of response to be ‘no impact’ (40%), it also shows that, if the other three categories were combined to a general ‘yes impact’ category they would represent a majority of 60%. Such a quantitative approach to representing the data disguises the context and qualitative value of the individual responses (Delyser and Sui 2012). For example, I found that many who responded ‘no impacts’ did so with an almost defensive use of language. For example, Carly’s

‘no impacts’ answer is: “I refuse to let that happen, I won’t be defined by a disease”; and Bella also writes: “I do not want to be identified by my diabetes. I happen to have it but I do not want it to define me”. These are forceful responses, suggesting that respondents are keen to deny any possible negative aspects on their identity due to diabetes⁶⁷.

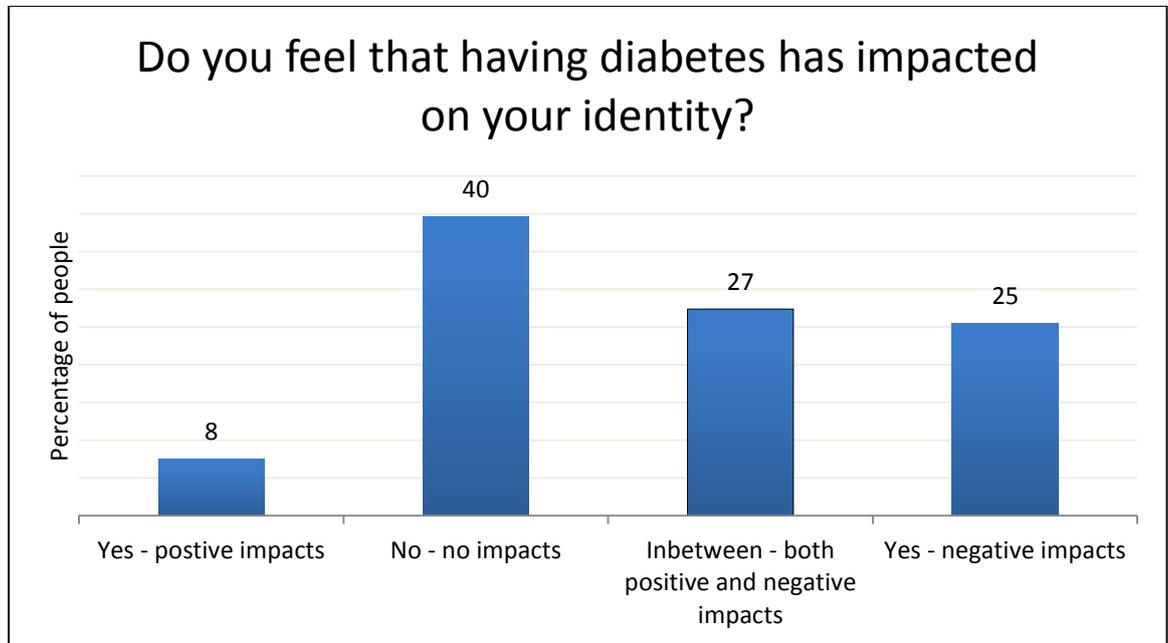


Chart 1. Questionnaire responses to identity question.

Perhaps explaining this sense of defensiveness, Locock and Brown (2010: 1499) discuss people with cancer who are reluctant to go to cancer support groups because of not wanting a “cancer identity”. Reflecting something similar, some of my interviewees discuss the terminology used to refer to diabetes. Sophie rejects the use of the term ‘disease’:

I think *disease* means, that I’ve caught that from someone else and I’ve not. *Condition* is something that I have to live with. *Illness*: people say, ‘it’s a right bad illness that you’ve got’ and I think, is it? Because most days I can live as normal as you [referring to people who may say it is a bad illness], so that’s why I say it’s a *condition* ... You’ve got live with it and make the best of it, whereas I think *illness* almost it puts a label on me that I’m ill more of the time than I’m well.

⁶⁷ Such a quantitative categorization of qualitative data is problematic. For instance had I split the ‘no impacts’ answer into more categories as I did for the ‘yes impact’ answer there may have been a more nuanced category spectrum. However I intend this analysis to be indicative, of diabetes most often affecting a person’s self-identity to one degree or another, rather than comprehensive. It is a way to represent the responses to this question at-a-glance

Jessica also talks about how diabetes affects her identity in the workplace:

It's not that I'm embarrassed about being diabetic ... I just don't think anybody's really interested ... I don't think, I'm not very different from anybody else, so why make out that I am? And I think, if you start saying to everybody, 'oh excuse me let me just take my insulin I'm diabetic', that's just totally unnecessary ... I don't understand why it would make a difference to you if I was sitting here having a meal or a drink with you, does it matter to you if I'm diabetic or not? I just don't understand why people feel the need to tell everybody⁶⁸.

Jessica's account, along with those of the questionnaire respondents, are not the same as brightsiding. Rather than telling of a great overcoming of diabetes, Jessica instead tells of her efforts almost to expunge the condition from her interactions with others. Sophie, meanwhile, does not deny that diabetes causes her many problems in life (her contributions will be returned to throughout the thesis), but insists that it is not a *disease*; instead, for her, it is 'merely' a *condition* that only periodically intrudes on her life. As Aujoulat et al (2008: 1236) write: "the tendency to separate one's identity as an ill person from other personal and social identities has been convincingly described as a coping strategy aimed at maintaining a sense of normality". I thus argue then that many of my participants attempt to "screen the real" (Diedrich 2007: 67) of diabetes with this attitude.

Through this 'screening' diabetes becomes something *unknown* which serves to reiterate popular conceptions of the condition as easy and unproblematically concealed. However, this conception is undermined by many other participants who express their frustrations at the difficulty of living with diabetes. Kirsten, for instance, says:

It's ... like people just think, 'oh just get on with it', so there is connotations of ... that [of diabetes being considered by others as easy]. But ... I've had people saying to me ... 'oh but you manage it really well so you're fine'. But managing it, that word 'managing' is like 24/7 it's a pretty huge effort, it's not just inject and that's me, so I don't think people quite understand the amount of mental, physical, emotional, absolutely everything you could think of.

⁶⁸ This quote introduces many more themes that will be discussed in later chapters. While Jessica tells here of concealing her diabetes by not talking about it, in Chapter 7 I will discuss how many PWD conceal their diabetes by not 'performing' it. The concept of diabetes as a hidden illness is therefore both material and linguistic.

PWD who are seen to be negatively affected by diabetes can be open to a moral critique. As discussed in Chapter 2, Broom and Whittaker (2004), writing of type 2 diabetes, describe the moral language that is often associated with ‘good’ and ‘bad’ control. Meanwhile, Rasmussen et al (2007: 204) identify, among their female participants with type 1, a “bad girl” or “good girl” dichotomy, with regards to keeping blood sugar levels under control. Such beliefs about diabetes can contribute to PWD remaining silent about their condition. Denise reflects on these linkages as she says:

I couldn't say to any of my friends ... having diabetes makes me mentally feel this way or that way because I just don't feel they would understand ... having a ... chronic illness. Now, if you had something like multiple sclerosis ... or Parkinson's disease, something they can see, then they probably would be [asking]... 'tell me how you feel'. Because diabetes is hidden, unless you've lost a limb or something or your eyesight ... it is invisible isn't it ... it's almost a bit like people who suffer from clinical depression because ... you can't see it ... I don't think they ... get a lot of sympathy; they get a bit of sympathy, but really people are saying underneath it, 'why can't they just snap out of it'?

Denise feels silenced because of the lack of sympathy that PWD receive. She is particularly frustrated by the treatment of those with type 2 diabetes, remarking that, “they [friends] don't understand and I think, they think, because I'm not on medication, I'm only practising at it ... Whereas I'm desperately trying to hold off having to go onto medication”. For her friends her diabetes is not serious, cast into doubt because she does not use medication. Throughout our interview, though, Denise repeatedly shares her fears of medication in general, explaining that she makes great efforts in managing diet and exercise to stave off having to use medication – although she is resigned to needing medication at some point in the future.

Because of diabetes' reputation as easy, many of my participants felt that they could suffer punitive consequences should they disclose difficulties or frustrations about living with diabetes. Sarah, recently diagnosed as type 2, remarks:

I haven't told anyone other than my husband and best friend about my diabetes, I avoid speaking or seeing other people. I worry that I will blurt it out and they will see me differently and treat me differently, and go away and talk about me and how I brought it on myself (I do realise that these are my feelings and not others', but I can't help thinking, if I think this, why wouldn't they?)

Sarah guards her diabetic identity closely for fear of being considered different. Other

participants also explained that they preferred to stay quiet because of a lack of popular knowledge about the condition. Gillian writes:

[I have a] fear of becoming a diabetes bore! Most of my friends are largely unaware of the condition beyond very basic info, so I wouldn't really talk to them about it. But on the other hand, some people do ask questions, which perhaps shows I'm too reticent?

Gillian ponders that maybe her friends are more open to discussing life with diabetes than she believes, but her fear of becoming a “diabetes bore” would situate diabetes too prominently in her identity and so she keeps quiet. We can start to see how diabetes recedes from social life: it is not to be talked about or remarked upon. There is a desire to ‘pass’ (Goffman 1968) as non-diabetic. Emma replies to a question on barriers to talking about diabetes: “probably more my own barriers about wanting to appear to be ‘normal’ or ‘unproblematic’”. Thus, diabetes can be unknown to others, feeding the discursive recession of the condition which takes simplistic beliefs about diabetes, for instance as easily managed, as fact. Nonetheless, as I discuss in subsequent chapters, diabetes can be a messy condition involving injections, blood and transgressions of body boundaries. There exists a pressure to conform to idealised body types, the creation of ‘docile bodies’, as Foucault (1991) has discussed. Frank (2002) argues, in his own autobiographical writing about living with illness (he writes about his experiences of heart attack and cancer), that it requires a significant amount of emotional effort, to sustain brightsiding or docility, lamenting that in a more accepting society such effort could be applied elsewhere to improve the life of the ill person⁶⁹.

⁶⁹ Hochschild (1979) refers to the ‘emotional work’ people can carry out as part of ‘deep acting’ in order to change the way they feel about something, such as their employment. In later work Hochschild (2003: 7) considers ‘emotional labour’, this time writing that it is intended to “induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind in others”. Those PWD who ‘brightside’, are conducting emotional work in order to change the way they and others feel about diabetes, insisting it is only a minor issue in their life, thus avoiding the mark of stigmatising disease. This emotional labour works to reassure others that their perceptions of diabetes as ‘easy’ are correct. Hochschild (2003) draws from psychoanalytic concepts, considering how this work and labour *can* create a ‘false self’ with psychological effects. She frequently uses the example of air cabin crew, and argues that some cabin crew workers may become so embroiled in their ‘performance’ that they burnout and experience periods of “emotional deadness” (ibid 2003: 187). This is not dissimilar to the potential emotional outcomes of the discursive recession of diabetes, as PWD feel they cannot talk about the emotional and practical problems that they face because of diabetes. Hochschild’s concepts are focussed on the service industry in the pursuit of further acknowledgement of emotional labour alongside traditional ‘exchange values’ of workers. The implications of this emotional work is different in this research context, but it is nonetheless instructive to think about how PWD ‘labour’ around their diabetic embodiment.

Charmaz (2008: 9) is perhaps most useful in helping to explain my idea of a discursive recession. She writes of Marilyn, who has chronic fatigue syndrome, as she struggles with the invisibility of this illness while attempting to speak about environmental impacts on health at a community meeting. Marilyn has been waiting for much longer than she expected to say her part, and by the time she does speak she is starting to lose control of her body:

Her mask [she wears a mask to limit the effects of nearby wood burning on her respiration], confusion, and difficulty with speech set her apart. Marilyn risked being disqualified from full participation [of the community group] before she could attempt to join in ... Paradoxically, when her appearance seemed unremarkable and she could articulate her thoughts clearly, other people discounted her ambiguous condition.

When Marilyn is experiencing the effects of her chronic fatigue syndrome, she is noticeably different. She tells of how “other people treated her as a spectacle or oddity” (ibid: 9). Conversely, when her condition is temporally ‘under control’ – when her body is not dys-appearing – others cast her illness into doubt. Indeed, Moss and Teghtsoonian (2008) talk of invisible illnesses being contested in such ways, and it has long been an interest for feminist health geographers (Moss and Dyck 2003; Crooks et al 2008). The invisibility of diabetes causes a similar contestation and so many PWD attempt to ‘pass’ as in control, duly downplaying the impact that diabetes has on their life and identity. I have argued, and will continue to do so, that this desire to pass leads to the popular conception of diabetes as easy, sitting among the ‘better’ chronic illnesses to have. I argue that this leads to a silencing (Charmaz 2002) of what it is like to live with diabetes. My thesis goes some way to unsettling this silence.

ROUTINE RECESSION

Discursive pressures are not the only factor in causing the diabetic body to recede. Routine recessions involve a sense of PWD becoming attuned to the everyday demands of the condition so that it fades from constant conscious reflection. As seen in the diary extract from Chapter 3, it is often suggested to PWD to record their blood sugar levels multiple times a day – ideally immediately before meals when blood sugar levels will most likely be resting – in order to detect patterns and minimise

deviations⁷⁰. Yet, as pointed out in Chapter 4, keeping such diaries can be a pest and even serve to exacerbate the presence of diabetes in one's life. Hence many PWD, such as Elise, do not always monitor their blood sugars so closely:

Sometimes I go for a whole day and I haven't written anything down and that's because I'm busy and I think ... if I don't do it for a day, it's not the end of the world ... Then I go home and think, 'gosh I should've have written that down' ... Sometimes, I think, 'do I really need to do all this?' But actually it does help ... because you do actually start to see patterns and you're actually confronted with the numbers ... Sometimes I'll think, 'oh I wasn't actually that high', but when you look back at it [her recordings] actually it's quite high ... you can't lie to yourself ... because ... you look at a day [of recordings] and you think, 'gosh, I haven't been under 10[mmol/l] today'. Because [without recording the readings] you can convince yourself it's just the odd one that's gone high.

Routine recessions do occur, the acute symptoms of hyperglycaemia are not always felt and, feeling 'normal', PWD can neglect to test and record their blood sugars. Although, as Elise points out, when the numbers are written down in ink, her consistently high blood sugars levels 'confront' her and disrupt her routine recession, and she suggests that she may have been lying to herself (perhaps unconsciously) about her high levels, and attention needs to be given to her body.

The time of diagnosis and the length of time living with diabetes are obviously factors in this routine recession. Sarah, whose questionnaire response is full of incidents of stress and difficulty, has only been diagnosed two months as she authors her response: "I hope that as I get used to it I become less stressed with it". On the other hand, Maureen, who was diagnosed aged eight and is now forty-one, reflects: "but I just think you get so used to it over the years you don't really notice. I probably have got routines but I don't really notice them". Maureen's diabetic body has receded: rather than diabetes being a disruptive force, it is assimilated, becoming part of a 'body ballet' (Seamon 1979), a routine conducted (seemingly) without thought. Derek and I also reflect on this issue with reference to self-management practices:

⁷⁰ The standard (DAFNE, but not exclusively so) recommended way of carbohydrate counting is to take 1 unit of fast-acting insulin for every 10g of carbohydrate. However, for some PWD the ratio may be more or less units of insulin per 10g. These ratios can vary at times during the day and so often clinicians encourage diaries to be kept to identify patterns. For instance, if someone's blood sugar is consistently high immediately before an evening meal, and they were confident that other variables, such as inexact carbohydrate counting, were constant, it may suggest a need to increase the ratio for their midday meal. Likewise, frequent hypos a few hours after a meal may suggest that the ratio needs to be lowered.

Derek: It's just, I don't know about yourself ... that's it you do it, if you don't do it you die, simple as that.

Mark: I've only had it for four years and I don't even remember not taking insulin. I take it after a meal, I can't remember having a dinner without taking insulin with it. It's just become so normal to me.

Derek: I think that's just what happens, it's just ingrained into your life and it's you, part of you, it's like having a crutch, somebody having a chair or something, that's their legs ... it's just part of you.

Sobchack (2010: 62 italics original) writes of the experience of having a limb removed, ultimately declaring that her missing leg became “an active, quasi-absent ‘part’ of my *whole body*”, arguing that “my phantom’s diffusion made way not for a return to my lived body’s previous way of being in the world but, rather, for another form of bodily incorporation and integrity, for another sense of myself ‘as a whole’”. Derek is describing a similar sense of himself as whole: the diabetes has become part of him, and he is no longer different from the norm, but merely living a different norm (Mol 1998).

I found prompting my participants to reflect on these body ballets quite difficult. For instance, I initially regarded my interview with Maureen as something of a failure. It was one of my shortest, only about fifty minutes long. It was somewhat awkward as her answers were mostly short and abrupt, and my probing questions mostly unsuccessful in eliciting deeper responses. This likely demonstrated her overall attitude to diabetes: it truly has receded into routine after all these years and occupies little of her thoughts. Other participants echo this feeling: Allison claims at the start of our interview that she ‘just gets on with it’ (life with diabetes) and experiences few problems. Allison’s husband, Steven, also type 1, makes similar remarks⁷¹. As these interviews progress, though, there starts to emerge accounts of everyday, mundane happenings that demonstrate a more attended-to and care-ful body than was initially suggested. Allison and Steven both frequently remark on the constant care taken in their eating routines, particularly around breakfast. Steven says:

At the weekends I always get up at the same time and I always make breakfast and we always have breakfast ... we try not to be absolutely bloody stupid

⁷¹ The interviews with Allison and Steven were carried out one after the other over the phone. While then they were not interviewed together, at times they would ask one another questions during the interview and Steven, who I interviewed second, remarked on aspects of the interview with Allison which he overheard and wanted to talk about.

about this. We've got to try and make sure that the ... regime of the day is not too far bent out of control. But that doesn't stop us from having late dinners or anything like that.

Although Allison and Steven have developed a routine for their breakfasting, this is not necessarily a recessive routine. Unlike Maureen's seemingly effortless diabetic body ballet, this regime takes work. Steven recognises the importance of maintaining vigilance with this routine: not to do so would be "bloody stupid", and, if he does not follow this routine, he acknowledges a potential loss of control. He tempers his account, though, to stress that, while this routine takes work, it is not all-consuming, for flexibility in eating times still exists. Such a recessive body is perhaps better explained by Frank's (2013: 41) idea of a "disciplined body" which "defines itself primarily in actions of self-regimentation". He writes that the disciplined body is made predictable through regime, linked to a fear of loss of control.

The most obvious accounts of a routine recession came from people with type 2 diabetes. Often type 2 can be managed through diet, lifestyle and oral medication, and so the self-management can be slightly less intense. Selena makes this clear in her interview, remarking on how little impact her diagnosis of type 2 diabetes, when she was sixty-five years old, has had on her life (Selena is now seventy-three). She tells me that this is because, prior to her diagnosis, she had always been keen on sports and exercise, always ate healthily and so, for the first seven years of her diagnosis, did not take any medication. It is only recently that she has been prescribed with metformin⁷². That said, she still presents something of a receding diabetic body: when talking about browsing online forums for information, she remarks: "sometimes it's over the top, though, it's too intense and because I'm type 2 and not [a more intensely managed type 1] ... I don't have problems with it. I'm inclined to back off". Selena's routine recession is not always easily accomplished, this is made clear as we discuss some issues that she has with obtaining an appropriate amount of test strips from her GP:

I mean the inference is always on 'manage your own diabetes' and then they deny us the tools to do so ... you're encouraged to manage your own diabetes, see them if you've got a problem, yes, but how do you know if you've got a problem [if you do not have access to test strips]? Well you're more likely to

⁷² Metformin is an oral medication taken by many people with type 2 diabetes to increase the effectiveness of insulin. It can also be taken by people with type 1 diabetes as a complement to insulin injections.

feel it in yourself [referring to me as a type 1 with frequent pronounced hypos] whereas I'm not.

Without an adequate supply of tests strips, Selena is unable to monitor her own body: she hints at a feeling of being detached from knowing, not always being able to rely on her own bodily knowledge and needing a 'cyborgian' assist in the form of test strips, in order to enable a routine recession. The difficulty in obtaining these strips shows how routine recessions, while possible, are not achieved unproblematically and can exist precariously. Selena expresses the importance of blood sugar tests when I ask if having test strips puts her mind at ease, to which she replies: "yes, yes ... as much for my head as anything else"⁷³.

These recessions tell of "habit as virtual infrastructure" (Bissell 2015: 131). Bissell argues that habit can be conceived as developed less by individual repeated practices and more by a distributed virtual resource – a common and unquestioned way of knowing how to do something. Following this thinking, we can see that the division of discursive and routine is not so neat. The recessions of diabetes that I have discussed – maybe also considered habits: the habit of not talking about it; the habit of carrying out self-management practices – are formed as much by a "virtual infrastructure" of the condition as by the PWD. We have seen how this virtual infrastructure channels the life of the participants discussed above into bodily and social concealment. Selena is generally habituated with her diabetes so it does not affect her, but still her own preference to test more regularly is denied, leaving an imbalance between the discursively expected way of doing diabetes and her own personal bodily management ideals. In the following section I will investigate further the imbalance present in this virtual infrastructure, the times when deviances from the diabetic norm become immediate in people's lives, the times of 'dys-appearance' (Leder 1990a).

THE DYS-APPEARING DIABETIC BODY

It is these recessions that often situate diabetes as a contested illness, since in everyday life it can become both socially and materially absent. Nonetheless, my participants

⁷³ The sense of anxiety that surrounds the availability of various pieces of diabetes 'kit' will be further discussed in Chapter 8.

frequently reflect on the everyday presence of diabetes in their lives. For Gary: “it’s the first thing I think about when I wake up, and the last thing I attend to before I go to sleep. Every. Single. Day”. The punctuation in Gary’s response is from his original text and effectively expresses the constant monotony he feels about living with diabetes. Others express frustration at the social repression of diabetes while also commenting on the lack of an easily obtained routine recession in everyday life:

Put very simplistically you must do insulin and you must do blood tests in order to have any chance of good control. So just do it then, surely it can’t be that hard? Well ... actually it’s not that simple is it? It’s hard work and it’s difficult to accept as part of your everyday life (Catherine).

They [people without diabetes] think it is not serious, ‘just eat healthily’ or ‘just take a pill’, whereas in reality it is a hugely involved disease, with all the blood glucose testing, carbohydrate counting, dose calculations etc, all before factoring in the unpredictability of diabetes and changes with hormones/weather/exercise/sickness etc (Rachel).

Here we see the emergence of a more dys-appeared body, one in which diabetes is a constant consideration, not subsumed as a habituated body ballet. It is important to note that length of time with the condition and type of diabetes are not necessarily significant factors for these two women: Catherine has had type 1 for twenty-four of her twenty-nine years, and still finds it hard to incorporate as part of her everyday life. Rachel meanwhile has had type 2 for three years of her twenty-four, suggesting that routine recessions do not necessarily develop over time or develop with more ease depending on type of diabetes.

Henry contests the easy development of such routines, despite his long time living with diabetes:

Forty years’ experience makes things ‘relatively’ straightforward, but it is nevertheless onerous. Blood sugar monitoring, carbohydrate estimation, adjusting doses to cope with exercise and the timing of all these relatively to each other requires serious focus, which takes time and effort which could be devoted to other things!

The idea that a body ballet can easily develop with diabetes is further debunked; the whole idea of such automatic routines is that time and effort can be devoted to other things and such repeated actions become practised with little thought. It is clear, however, that some PWD do develop somewhat automatic routines for their daily self-management and I do not intend to deny the validity of how these participants

live with their condition, but only to argue that the extent of a PWD's routine recession lies on a spectrum. For some PWD, diligent attention to their diabetic body is a major undertaking, for others it is minor, but this undertaking, for all, exists. In the following sections I turn to look more closely at the intimate spaces of the body to discuss how my participants expressed their dys-appearing body. Ideas of the 'uncanny' permeate the following analysis in this chapter in three ways. The first involves encounters with the uncanny which remind PWD of their own precarious body which is subject to possible future impairments⁷⁴. The second is to the idea of seemingly automatic processes, of hypo, taking partial control of a PWD's body. The third is the idea of a supposedly 'dead' entity being 'alive', which shall be discussed, later in the chapter, with reference to imaginings of the body interior.

FUTURE COMPLICATIONS

A common theme to emerge from my analysis was a fear of long-term complications due to diabetes. These fears seemed to rest on two key areas of the body: the eyes and the limbs. Denise recalls working as a nurse, many years before her diagnosis with type 2 diabetes, and a particular encounter haunts her now that she has been diagnosed:

I must have bathed ten men all of whom were amputees and I would say ... seven out of the ten of them were diabetics and it would be type 2 diabetes ... It started with toes coming off and then it was a foot and then it was a below the knee amputation and, then ... it was a whole leg off ... It's stuck in my mind and that is the vision I have about diabetes. I don't want to lose my limbs ... I know it can affect your heart and ... other things as well but it's the foot thing or the leg thing that really [worries me].

Denise's fear is of changes to her bodily integrity, which will render her body different and unfamiliar. The fear of losing feeling in one's feet or ultimately having an amputation is not uncommon (Balfe et al 2013c found similar fears among their participants), but for many of my respondents it is considered avoidable if attention

⁷⁴ For example, Charmaz (2008) writes of a man, Ron, who uses a wheelchair and whose very positive approach to his impairment means that he is rarely aware of being 'disabled'. While it might be possible to critique Ron as 'screening the real' (Diedrich 2007) and heaping unfair expectations on other wheelchair users, who may experience more disability in their everyday life, Charmaz considers how Ron's approach allows him to feel 'normal' in most everyday situations. However Ron's positive approach can stutter, when he encounters other wheelchair users struggling with their disability, and is so reminded of his own potential disability.

is paid to one's diabetic body. The body then cannot easily recede; for, even if the checking of one's feet – for irregularities that may signal the onset of neuropathy – becomes part of one's routine, it is still a routine to which my participants are vigilant. For example, asking my participants how seriously they regard their diabetes, they respond:

Extremely seriously. I have no intention of having my feet amputated. I cook all the time from scratch and I ensure it's carbohydrate counted and usually fairly low in carbohydrate (Annette).

At a time when my control was not very good I had neuropathy⁷⁵ (feet) but once I regained control it went away (Celia).

Not very serious at all *if I take care of myself*, especially my feet (Brenda, my emphasis).

Potential loss of sight was also a recurring fear. George, twenty-eight, diagnosed when he was four, tells me early in our interview that diabetes does not have a big impact on his life, suggesting that his long time with the condition has led to a routine recession, leading me to ask:

Mark: Do you think overall you have the diabetes under control?

George: Well no ... they're taking pictures of my eyes now, every six months, I've got diabetic eye changes ... Every year I get diabetic eye changes and now they've decided they're going to check them every six months. That's something I'm very concerned about, it's my eyesight, it almost scares me, obviously I don't want to be blind. Yeah I find it a very scary thought.

Anna remarks: "my biggest fear is losing my sight. I say ... take a limb off, but my sight I'm not going to lose that"! Again, there is the sense that, in order to maintain bodily integrity, the diabetic body must constantly be the focus of attention. George and Anna are scared of losing their sight, since it would mean a switch to a completely different way of being-in-the-world. Douglas was the only participant who was suffering from severe loss of sight, and he reflects that, due to his dependence now on his wife for many everyday tasks such as driving, cooking and calculating medication,

⁷⁵ Neuropathy refers to nerve damage which limits the ability to feel parts of one's body. Neuropathy in the feet is a common long-term symptom of diabetes (especially in those with frequent long-term high blood sugar). It is particularly dangerous, as people may not feel injury or infection to their foot until it is too late and amputation may be the only treatment option. PWD are encouraged to make frequent visual checks of their feet for this reason.

he feels like a “package”. Throughout my data, then, there is a fear of losing bodily integrity. This demonstrates that the diabetic body is often balanced on an uncanny knife-edge between having control of your own body and becoming a more passive “package” that loses control and independence. This uncanny feeling, of changes to bodily integrity, persisted throughout my data. While Jessica fully subscribes to a discursive recession (see earlier quote in this chapter), she is also aware of the seriousness of her condition. She states that she is keen to enjoy her life now by going on frequent holidays and buying a nice car, and doing so *before* she thinks she will be unable to enjoy them due to progressive diabetes complications. Likewise Denise expresses her resignation that “it is progressive and one day it will get you in the end, maybe. Hopefully you’ll have lived a [good life] ... we all have to die of something”.

HYPOGLYCAEMIA (HYPO)

The experience of hypoglycaemia is a key embodied event for many PWD⁷⁶. It is a point when their body most acutely dys-appears. Sheila describes one instance:

I think it’s the typical sensation where you go weak and shaky and you’re losing control ... that’s a sense of losing control, not being able to do something about it ... Sometimes when I’ll be going into a hypo and I’m terribly weak and shaky ... I’ll go to my husband, ‘I’m having a hypo’, and he’ll say, ‘right, OK, what do you want?’ and I’m so confused I don’t know what I want and I’ll say ‘get me something, just get me something’, and he’ll go ‘right do you want Lucozade, do you want chocolate, what do you want?’ ‘I don’t know, just get me something’, and I’m shouting at him and he’s getting angry at me for shouting at him and I just want it over and done with, I just want it out the road.

This quote from Sheila provides a telling recounting of the hypo experience, taking me through the back and forth with her husband, expressing the increasing irritation of both. Her inability to answer her husband directly expresses the irrationality that she experiences and the loss of bodily control. Anna provides another example of having a hypo, noting on how she ultimately drives “automatic”, her diabetic body taking full control of her actions:

⁷⁶ Hypos are more an issue for people with insulin controlled diabetes (mostly type 1) than non-insulin controlled diabetes (mostly type 2).

[Anna is leaving work] I drove along the road and I couldn't remember where I was going, how to get home ... I drove for two hours; don't know where I was for those two hours ... and now and again I would take a wee kind of sane [moment of clarity] ... and I phoned my mum and said, 'right I know where I'm at, I'm near ... turn to my right, straight down the road and I'm home'. By the time I came off the phone, I'd forgot that and I went in the wrong direction ... They roughly knew where I was; my sister had to come out in her car to look for me and then she had to bring me home. Now for two hours I drove about, you must just drive automatic because I couldn't tell you where I was.

Anna's account seems similar to the experience of a body ballet, something largely unconscious in a person's negotiation of a place, but it involves a strangeness which is absent from the more peaceful acceptance of routine as described by Seamon (1979). The experience of hypo is the uncanny alternative to body ballet. Anna drove "automatic", the mechanical processes of the hypo taking over. Indeed, almost all of my participants who experience hypos tell of involuntary bodily processes taking over: sweating, shaking, light-headedness; more specifically, one mentions trembling lips (Lillian) and another, the turning pale of earlobes (Richard).

For a few participants, however, such bodily processes were not evident. Samantha tells of how she has lost her hypo awareness, her body feeling no different to her during hypo as when it is not experiencing hypo. She told a story about how, even when she felt fine and seemed fine to her son, her meter was telling her that she was seriously low: "I said, 'it's 2.1[mmol/l]'. I said 'I feel fine I'm talking fine'. He [her son] said, 'you look fine', and I said 'come and do it again [the blood test] ... because maybe there's something [wrong with the device]', and it was 1.9[mmol/l]"⁷⁷. Samantha's body, like Selena's who I discussed earlier, depends on the cyborgian relationship with diabetes technology, for she cannot rely on simply knowing when she has a hypo or just how severe it is without recourse to the testing kit. Samantha needs to test frequently in order to know her own body. Even among the more sensitive diabetic bodies, this intervention can be needed as confirmation because the body is never totally dependable.

In terms of losing control, the experience of hypo can be considered akin to the experience of epileptic seizure. Smith (2012) explores the seizure episode in great depth. He talks of the existential problems of the seizure event: of people with epilepsy's attempts to ground their spatiality, before, during and after seizure, in order

⁷⁷ A reading of below 3.5mmol/l being considered a severe hypo by DAFNE standards.

to hold on to a bounded sense of self. He also discusses the perceived social consequences of people with epilepsy as they recover from seizure in front of others⁷⁸. Interestingly, my data is sparse in examples of hypo experience in front of others. This may be because, as I will discuss in Chapter 6, unlike most people with epilepsy, who have seizures, PWD often retain some control over their bodies during hypo and are able to conceal the hypo by either relocating themselves or by bearing the symptoms until such time as they can treat it privately. While the account of Anna suggests a full blown loss of body control, Sheila's and others like it suggest that awareness remains during the hypo experience, but as an uncanny awareness; not full control but not complete lack⁷⁹. Similarly, Jessica describes her awareness of hypo and the need to treat it, but she experiences an eerie laxity of urgency:

Jessica: I'm aware ... and I'm thinking, just get something to eat! But I cannot decide what I want to eat, so if you gave me something and said 'there eat that biscuit' I would eat it. If you said to me 'do you want that biscuit or that biscuit'? I probably couldn't make that decision and I know that.

Mark: But you know you have to make that decision?

Jessica: I know I have to eat something, I just cannot decide, it's like; it's really awkward to explain, it's really hard to explain.

Mark: Does that make you worry?

Jessica: It makes me very agitated ... I know I get agitated, I can't help it and I've had my husband sometimes say, 'Jessica do you want something to eat'? ... I've said, 'no I'm fine', and I know I'm not but because he's told me to take something to eat I wouldn't. I'd say 'don't tell me what to do; it's me who's the diabetic, it's me who knows so don't you tell me'. I'm very like that if I'm hypo.

For Jessica, rather than a total loss of control there is an uncanniness, an otherness during the hypo experience that resides in the body alongside more rational thought processes. Likewise, Linda also considers this uncanny otherness during hypo: "I feel myself a little bit more selfish; I notice myself that I might push my way to the food.

⁷⁸ In the following chapter, I will examine more of the social and spatial context of the hypo experience. This section is only establishing hypo as an experience which demands a constant awareness of the body.

⁷⁹ Researching the time-space geographies of people with epilepsy, Smith (2013), finds that people are unaware of what their body is doing during a seizure and so rely on others – possibly family members, friends or bystanders – to relay their body's actions to them after the event. While a similar 'reporting back' is evident in some of the experiences of hypo from my participants, most were able to talk about their experience of being hypo from their own, first-person, perspective.

Before I even know I'm having a hypo, my body is going out for myself, its selfishness, disregard for others can come in". Svenaeus (2013: 88 italics original) writes that the anorexic body can be perceived as uncanny, "because the body in such cases displays a kind of life of its own that is experienced as a foreign *will* by the person in question". A similar phenomena is clearly happening during hypo for some of my participants. For Jessica, it involves an irrational rejection of food; while, conversely for Linda, it is an overwhelming urge for food immediately. Either way, the body is briefly, intermittently, experienced as other, complicating rational strategies for treating the hypo.

Many of my participants reflect on the difficulty of maintaining discipline over their bodies when treating hypo. When hypos are 'minor'⁸⁰, between 3.5 and 4.5mmol/l, the recommendation from DAFNE is to consume 1.5grams of fast-acting carbohydrate and then wait for fifteen minutes for the hypo feeling to go away. Few of my participants exercised such discipline! For instance, Arthur says:

Having an actual hypo ... I just want to eat and I could eat [anything]. I've found myself [with] two rolls ... and a bowl of cereal and a couple of biscuits and then I feel so bloated and full. I feel sick and it's my mind fighting with itself because I know I don't need it, but I don't feel better until I've basically stuffed my face, which then gives you the other problems; a couple of hours later you're going to be too high.

The 'yo-yo' effect following hypo is frequently described by my participants, many noting that the battle to re-obtain a satisfactory blood sugar level could take that entire day as they fluctuate between highs and lows. Frank's (2013: 41; 42) "disciplined body" offers further contextualisation of this disorganised body as he writes: "to the extent that these treatments are carried out like a military drill, for the sole end of getting it right in itself, then desire is lacking and the pure ideal type⁸¹ is approximated". For Frank, someone experiencing a disciplined body dissociates their body from their self, considering the body an 'it' that has to be carefully regulated at the expense of desire. My evidence demonstrates that such a separation of the body

⁸⁰ Of course, such a 'minor' hypo can still have dangerous impacts. This classification of minor refers more to the numerical blood test result as opposed to the actual embodied experience.

⁸¹ Frank is considering the ideal type of the disciplined body as regimented to a state of complete control.

in hypo is especially difficult, the ideal type is not approximated, and the desire of the body is hard to deny⁸².

That said, most of my participants reflect that their hypos are normally minor and easily treated. Some even suggest that they can ride out a minor hypo while in the company of others, being able to hold onto a degree of bodily control, to withstand the body signifiers, and treat it soon after when they have time to themselves. One survey respondent, Gillian, even expresses surprise at my question about fear of hypos in public space: “you can’t see hypoglycaemia, so nobody would notice ... This seems like an odd fear to me”. My data suggests that the main social signifier of diabetes that would betray this hidden illness is instead TIM. These processes and their social significance will be discussed in detail in Chapter 7. While the experience of hypo remains a key moment of disorder in the life of a PWD, the evidence in this chapter highlights more the constant bodily vigilance that has to be practised in order to avoid hypo.

When Mol and Law (2004: 43) write of hypoglycaemia, they write of “embodied action, enacted bodies”, attesting to the many embodied tensions that exists for a PWD when managing their chances of experiencing hypoglycaemia. They explain that while deliberately ‘running blood sugar levels high’⁸³ may increase the likelihood of diabetic complications in later life, it also limits the immediate likelihood of hypo. Conversely, they write that running blood sugars tight may limit future complications but increase the chances of immediate hypo, creating a body that is untrustworthy for certain tasks like driving or holding a baby. I will discuss these

⁸² However, some of my interviewees maintained very strict diets. Hayden especially, who has lived with type 1 for thirty-five years and is now seventy-one, takes the same amount of fast-acting insulin for every meal and ate only enough carbohydrates to match this amount. He says that if his portion size is too small, he will eat extra bread; and that, if it is too big, he will not eat it all. Hayden reflects that this is his own preference and not as a result of an imposed discipline. Such self-regimented bodies may then exist, with some PWD happy to stick to rigorous regimes in order to ensure a consistent blood sugar level. In contrast, Albert, who had recently been diagnosed with type 2 diabetes, reflects on how his life has been “ruined” because he is no longer able to eat sweet things as freely as he had done in the past.

⁸³ ‘Running blood sugar levels high’ – refers to a practice of many people with type 1 diabetes of deliberately aiming for higher than advised blood glucose levels (as noted previously, the suggested range for blood glucose levels is between 4mmol/l and 8mmol/l, so high would be anything above 8). My participants often ‘ran high’ in order to limit the likelihood of a hypo occurring. This will be discussed with reference to the spatial anxieties of my participants in Chapter 6. Alternatively, many people with type 1 diabetes may choose to run high in order to lose weight, a common side effect of frequently higher blood sugar levels. This is sometimes referred to as ‘diabulimia’. Only one participant, Adam, admitted to running his blood sugar levels high for this reason. As mentioned in Chapter 2, Balfe et al (2013b), cover the issue of diabulimia in more detail with regards to young women.

tensions in relation to my own data in the following chapter, but the point to consider here is that the threat of hypo is a constant in the life of PWD. From my participants, there emerges a constant mindfulness of the body in order to deter hypo. Graham, despite having type 1 for six years and only having experienced one hypo, still fears the experience: “I fear all hypos, still it is my biggest worry ... just the fear of having one in general. I think because I’ve only had one, and a mild one at that (4.2[mmol/l] so not even below 4), I’m still wondering what a full blown hypo might entail”.

Lydia, also type 1 and diagnosed for seventeen years, expresses her ever-present worries about hypos as well: “I have been told that I can do any sport but I am still unwilling to try a lot of them in case I go low ... I haven’t learned to drive because I am scared I will go low and crash the car and kill people”. Certainly, her interval since diagnosis supports the argument that the diabetic body does not necessarily easily recede over time. The fear of hypos can restrict time-space geographies, clearly evidenced by Lydia being less mobile than she might otherwise be due to her fear of consequences should she hypo while in control of a car. Likewise, Richard describes being pulled over by the police, on suspicion of being drunk, while driving and experiencing a hypo. After recovering, he vowed never to drive again and gave his car to his daughter. While possibly creating “diminished worlds” (Wilton 1996: 69) for some PWD, hypos also make it difficult for the diabetic body to recede (this restriction on mobility will be discussed in detail in Chapter 6): there always needs to be attention paid to blood sugar levels, to the various bodily warning signs, such as shaking hands and increased sweating that my participants widely reported, as well as to the non-felt signs such as a low blood sugar reading on an electronic meter.

TOWARDS SPACE-IN-BODY

Diabetes is undoubtedly a very embodied condition. There is no shortage of disorganised episodes that suggest an imbalance between personal body practices and the ideal ‘virtual infrastructure’ (Bissell 2015) of diabetes. A more thorough imagining of one’s diabetic body, from the ‘inside out’ rather than the ‘outside in’, may lead to some reconciliation between these two poles. Unfortunately, my participants often find it difficult to talk about their body and its internal intimacies. Anna provides the most in-depth reflection of all my participants:

Well I've never really thought, obviously I knew the pancreas didn't work and I knew kidneys ... when they were showing me how, it does this to your liver and the trace [of protein] ... what that'll do and then like your heart ... just the whole idea of like looking inside your body was a wake-up call for me ... I never thought about my insides ... now I'm very aware that I must look after inside of me as well as the diabetes because of the problems with my eyes⁸⁴.

Anna refers to some of the exercises from the DAFNE course that she attended. One included studying a series of retina photographs from PWD and ordering them from least damage to most damage. She says that she was shocked to see the difference between the two poles and shocked further when another participant on the course admitted to having retinopathy. On another DAFNE course that I attended, one doctor presented the group with a series of cafetieres, each representing kidneys at various stages of renal failure. In each one he had placed a liquid solution with various pieces of detritus floating throughout to represent protein, and with each cafetiere he had made increasingly larger holes. As he plunged each one, the group could see more and more of the detritus escaping through the holes. He said that this demonstrated increasing damage to the kidneys in someone who had not controlled their diabetes well⁸⁵. Anna had witnessed this same demonstration on a different course, and, along with her fellow participant reflecting on her damaged eye, it caused her to become more aware of her inner body. A phenomenology of the bodily interior, which forefronts the 'organic' (of the organs) level may then de-mystify these inner spaces and provide PWD a fundamental reference point to help them understand their condition.

To express effectively what I mean by space-in-body, it is useful to turn to Hillman and Mazzio's (1997) edited collection, *The Body in Parts*. They write, in their introduction, that in early modern Europe (16th and 17th century) individual body parts emerge as 'things' in their own right and no longer have to be understood as incorporated with the rest of the body whole. They neatly summarise the collection:

⁸⁴ Interestingly, Anna hints that she regards caring for the 'inside of her' as different from caring for her diabetes, as she says: "I must look after inside of me as well as the diabetes". This response perhaps explains why my initial research participants found my 'internal' questions difficult to answer. After the first few attempts I stopped asking about body interiors. Anna's 'interior' account emerged without my probing.

⁸⁵ The kidneys normally should catch protein, but consistent high blood sugars can damage them, causing them to be less efficient so that more protein escapes into one's urine. This is the onset of renal failure. Therefore, PWD undergo frequent urine tests to detect increased levels of protein.

The ontological status of the part [of the body] is revealed again and again in the essays here [in the book] to be in endless flux between the positions of subject and object: as vehicles of culture and symbolisation, as organs with eerily individuated agencies, as objects of libidinal cathexes, as instruments of sentient experience, as imagined *loci* of self-knowledge and self-alienation. What is imagined here is indeed, as Pascal vividly put it, a ‘body full of thinking members’ (Hillman and Mazzio and Pascal quoted in Hillman and Mazzio 2007: xii emphasis original).

This quote is steeped in ideas of the active body: parts of the body can be both something apart from the self and yet integrated to it. This acknowledgement of internal parts provides a different mode of analysis, with the focus shifting from body-in-space movements to the unseen sites, movements and experiences of the internal body, as also described by Leder (1990a). The idea of a subjective part, operating with its own agenda, against the will or desire of the rest of the body is discussed in Mazzio’s (1997: 58) chapter. Taking the tongue as synecdoche for the body, she considers how, through speech, the tongue can betray the body, an “internal émigré” capable of both good and evil, regarded as a subjective part: “the fact that a conversation with one’s tongue was even an imaginative possibility speaks to its status as alternately scapegoated or sanctified body part” (ibid: 58).

Returning to academic geography, Thrift (2004: 86) calls for those using NRT to think of objects as having their own agency and as being “more than mute props to which humans react”. Mazzio reflects the perceived agentic capability of organs, although, admittedly the tongue is not an ‘internal’ organ in the same way as the pancreas. Collis (2007) meanwhile demonstrates the affectual capability of internal organs as she looks into the emotional response of a group of women who underwent hysterectomy. She finds that some women mourn their uterus for its part in conceiving children and starting a family, while others note that they feel a loss of femininity with its removal. The womb and uterus is considered as signifying key aspects of being a woman through fertility. Other women, in Collis’ study, conversely report no emotional attachment to their womb or uterus, considering it as having fulfilled its purpose of having children and so being easily discarded. Locating the source of diabetes in the pancreas has enabled PWD to identify their own “internal émigré” (Mazzio 1997: 58). The following sections introduce a case study of two online bloggers/cartoonists who attempt a visualisation of their bodies’ interiors, specifically the pancreas, in order to negotiate their identities as PWD.

MEGAN RADFORD

Megan Radford is a popular writer and blogger on a variety of subjects, including her experiences of living with type 1 diabetes, with which she was diagnosed aged six. Radford hails from Vancouver, Canada, and her blogs and sketches often reflect her annoyances at living with the condition (Radford personal website). The following examples illustrate a personification of the pancreas and its perceived ability to affect Radford. Figure 9 represents Radford's experience of Halloween during which, due to her sugar intake, her pancreas "shivers in fear", suggesting both a physical internal movement and also an emotional response specifically from this 'part' of Radford's body that seems independent of Radford's desire to over-indulge. The next sketch, Figure 10, depicts Radford's vision of the "Diabetic Superbowl" where PWD compete against pancreata. In this sketch, she notes that a PWD's pancreas is defective, personifying the pancreas as lazy and almost self-indulgent, rather than contributing to the overall optimally functioning body, and also as actively mean, purposefully withdrawing its contribution. Such is the foundation of this sketch series, which sees the pancreas team having to be overcome by an active team of PWD, a strong metaphor for the dys-appearing body. Figure 11, also from the "Diabetic Superbowl" series, envisions the fans of team pancreas; to Radford, they are biological cells and active collaborators in the pancreata's laziness and withdrawal of labour from the body. They are seeking to "divide" the other team, another strong metaphor, this time of breaking up a coherent and functioning body into conflicting, rather than cooperating, parts. Thinking through space-in-body, these sketches show how we can start to perceive and visualize a "body full of thinking members" (Pascal quoted in Hillman and Mazzio 1997: xii).

Radford, elaborates on why she chose to represent her diabetes through the use of such cartoons and blogs:

I got really tired of all this [assumptions and stereotypes about diabetes] – to me, diabetes was annoying, scary, and morbidly funny at times. Making it funny and visualizing the disease as something inside me (not me, and conversely not entirely separate from me) made it something I could understand. Some people take the disease on vehemently as a part of their being – I wasn't entirely comfortable with this. Some people ignored it and/or viewed it as entirely separate, a disease that is not a part of themselves. I wasn't comfortable with this either. I fall somewhere in the middle of these two poles, and the cartoons are my way of visualizing this, accepting it, and

making it funny and therefore a little less scary (Radford, personal email with author, 24th September 2012).

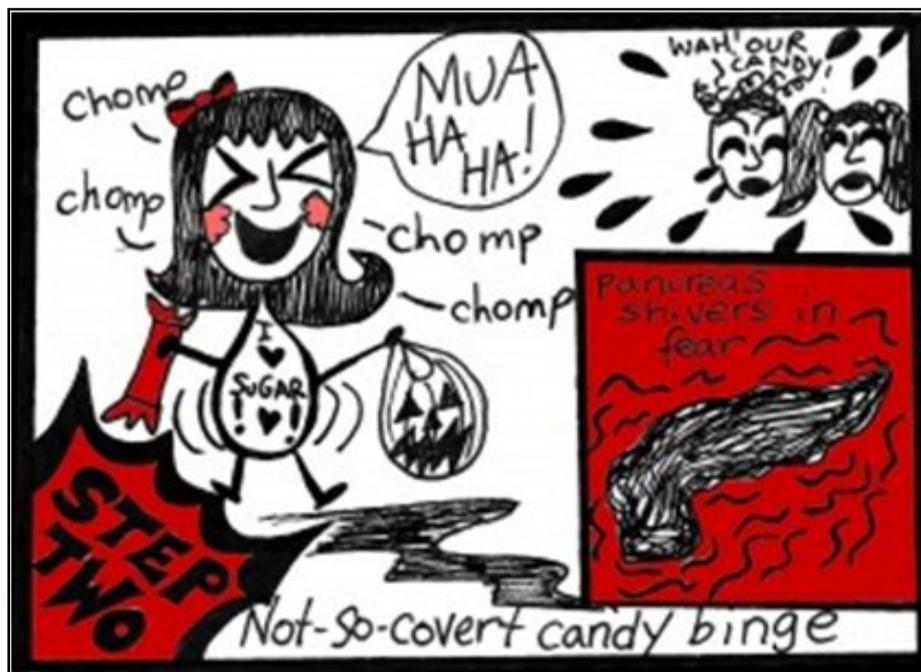


Figure 9. Radford's depiction of her Halloween, which due to her over-indulgence in sweets causes her pancreas to 'shiver in fear' at the thought of so much carbohydrate which it cannot handle. Reference: Radford Halloween.

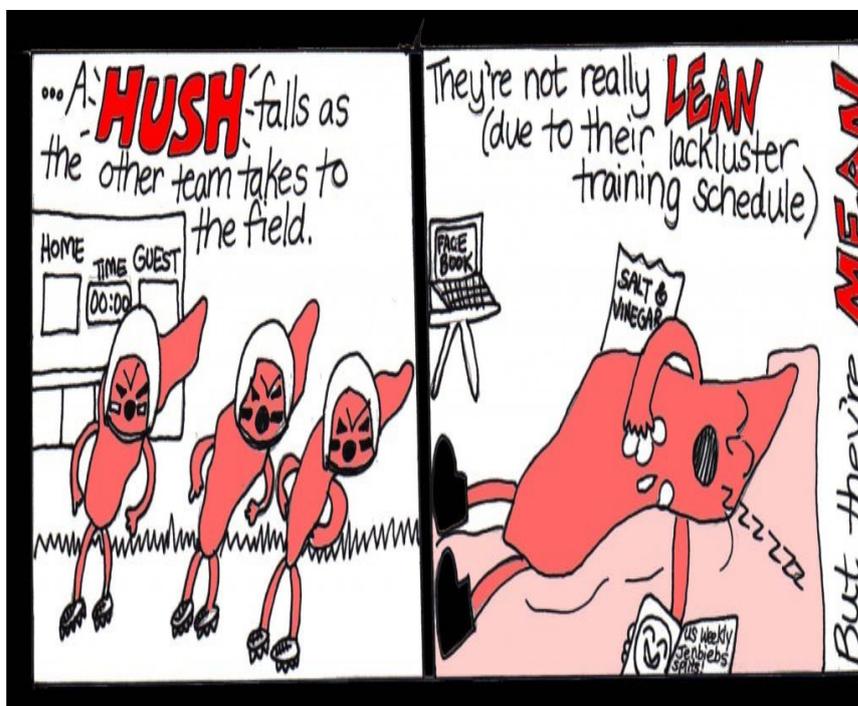


Figure 10. Radford's depiction of the 'diabetic superbowl' and the lazy but mean pancreas team. Source: diabetesdaily website. Reference: Radford Superbowl.

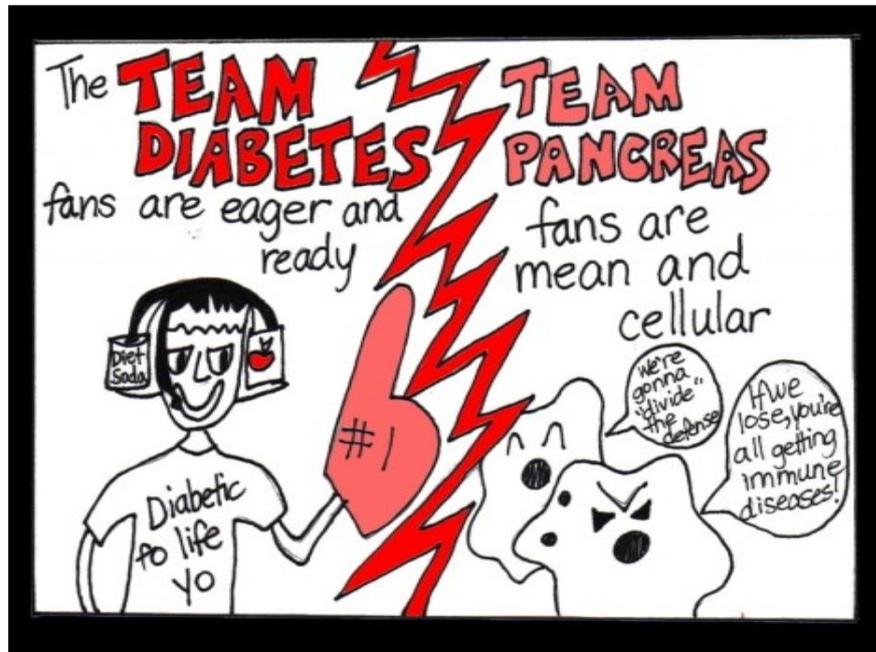


Figure 11. Radford's depiction of the opposing diabetic superbowl fans. Source: diabetesdaily website. Reference: Radford Superbowl.

Here Radford extols the benefit of *placing* her diabetes, placing it somewhere between obsession and ignorance. She negotiates this spatially through ascribing the pancreas a comic personality, thereby setting it up as ‘another’ but still ‘another’ that is inside oneself, ‘another’ that is at least supposed to be part of oneself but is not always usefully so. Brown and Tucker (2010: 239) offer a useful conceptual reference for this positioning, describing an “intermediary reality” where “experience does not belong wholly to either subject or object”.

HAIDEE SOULE MERRITT

Another example to consider is that of Haidee Soule Merritt. Merritt is the author/illustrator of a comic diabetes picture book, and she blogs about her experiences as a diabetic, mostly through sketches rather than text and is an editor of online diabetes magazine, *Insulin Nation*. Merritt lives in New Hampshire, USA and has lived with diabetes most her life; she is now in her forties, reflecting that she does not know what it is like to live without diabetes (Merritt personal website). Her active blogging further supports the idea that the diabetic body never fully recedes, not least when introducing a new character to her blog:

Another new character to let loose, since little good is done keeping him to myself. Meet *Bad(ass) Pancreas*, the unwanted, uninvited guest that sucks your energy and leaves destruction in his path. Demanding of attention, chronically critical and hopelessly impatient. You bend over backwards to make him happy – to keep him quiet – but it’s never enough. A crude character with a feral tongue and a fondness for cigarettes and booze (Reference: Merritt, *Bad(ass) Pancreas*).

In Figure 12, Merritt introduces *Bad(ass) Pancreas*. This sketch effectively ties in with Svenaeus’ (2000a) idea of the ‘unhomelikeness’ of illness where one’s body *is* one’s home. Not only will *Bad(ass) Pancreas* invade the man’s life but also his home: it is “here to stay”, its various pieces of luggage, sports equipment and cooking equipment highlighting that *Bad(ass) Pancreas* is preparing to infiltrate *all* aspects of the poor man’s life. Even the clock on top of the backpack can hold significant meaning in a PWD’s life, Stuckey (2007) revealing how one woman perceived a clock to be a reminder of her constant, daily self-management routine. The body *is* home for the man, as Svenaeus (2011) would argue (not merely a metaphorical sense of home⁸⁶), but, through the arrival of *Bad(ass) Pancreas*, he recognises the shift to unhomelikeness. Figure 13 illustrates the dys-appearance of the diabetic body, with the man lamenting that he had fewer unpleasant body surfacings with his previous homelike body. This sketch highlights the recursive relations of body-in-space with space-in-body, but also captures the importance of the internal origin of these abject surfacings, imagined as the rear end of the pancreas.

Through looking at the space-in-body, internal places can be seen to influence a person’s behaviour. *Bad(ass) Pancreas* highlights this when it comes to diabetes, Figure 14 refers to that fact that diabetes can affect a man’s sexual performance and subsequently feelings of masculinity. It will have become clear now that Merritt’s *Bad(ass) Pancreas* is not necessarily a product of her own experience. She explains that the decision to portray *Bad(ass) Pancreas* as belonging to a man was an almost

⁸⁶ Svenaeus’ use of the term ‘home’ has been criticised by some who feel a metaphorical use of the term home implies safety, which is not necessarily how home is experienced (Ahlzen 2011). Svenaeus (2011: 341 *italics original*) responds:

To the objection that health is not really homelike being-in-the-world and that this is merely a metaphor, I would consequently reply that the homelikeness of health is as close to being at home as we could possibly get. The meaning of being at home is not transferred to health by way of the example of a person living in a house, or the meaning of illness by way of the people living in the streets devoid of shelter. The lived body in its being-in-the-world *is* the primary home of human being.

unconscious decision, as she believes that the series would have more appeal with a man as the central character⁸⁷.



Figure 12. Introducing Bad(ass) Pancreas. Source: Merritt’s personal website. Reference: Merritt Bad(ass) Pancreas.

Merritt explains, in a personal email (23rd February 2013), that Bad(ass) Pancreas was borne of a desire “to look at the disease and the organ from different perspectives, which, I should add, are not necessarily my own”. She stresses as well that “of course this is a cartoon character with a mind of its own etc”, an acknowledgement of the imagined subjectivity held by the pancreas, a character in its own right functioning independently from other parts of the body. Merritt is also imagining Bad(ass) Pancreas as a more universal character, reflecting that it is not only deriving from her own experience but from others’ as well.

⁸⁷ The following quote better explains Merritt’s decision and thoughts on this topic:

I do a lot of my characters as men because I think it has a better chance of appealing to more people. It’s my personal feeling that women can put themselves in the role of men a lot more easily ... In my mind, it’s more acceptable for a woman to identify with a man than it is the other way around. It’s safer. Even children’s literature seems to imply that stories with girl characters are written for girls whereas books written about boys are acceptable to both sexes. So, that decision was more a (subconscious?) marketing decision than me wanting to be a man and/or have a penis of my own (Merritt, personal email with author, 23rd February 2013).

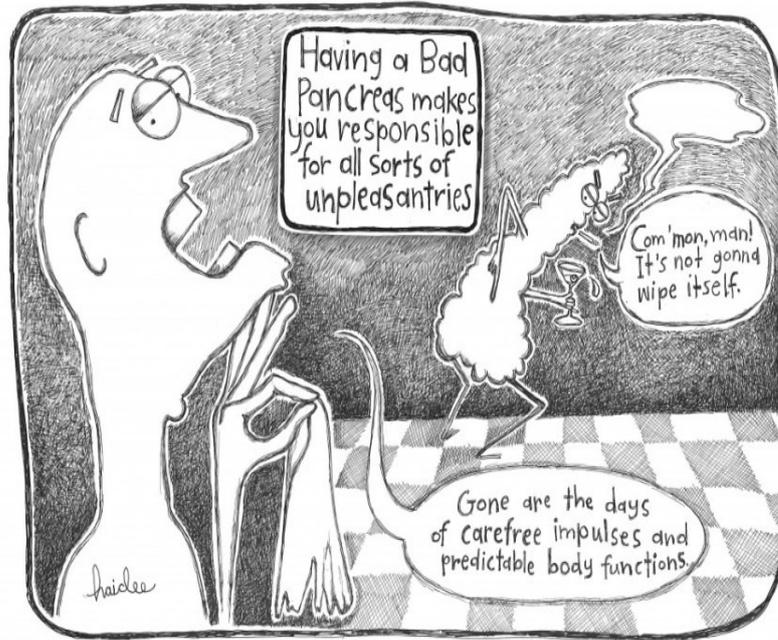


Figure 13. Impact of the Bad(ass) Pancreas. Source: Merritt’s personal website. Reference: Merritt Bad(ass) Pancreas.

The theme of relationships continues in Merritt’s drawings, Figure 15 showing how a hypo can affect a person’s relationship, envisioned as Bad(ass) Pancreas casually manipulating the PWD to cause a dramatic outburst. The more serious effects that a hypo can have on a relationship are examined by Rajaram (1997), who discusses how such outbursts can often be violent and lead to couples separating. In Figure 16, Bad(ass) Pancreas is considered a participating member of a couple’s relationship, fracturing the love heart in the background and upsetting the couple, insisting that there is “no room for a normal relationship” when you have diabetes.

Cohn (2010: 77) writes that images of brain scans serve to externalise mental illness, so that the illness can become a more tangible social object able to be the subject of conversation and helping to legitimise the illness and its effects. Arguably, this is akin to what Merritt is doing in this series of sketches, deliberately externalising the pancreas through visualisation; thereby, such a recessed condition can become palpable in conversation. Likewise, Kingsbury (2007) explores the ‘extimacy of space’, considering how intimate feelings of individuals can be inscribed on external objects; in the case of his research, yellow ribbon magnets being an object receptor for feelings of anxiety about loved ones serving abroad in the armed forces. Although

the pancreas in this case does not exist external to the body⁸⁸, like the magnets or scans, in Merritt's imagination it often does, reflecting her desire for diabetes to be an 'extimacy' both other to her and external to her so as to be acknowledged by others, but always still fully felt by her. Indeed, true to the concept of 'extimacy', Merritt explains the motivation behind her drawings of Bad(ass) Pancreas:

Well, let's see ... it just seems that we have this unruly organ that sort of messes everything up, not just on a biological/physical level but on a social one as well. The organ is the cause of medical complications but SO much more: our moods, our interactions with others, the way we react to the world around us. It has enormous influence but also seems to be out of our control, like an unwanted guest. The organ is internal, yes, but that's only half the story (Merritt, personal email with author, 22nd October 2012 emphasis original).



Figure 14. Bad(ass) Pancreas affecting masculinity. Source: Merritt's personal website. Reference: Merritt Bad(ass) Pancreas.

⁸⁸ Although later in the chapter, we will see how a substitute to the pancreas can exist as external to the body in the form of an insulin pump.

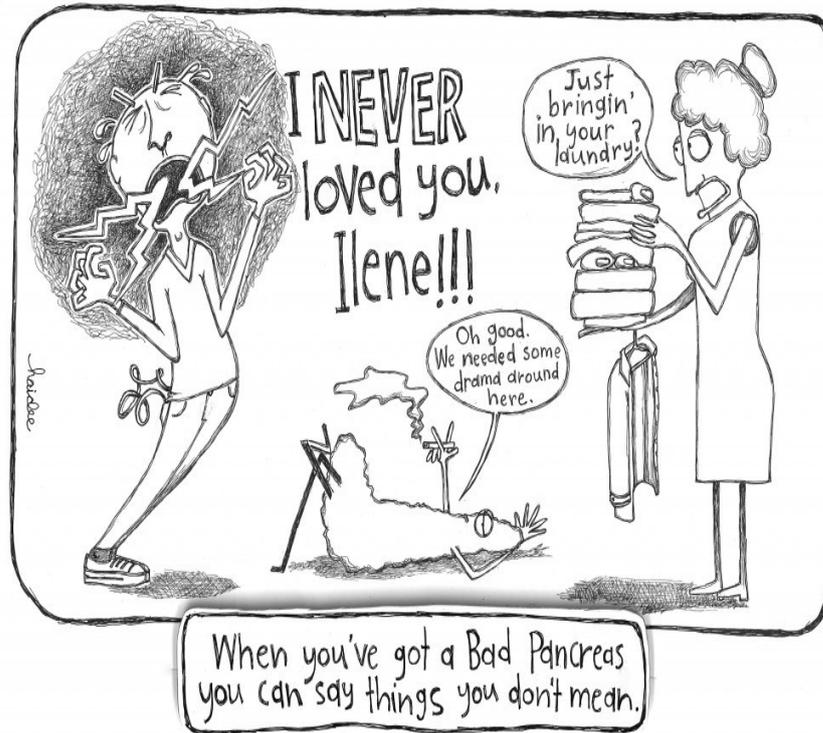


Figure 15. Bad(ass) Pancreas manipulating a relationship. Source: Merritt's personal website. Reference: Merritt Bad(ass) Pancreas.

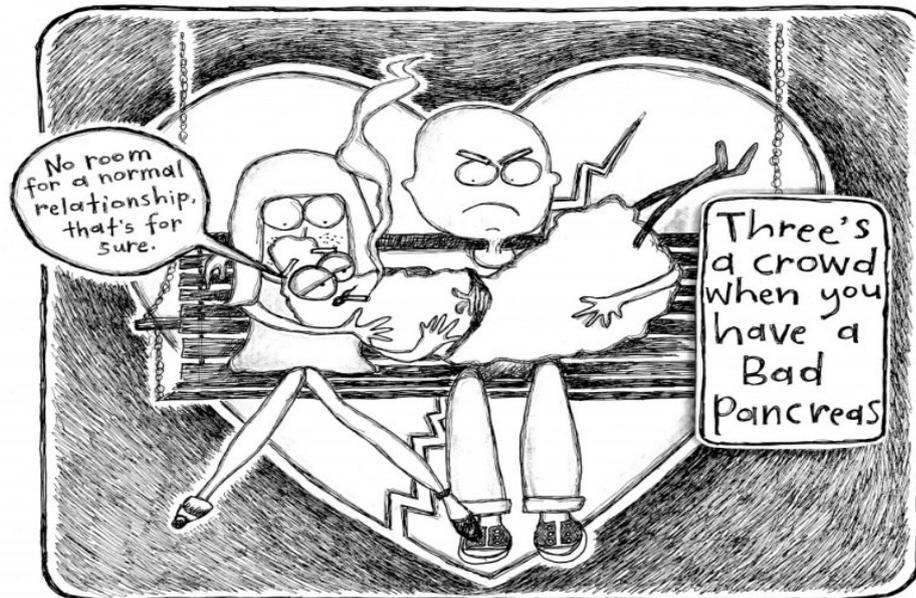


Figure 16. Bad(ass) Pancreas continuing to impact on relationships. Source: Merritt's personal website. Reference: Merritt Bad(ass) Pancreas

For Merritt, the pancreas is a key site within the body whose influence extends into the body-in-space, an influence that is almost futile to resist. She writes how the fact it is internal is only “half the story”, a salient point for my argument here. Turning

this statement around, though, I have also shown that diabetes considered as an external condition is also only half the story. In a further email, Merritt writes:

What inspired the [Bad(ass) Pancreas] was simply the idea of having an organ that causes chaos in every area of a diabetic's life. Something we diabetics could not only *see*, but also *blame*. It's obviously – for many reasons – not very realistic: disruptions are more the fault of a NON-functioning organ than one that actively (and intentionally) intrudes (Source: Merritt personal email with author, 23rd February 2013 emphases original).

Merritt highlights the importance of giving PWD something to see and blame. She acknowledges the irony of these sketches: Bad(ass) Pancreas intrudes and affects because it does not do anything, it is the absent labour that causes frustration. Hence, even an organ that is somewhat redundant is still able to be a pervasive affecting force within a PWD's body.

Leder (1990a) writes that the normal, healthy body dys-appears at times of pain and disease, leaving a body that now has to reflect on its problems. The troubling division in these sketches, and the idea of the pancreas as both part of one's body and separate to it would likely be unsurprising to Leder. He argues that “the painful body is often experienced as something foreign to the self” (ibid: 76), and that in times of disease “a specific organ, rather than serving the rest of the body, manifests an independent pattern ... an organ suddenly goes its own way, failing to perform its required role in proper coordination with others. One's body falls away, apart, from itself” (ibid: 88). Later, he expands on the subject of a complicated identity occurring at times of dys-appearance:

In experiential terms, one becomes aware of the recalcitrant body as separate from and opposed to the 'I' ... this arises from an opposition *within* the organism, not between it and an ontologically separate thing. The self that takes note of the body remains a moment of the organism, an *embodied* self (ibid: 88 italics original).

The fact that Radford and Merritt draw the pancreas as an external presence highlights the complicated embodied self of a PWD. Figure 17, shows Bad(ass) Pancreas back inside the man's head reflecting on the mess he has made to the man's identity, leading him to question “what the fuck is wrong with me”? The evidence of a gin bottle harkens back to the idea of hypo and losing control. Many people liken the experience of hypo to being drunk, and Bad(ass) Pancreas here seems to be cleaning up the mess of something he has done: possibly he made the man experience a hypo.

This sketch expands on this complicated diabetic identity, powerfully conveying this sense of unhomelikeness. The pancreas is both part of the body and not part: it is at home, it belongs in the body, but it is not at home in the right way. It is comparable to the lazy teenager who lives at home with parents, but is reluctant or negligent at chores and so does not contribute to functioning of the household. Figure 10, from Radford, keenly displays this construction as well, the pancreas pigging out in its room, half asleep with *Facebook* open on the computer.

Simonsen (2007: 177) provides a way of understanding a possible reason why Merritt and Radford chose to draw the pancreata as both internal (subjective) and external (objective):

The social body is also an imaginary body that is created through the relations of vision or touch between bodies recognisable as friendly and/or strange. Encounters with other bodies therefore involve practices and techniques of differentiation. Familiar bodies can be incorporated through a sense of community, being with each other as like bodies, while strange bodies more likely are expelled from bodily space and moved apart as different bodies.

In this quote a sense of body-in-space prevails, with the imaginary body being created through relations with other bodies. In Radford's and Merritt's sketches, the other body is that of the pancreas, now embodied as a personified character and able to be differentiated against, for example by being "expelled from bodily space". To revisit Brown and Tucker's (2010: 239) "intermediary reality", however, the pancreas is still a familiar body and Merritt still draws it inside the person's mind, still participating in the person's everyday life. Radford, meanwhile, definitely acknowledges that the pancreas is part of her, her email response expressing her struggle to understand where the pancreas fits in: for her, it is "not me, and conversely not entirely separate from me". Indeed, to complicate the pancreas' role further still, Bad(ass) Pancreas in Figure 17 is helping the man to recover, it is cleaning up, the morning after its 'house party', acknowledging that it does have a role to play in the functioning of the body if remaining somewhat unrepentant.

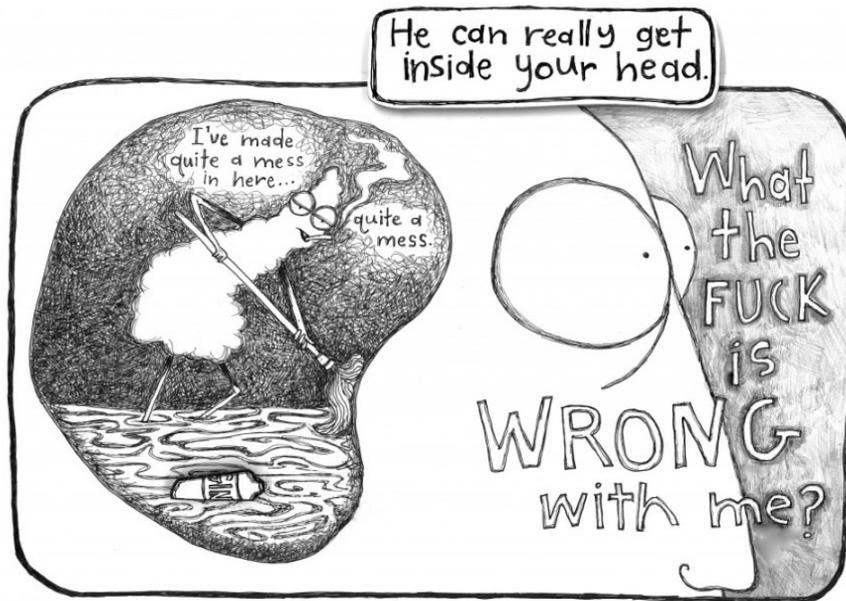


Figure 17. Bad(ass) Pancreas inside a man’s head causing mischief and doubt. Source: Merritt’s personal website. Reference: Merritt Bad(ass) Pancreas.

BODIES AND ORGANS

Through the sketches and email responses of Radford and Merritt, we see the emergence of a diabetic BwO. Fox (2012: 164) writes that “the BwO is like an uncharted territory, but one whose possession must be fought over, inch by inch. The BwO is endlessly territorialised, deterritorialised and reterritorialised. Territorialisation is a function both of the forces of the physical and social world, and by the motivated, ‘experimenting’ BwO as it becomes other”. The BwO is an ideal, but unattainable, body, to which Deleuze and Guattari (2003) suggest we must strive, even if only theoretically. It is a ‘balanced’ body, *upon* and *inside* which no one territorialising force – of, for instance, biomedicine, culture or social context but also of pain, disease or discomfort – is dominant. Although there is a focus on one particular organ in this chapter, Deleuze and Guattari (2003: 158 my emphasis) explain that “*the BwO is not opposed to the organs*; rather, the BwO and its ‘true organs’, which must be composed and positioned, are *opposed to the organism*”. A self-composing and positioning of organs helps to establish a “plane of consistency”, rejecting a hierarchical, biomedical understanding of the body that is the organism. Deleuze and Guattari (ibid: 149), at the beginning of their chapter about “making yourself a body-without-organs” describe a series of closed-off bodies, all orifices

sealed, and through which pain could travel in something of a closed loop. Later they explain the balance needed for creating a BwO:

You have to keep enough of the organism for it to reform each dawn; and you have to keep small supplies of significance and subjectification, if only to turn them against their own systems when the circumstances demand it, when things, persons, even situations, force you to; and you have to keep small rations of subjectivity in sufficient quantity to enable you to respond to the dominant reality. Mimic the strata. You don't reach the BwO, and its plane of consistency, by wildly destratifying. That is why we encountered the paradox of those empty and dreary bodies at the very beginning; *they had emptied themselves of their organs* instead of looking for the point at which they could patiently and momentarily dismantle the organisation of the organs we call the organism (ibid: 160-161; italics original).

Deleuze and Guattari lend support to the idea of space-in-body, proposing that the organism should not be completely abandoned. As we have seen with the experience of diabetes, one can never utterly destratify and people still have concerns with their eyes, their feet and their vitality. But to give in completely to this diabetic organism can result in a fatalism, perhaps in examples of these “dreary bodies”, earlier in this chapter: Jessica's body is, in some ways, ‘closed-off’, as she refuses to disclose her diabetes to her work colleagues; as are Sarah's and Gillian's as they internalise their anxiety.

However, the envisioning of the pancreas by Radford and Merritt provides a route away from thinking of this troubled body and, instead, to a body that is constantly changing, never stable or definitive. Deleuze and Guattari (2003: 161) consider that the construction of the BwO can be easily “botched”, either through failing to achieve it at all or going too far:

If you blow apart the strata without taking precautions, then instead of drawing the plane you will be killed, plunged into a black hole, or even dragged toward catastrophe. To achieve the BwO one needs to find an advantageous place on it, find potential movements of deterritorialisation, possible lines of flight, experience them, produce flow conjunctions here and there, try out continuums of intensities segment by segment, have a small plot of new land at all times.

Indeed, this eking out of the diabetic BwO is precisely what Radford and Merritt are trying to accomplish. Fox (2011) argues that in healthcare practices there is often a body-*with*-organs, which is territorialised disproportionately by biomedical or healthcare powers, to which ill and impaired people are susceptible. The BwO, is an

endeavour to *reterritorialise* by resisting these dominant powers. Fox (ibid: 369-370) writes that for a BwO, ‘health’ is not defined in biomedical terms but:

‘Health’ is the body’s capacity to affect and be affected, to form new relations, and thus to resist forces of territorialisation that limit these capacities. The ‘health’ of a body is the outcome of biological capabilities and cultural mindsets, alliances with friends or health workers, struggles for control over treatment or conditions of living. It is neither an absolute (defined by whatever discipline) to be aspired towards, nor an idealised outcome of ‘mind-over-matter’. It is a process of becoming, of rallying capacities, resisting physical or social territorialisation, and experimenting with what is, and what might become.

Radford and Merritt present an approach to this reterritorialisation by, imaginatively, removing the pancreas from the body, thereby allowing them to resist powers of territorialisation, such as Radford explains in an earlier quote, as she identifies two extremes of ‘having diabetes’: being ‘vehement’ or being ‘ignorant’. Merritt also reflects this reterritorialisation by acknowledging the frustration that the Bad(ass) Pancreas has both ‘biological’ and ‘social’ consequences for PWD, who therefore need something to ‘blame’.

So far, this chapter has focussed on how diabetes can ‘break-up’ an optimally functioning body. However, new and emerging treatments for diabetes are seeing the increasing use of ‘replacement’ therapies such as insulin pumps, which simulate the work of the pancreas. Arguably, pumps provide more integrated management than MDI with recent studies showing that they decrease hypo occurrence and improve HbA1c (Valla 2013). With the technology of the pump ‘replacing’ the pancreas, ideas about the ‘cyborg’ nature of PWD are never more apt. Wilson (2009) insists that the concept of cyborg in human geography is rarely employed further than an ontological way of understanding dualisms (of, for example, human/machine), and he argues instead for the ‘cyborgian’ to be considered as a situated way of knowing. Considering the cyborg as a way of becoming as espoused by Wilson allows us to see how PWD consider bionic technologies to be either beneficial in creating ‘easier’ diabetic identities, or, conversely, as contributing towards more troublesome diabetic identities.

The use of an insulin pump, as opposed to insulin injections, can perhaps allow for a sense of a BwO. In Figure 18 Radford claims a diabetic identity, arguing that being different can be more fun than conforming to normal expectations of having the

latest cell phone or conforming to the poser image of Zack Morris⁸⁹. This claiming of a diabetic identity is similar to Davidson's (2008: 800; italics original) findings that "self-identification as autistic – as opposed to being stuck with a label professionally applied – is crucial for the sense of empowerment and entitlement that can motivate movements for change". Radford rejects the territorialising ideas of diabetes as hidden; instead, she deterritorialises, by being out and proud of her diabetes, forging her own preferred cyborg identity. She is advocating the multiple norms of Canguilhem (Mol 1998) and 'the normality of being different' as described by Hansen and Philo (2007)⁹⁰.

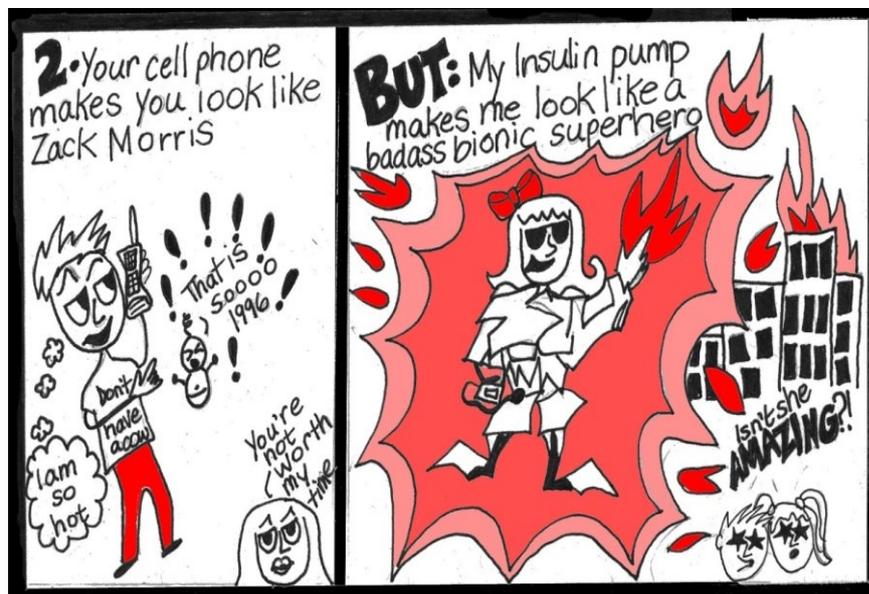


Figure 18. Radford claiming a cyborg identity. Source: diabetesdaily website. Reference: Radford cyborg.

The pump technology is ever advancing. Most recently, in the USA, there have been trials of a bionic pancreas (Russell 2008; Russell et al 2012), which involves an

⁸⁹ A character from US 1990s sitcom *Saved By The Bell*.

⁹⁰ Wilton (2003: 382) argues that "psychoanalysis as a medicalised discourse informed by the assumption that in order to cultivate a 'healthy' ego, disabled people, like women, must resign themselves to their 'loss' ". He argues that such a discourse neglects the perspective of people with disability while offering various theories about them and compares this discourse to the medical model of disability which attributes disability to a person's impairment rather than any other structural factors. He supposes that when the perspectives of disabled people are considered "it becomes much more difficult to sustain disabled bodies as fundamentally deficient" (ibid: 382), and that "those locales in which disabled bodies are able to resist conformity with dominant representations may help to foster uncanny moments in which the distinction between self and devalued other is less certain" (ibid: 385). In my analysis we are hearing from PWD, who, although, not necessarily 'disabled', are still subject to certain normative expectations in which having diabetes is a 'loss'. Radford is clearly challenging this in Figure 17.

insulin pump, glucagon pump and continuous blood glucose monitor working with reference to each other. Automatically one's blood is tested, at defined time intervals, and the devices make a 'decision' on how much insulin (to lower blood sugar) or glucagon (to raise blood sugar) to release into the person's body. One of their trialists, Kelly Close, a contributor to online magazine *diaTribe*, has recently written an article about her experience on a five day trial having this device attached. Her account highlights this sense of a BwO enabled by a close but far less intensive relationship with self-management technology. She reflects that:

My bionic pancreas never failed me. I felt like the 17 year old, completely carefree Kelly I used to know back before I was diagnosed. Getting rid of hypoglycaemia and hyperglycaemia for a week was one of the most powerful things I've ever experienced (*diaTribe* June 2013: 11).

Close muses further on the benefits of the bionic pancreas and this relinquishing of control:

During the trial, I also had an epiphany about living with diabetes: 'Oh my gosh, I waste so much time having diabetes!' ... I felt like my whole world changed when I was constantly in a state of normoglycaemia⁹¹. And then I wondered how much I try to be 'normal' and make it 'seem' like diabetes is easy to manage – that mentality is also probably exhausting, even though I'm not even aware of it (*diaTribe* June 2013: 10).

With the bionic pancreas, Close suddenly becomes aware of her previously receding diabetic body, her body-*with*-organs, and begins to appreciate the freedom from the territorialising forces of attending-to her body, hypos and perceptions of diabetes as 'easy'. We have seen Radford's and Merritt's distrust of their pancreata, a fractured organic identity where the pancreas exists as embodied other, but now we see the outlines of a 'bionic' identity emerging, a trust developing between human and machine.

However not everyone has such an easy relationship with the bionic pancreas. Interestingly, *diaTribe* authors also write of a similar trial conducted with children at a US summer camp, reporting that some of the children expressed an anxiety about relinquishing control of their diabetes, of the machine taking over without their conscious input, when for so long their conscious input was utterly essential and

⁹¹ 'Normoglycaemia' referring to being between 4 and 8mmol/L.

lessons of self-body-vigilance so crucial (*diaTribe* August 2013). As Leder (1990a) states, a man who has had a heart attack while playing tennis may well recover and be told his heart is functioning normally, but the experience of a failing heart renders him ever suspicious and distrustful of his heart, especially when playing tennis again. Contrasting opinions are clearly emerging; Close relishes the freedom from diabetes self-management that the bionic pancreas gives her, while the children at camp, if overwhelmingly enjoying the bionic pancreas trial, also admit to an uneasiness about depending on the (automation of the) machines.

All of my participants who use pumps found them to be an improvement over multiple daily injections (MDI). Yet, among those who do MDI, there was often some scepticism about the pump, similar to the uneasiness of the children at the camp. For instance, Derek says:

I know there's new technology coming in [referring to insulin pumps], it's a bit intrusive for me ... I would stick to the pen [referring to MDI]. I don't want things hanging out me, it's just too intrusive ... It would feel very intimidating⁹²; a lot of the questions you've asked previous you'd get a totally different answer if that was the case. No it's not for me. Aye, it might be a ... kid-on [pretend] pancreas, but it might work similar to how the pancreas would work, but sorry not for me.

Ideas of the uncanny, unhomelike and unfamiliarity again come to the fore. Derek is clearly now accustomed to his MDI, and it is comfortable and familiar to him, an assimilated “crutch”, as he says in an earlier quote. Switching to a pump now, even though he admits it would be more of a replacement for his pancreas than is MDI, would change his sense of bodily integrity: with “things hanging out me”, his body would become unhomelike. For Derek, this increased cyborg identity would be too much. A similar phenomenon of rejecting a supposed body enhancement can be seen in Slatman and Widdershoven (2010), who tell the story of two hand transplants, one successful and one unsuccessful. In the latter case, the receiving person felt the hand to be an irreconcilably unfamiliar presence on his body and ultimately had it removed, despite the operation being a medical success. Alice also tells of a conversation with another PWD who was excited about moving onto the pump soon: “I’m not being vain but having an insulin pump on me would be a constant reminder that something is wrong with me and I wouldn’t want somebody to see it”. Like Derek, Alice feels

⁹² He means he would feel intimidated by the machine and its ‘fusion’ with his body.

the pump to be too intrusive, a too obvious reminder of her condition both to herself and possibly also to others. Derek and Alice are keen to keep their diabetes ‘undercover’ and visibly receded. In fact, Derek also mentions that, while refereeing boxing bouts, he prefers to keep his diabetes completely hidden (in part, by leaving his kit, and doing his self-management in his car) so as not to attract doubts from organisers over his ability to stay in control in the ring. The idea of a pump could possibly further stoke his fear of discovery – supporting my claim that, even as PWD may claim an easy routine recession (as does Derek earlier in the chapter), they still refer to moments and/or periods of dys-appearance.

When I met Gretchin, she had recently switched from MDI to a using a pump and she reflects on her initial fears:

There was then the big question. What if the pump fails? This was something that initially scared the living daylights out of me. I had thought out every scenario, What if I’m out with my friends? What if I forget what to do? My manual was rather large for carrying around all the time.

Gretchin captures this feeling of unhomelikeness in her account, her familiar reality replaced by a piece of electronic technology, with the fear that it may fail for reasons out of her control. Gretchin nonetheless says that, due to her pro-active approach to diabetes care (she is involved in many Diabetes UK events and schemes in Scotland)⁹³ and varied support network, she was soon able to incorporate the pump into her life: “controlling your own health at the press of a button is a totally new concept and one that definitely takes some getting used to. However, I wouldn’t change it for anything, the pump has changed my life and it’s definitely going to be a long-term relationship”!

Scheldeman’s (2010) study of children switching to insulin pumps is revealing as to how the pump can be both accepted and rejected by a PWD. She found that some children had very positive relationships with their pumps, embracing the advanced technology, and she hence discusses how the pump can be incorporated into one’s embodiment, leading to its recession in everyday life. She argues that managing diabetes becomes a more mental process, with the diabetic body receding: “before the pump, with bruises and pain they could not forget” (ibid: 154). Yet, she also found

⁹³ This is not to say that Gretchin is a ‘brightsider’. Her current proactive approach, she reflects, is largely in response to her being out of control in her younger teenage years and the sudden death of a close friend (not related to diabetes) which shocked her into improved self-management. In later chapters we will also hear how Gretchin’s proactive approach is sometimes a ‘drag’ for her.

that for some children the pump is not so easily incorporated and, ultimately, can be rejected for other management strategies, much like the preferences of Derek and Alice. Scheldeman (2010: 154) hence supposes that the pump can lead to “experiential disappearance” of the diabetic body for some of her participants. My findings generally support this idea, but also demonstrate how the pump can cause the receding diabetic body still to dys-appear at times. For instance, as hinted above already, some of my participants, like Olivia, are conscious of how their pump made them look:

I thought ... where am I going to put this thing? ... Because they've not worked out how to attach it to you in any way that's particularly discreet. I tend to wear a lot of tight fitting clothes and if I'm wearing a tight dress ... and the neck comes up to here [signalling her neck line] and I'm sitting in a restaurant, I'm sitting doing all this [Olivia makes awkward hand gestures, mimicking trying to subtly conceal and operate the pump on her body] ... or I'm trying to get it up here [through the top of her dress] or whatever. I do it but sometimes it's really awkward ... I just think, right, where the hell am I going to put this thing? And in those instances, if I've got a dress up to here, I'll need to go to the toilet.

While Scheldeman finds this “experiential disappearance” among children, it may not be so easily obtained for adults, who have a different set of social and personal expectations. Olivia's daughter also has type 1 diabetes and uses a pump:

[My daughter] wears hers on a wee belt and a wee pouch round her waist and she was saying to me yesterday, 'why don't you get a pouch and a belt and you could wear your pump like me? Nobody would think you're fat. Everybody at my school knows I've got diabetes and they don't think I'm fat' ... I said 'mummy wears quite a lot of dresses that are quite tight' ... That's just a no go I wouldn't wear [that], you've got a nice dress then you've got this belt about you.

It may disappear more easily for children than for adults who are arguably more aware of their bodies being encumbered, although Olivia's daughter's fears of being perceived as fat because of her pump belt demonstrate that, even among young children, there can be concern over how the pump affects one's body image. While for some, like Gretchin, the pump may lead to a *less* problematic diabetic identity, as they edge towards a BwO, for others, like Derek, it can lead to one *more* problematic, as they edge towards a body-*with*-organs. Olivia represents a more intermediary perspective, generally receptive of the pump and its advantages, but still aware of the times when it can cause one's diabetic body to come into sharp focus.

CONCLUSION

With this chapter I have demonstrated that the diabetic body may appear as recessive to others, but for PWD it is in a near constant state of dys-appearance. Diabetes is a thoroughly embodied condition and experience. Many of my participants remarked on the incorporation of diabetes into their everyday lives, but this was not straightforwardly commensurate with diabetes receding, for attention to and anxiety about the body persisted. Many of my participants expressed frustration at the hidden labours and anxieties of the condition, ones for which it is hard to gain any empathy from others. By delving into a case study of imaginings of the body interior I was also able to explain the interior source of these bodily-facing anxieties: the pancreas was imagined as a fiendish other within, pulling the strings of the diabetic body. Through my correspondence with Merritt and Radford, I was able to present two PWD who describe their everyday strategies of dealing with the condition by exploring the biomedical realities of their own body, of a defunct pancreas, and imagining this pancreas as a social actor in everyday life. It is this contrasting sense of inside/outside of the pancreas and its transition from passive to active (but active in a negligent sense) that so intrigues me in Radford and Merritt's sketches. The imagining of the pancreas as exterior is an almost violent wrenching of this internal part to the visible domain of life, towards the body-in-space, an act of spatial 'extimacy' (Kingsbury 2007). Its perceived agency and personality, along with the retention of its tongue like shape, I feel configure it as uncanny. Drawing on the concept of uncanny as discussed by Freud, Svenaeus (2000a: 4) writes: "the uncanniness would thus seem to relate to the possibility of something dead being alive, or conversely, of something living being controlled by mechanical, 'dead' processes". For Radford and Merritt, the pancreas is something both dead and alive. It is dead in its lack of function, and yet alive in its seemingly conscious rejection of function. The body is then kept alive, despite the pancreas, by the mechanical processes of self-management. The pancreas is a truly uncanny presence that emanates throughout the body. One's space-in-body, the interior organs, sites and flows of blood, will then inevitably influence one's social and spatial interactions in everyday life. This chapter is indeed a 'return' to the body (reflecting a principle of geographies of disability outlined in Chapter 2), to the profound differences of having a diabetic body: a body in conflict with itself, creating

a set of bodily anxieties about losing body parts and forfeiting bodily control, as in the case of hypoglycaemia.

Radford's and Merritt's sketches of the pancreas, along with their written reflections, open up a way for them to think creatively about their diabetes and its impact on their identity. Through this approach, which focuses on a particular organ, ironically, we see the emergence of a body-*without-organs*, a body that is in conflict with itself. It is this *incomplete* body that I feel is so important when coming to understand the lived experience of diabetes. Diabetes is not a stable condition; therefore one's relationship to it is never stable, but always changing and indeterminate. However, advancing technologies, namely insulin pumps, can lead to some PWD experiencing a more stable relationship with their diabetes. This is not the case for all, though, and for some, the mere idea of the pump seemed a step too far into the uncanny, a constant reminder of their bodily difference. Marrying the conceptual reference points of uncanny, BwO and cyborg allows a portrayal of the diabetic body as unstable, fluid, becoming but never complete. In the first part of this chapter, we saw the diabetic body as uncanny, and borrowing terms from Deleuze and Guattari (2003), the body can be thought of as being 'territorialised' by uncanny forces: fears of embodied difference, anxiety over hypo occurrence and the presence of an 'other' within the body. These territorialisations are resisted, attendance to the body can decrease the likelihood of complications, support from friends and family can off-set the severe consequences of hypo (the following chapter covers 'resisting' hypos in more detail) and the internal other can be set apart for admonishment. Embracing a cyborg identity, through the insulin pump, represents the next level of resistance, allowing some degree of freedom from a closely attended-to diabetic body. For some PWD, though, the pump causes its own form of territorialisation, the cyborg part of the body being too prominent, both materially and mentally, so that a PWD is constantly reminded of their different body. For these PWD, who do not like the pump, their tools of *deterritorialisation* are both *physical*, such as MDI, and *conceptual*, such as being able to conceal diabetes. For PWD who prefer the pumps, these same tools do not enable the most seamless self-management and so, are instead, forces of *territorialisation*.

Stuckey (2007) advocates the use of creative methods for treating and caring for diabetes (as discussed in Chapter 4) and I hope that this chapter further supports the usefulness of more varied forms of expression. A recent BBC News article

examines the impact that doodles and cartoons drawn by patients can have on the clinical encounter, resulting in more understanding from the clinician (BBC News Article 2013). Indeed, Anna reacted positively to activities on the DAFNE course which demonstrated interior processes in external environments, causing her to become more aware of the damage that may occur in her body due to poor control. This chapter can then serve to detract from the ‘gluco-centric’ view of living with and treating diabetes. Through the ‘extimacy’ of their sketches, Radford and Merritt bring the *space-in-body* into the *body-in-space*, thereby exposing a broiling sense of, otherwise invisible, anxiety that can exist in the dys-appeared diabetic body⁹⁴.

⁹⁴ I do realise that space-in-body is still limited in this chapter. The ‘geographical system’ that Philo (2000: 13) refers to is not nearly fully explored here, and only one internal site, that of the pancreas, is considered. There are more internal sites to diabetes; there are also flows, and indeed the irregular flow of blood around the body of a PWD is what causes the most visible body-in-space effects of hypoglycaemia and hyperglycaemia, a further example of how the realms of interior body and corporeal space are entangled, reciprocal.

CHAPTER 6**THE SPATIAL CONTINGENCIES OF LIVING WITH DIABETES**

“Why the pluck would you want to be injecting insulin 99% of the places you mention? ... All you do is eat a couple of sweets to solve the problem [of hypoglycaemia]. What has safe got to do with it?” (Elliot).

INTRODUCTION

In Chapter 2 I introduced the wealth of literature concerned with the effectiveness of DAFNE courses in improving life with diabetes. I argued that, while this research has merit, its usefulness for understanding the day-to-day life of PWD is limited. It flirts only briefly with spatial issues, often confining the evaluations of the DAFNE course to immediate eating practices. Living everyday with diabetes is so much more, and I argued that an increased sensitivity to space and place is vital when attempting to understand the lifeworld of a PWD. Such investigations have been commenced by Mol (2008), and I wish to expand further on her observations. In this chapter I will discuss the spatial contingencies of life with diabetes. Taking certain spaces in turn, I will make reference to parts of my questionnaire which asked participants to rate how ‘safe’ they would feel if they were to experience a hypo in a list of various public and private spaces. These results will be presented in chart form to show trends. I will also draw upon interview responses, allowing them to complicate the basic questionnaire results. Of course, my directing of questions in both the questionnaire and interviews to broad spaces such as home, work and public spaces meant that I often controlled the direction of this spatial discussion. However, contradictions between the questionnaire rating scale questions and written or oral responses from participants demonstrate how these discussions were much more intriguing than simple assumptions; of, for example, private and home spaces = safe / public spaces = unsafe. Participants co-opted the questions to express their own distinctive spatial frustrations and spatial strategies, and their responses are imbued with ideas about concealment and exposure of diabetes in certain spaces. This finding raises questions about how the treatment and care of PWD should be approached by clinicians, with perhaps more focus on diabetes as a spatially diverse condition rather than one that is bounded only within the ideal practices and aims taught in hospital spaces. While the Scottish

Government aims for a ‘person-centred’ (DAP 2010) approach, the evidence from my fieldwork shows that a ‘gluco-centric’ approach still persists in Scotland. In what follows I will focus in turn on the broad spatial fields of home, work, public and clinical, all the while discussing the significance of each for a geography of diabetes. I will then discuss how PWD experience space anxiously, so affecting their everyday mobilities, through introducing the idea of ‘spontaneous geographies’.

HOME SPACES

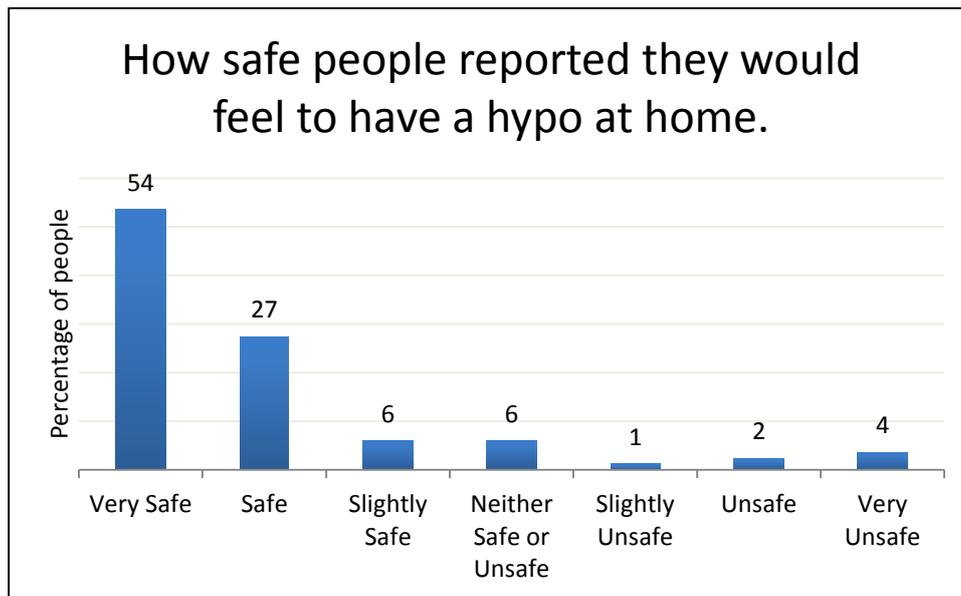


Chart 2: Feeling of safety if having a hypo at home.

Home space was overwhelmingly considered ‘very safe’ or ‘safe’ for experiencing a hypo (Chart 2). For instance, Rachel replies that: “I feel most comfortable testing blood sugar at home, and it is the place most of my diabetes experiments take place ... eating new/different foods, or high carbohydrate foods, and experimenting with insulin doses/timings to match”. For Rachel, the home is the place where diabetes is set up, tested and prepared for with the kinks ironed out before venturing into public spaces. Establishing preferred control of diabetes is often a process of trial and error, and therefore having home as a space where such errors can be made in relative safety is important for Rachel. This was a common opinion, with many participants regarding home as a safe place for experiencing a hypo or carrying out TIM. Participants often remark on the privacy of the home and on the ease of access to supplies, Ken writes: “I feel much more secure at home where I know I have everything I need to hand and where I have privacy if I feel unwell”. Indeed, many

participants note that they feel safe at home they would be around friends and family who would know what to do in the event of a severe hypo.

This safety net is absent for people who live alone, for whom home is perhaps an unsafe place, as Catherine writes:

Living alone with diabetes really sucks sometimes! Waking up in the middle of the night all sweaty and confused then having to try and sort myself out is just rubbish ... I also believed for a long time, as did my poor mum, that if I had a serious hypo in the night I could die because there would be nobody there to give me the glucose injection.

Some participants report feeling unsafe when there is no family or friends to whom to disclose their diabetes for safety purposes. Indeed, while Catherine lived for a long time with a tense fear of hypo, Frederica did have an extreme hypo while living alone and considers this experience:

I came round with the police knocking on my door. I had been battering around my bedroom (bruises to show for it) and my neighbours thought I was being beaten up so they called the police. It was 4.30am and the police were shouting at me through the open window. I felt terrible and mortified. The police wanted to check my house to make sure that I really was on my own and that I didn't have someone in there hurting me! Awful!!!!

Given Chart 2, which starts this section, it is easy to assume that home is safe, private, supplied and occupied by knowledgeable and caring others. Yet, home is often ridden with tension, considered as isolating and potentially dangerous for people who live alone. Myers (2012: 455), finds something similar for men with HIV/AIDS: he discovers that while home is often considered a "secure haven", it can also be a "site of despair". Catherine continues her account, recalling that she finally overcame her fear: "I was then told that would never happen by a DSN [diabetes specialist nurse] and felt really, really stupid. Her laughing at me did not help"! Of course, the DSN's advice is not necessarily true, considering Frederica's story, when a similar event did happen.

The incidence of hypo is not the only concern for people at home; the drudgery of practices that can accompany living at home with diabetes can create something of a 'chore' space. Crooks (2010) notes how many women with fibromyalgia syndrome (FMS) often feel fatigued and unable to carry out household chores. Many respondents to the questionnaire also highlight the fatigue that can accompany high

blood sugar levels⁹⁵. Gilly reveals the delicate balance that exists for all PWD: “[I] lack energy when blood sugar levels [are] higher than should be and generally lack interest in the home at the moment. When doing well have lots of energy and get up and go”. For Gilly, there is a clear difference in energy when blood sugar levels are “doing well” or not. Other responses supported this claim, Clare writes: “I do find household tasks harder when blood sugars are higher than I would like through lack of energy”. Crooks (2010: 59) considers how the women with FMS in her study often had “temporally dynamic” or “routinely unpredictable” lives while at home. This is because, while they were for the most part “spatially routine” in that they spent a lot of time in their homes, what they did in their home and when they did it was dependent on how fatigued they felt, an unpredictable state of being. A similar phenomenon emerges from some of my participants who maintain that, while they do not see diabetes affecting their home life greatly, they are still at the mercy of fluctuating blood sugar levels, influencing their level of fatigue and ability to “get up and go”⁹⁶.

A predictable routine does emerge from the data, though, with the recurring theme of food, as many participants make reference to their need to be aware, unremittingly, of what meals they are eating. Gretchin remarks:

I found it difficult when I moved in with my boyfriend because I was cooking for two rather than cooking for one. When I was making my meals ... I'm good, I'll stick to it so I was measuring my food ... so now that he's there, there's a distraction to me when I'm cooking ... I might not do the blood test. Not that he wasn't there before, but he wasn't there constantly ... I found it difficult with flatmates as well. Sometimes if I go out to the gym, I would test my blood, take my insulin, put my dinner on and they'd be defrosting something in the microwave and I need the microwave [blood sugar level will usually be quite low after exercise and so eating soon after is quite important] ... I shared a flat with five other people for a while, so that was quite difficult.

Gretchin experiences annoyances and distractions living at home with her boyfriend and flatmates, recalling that, when by herself, it is was easier as she did not have to worry about others. The eating practices of PWD can often lead to a lack of desire around food and Sarah explains this further: “it impacts meals. I don't cook very often

⁹⁵ When blood sugar levels are high, the body is not turning carbohydrate into energy due to a lack of insulin and so fatigue is a very common symptom.

⁹⁶ The responses to the question about how diabetes affects life in the home are also interesting from a gender perspective. It is perhaps not surprising that the responses about lacking energy or interest in doing housework came from female respondents. The conception of home as safe, as a haven from the stresses of the day, has been critiqued as a masculine perspective, as for many women the home is a place of work (Blunt and Dowling 2006).

now. The metformin has made me lose my appetite, alongside the not knowing what to eat, so I don't make an effort to make tasty food anymore". Home for Sarah has become a place of drudgery, there is little pleasure to be taken in the preparation or consumption of "tasty food"⁹⁷.

Supporting Lawton et al's (2011) finding that, even after a DAFNE intervention, many PWD are still reluctant to experiment with new foods and persist with their pre-DAFNE meal routines⁹⁸, Glen says that: "there is ... a sense of habit and a sense of standardisation" when it comes to choosing food. He continues to say: "you stick to certain things that you know ... the [same amount of] carbs because you don't have to weigh them out again ... or it's easy to go for the things that are packaged that have the [carbohydrate content] numbers on them". PWD such as Glen and Sarah are enacting what Frank (2013: 41 *italics original*) describes as a "disciplined body-self [which] defines itself primarily in actions of *self-regimentation*". The routine recession developed in relation to food here creates a bleak outlook for these PWD: while their bodies may be 'safe' at home, they are not lively.

Many PWD will implement a tactic of carbohydrate (carb) counting at meal times, in which they calculate the number of carbohydrates in a meal and then administer the correct amount of insulin so as to avoid blood sugar levels going too high or too low. Such practices can be very time consuming, comprising a chore in relation to food, as Valorie writes:

Well all the detritus gets on my nerves, the mental arithmetic is a bit of a bore frankly. But not insurmountable – I'm not in pain, am I? I'll very often start eating a meal and suddenly say to my husband: 'why didn't you tell me I was diabetic'?! Because I've forgotten to count carbs, test or inject – so clearly it doesn't play on my mind 24/7, does it!

The "temporally dynamic" home life of the women in Crooks' (2010: 59) study does not then necessarily exist for all PWD. While a significant temporal element emerges at meal times with all the extra counting, testing, injecting, weighing and logging

⁹⁷ Sarah continues her response writing that her lack of desire around food "also impacts on my husband, who has eaten an awful lot of toast for dinner since I was diagnosed". This, yet again, reflects a gendered aspect to home life with diabetes, which would make an interesting avenue for further study, building on work discussed in Chapter 2 by Sardaki and Rosenqvist (2002).

⁹⁸ Glen had not attended a DAFNE course but had attended a similar education course in Glasgow which taught many of the same things, such as carbohydrate counting and adjusting insulin doses to match. Glen referred to this as his "re-education".

blood sugar results – “the detritus” as Valorie mentions – this situation is not dynamic or unpredictable, but rather predictable and necessary, a daily grind and drudgery. This drudgery turns the home environment into a mundane place with certain pleasures around cooking and eating being restricted, instead replaced with a wearying and necessary routine. Crooks (ibid: 55) considers that women in her study come to experience their homes in disabling ways due to their condition; while they may be “physically comfortable” in this safe environment, they may also be “emotionally uncomfortable”. Sarah had only been diagnosed for two months at the time of writing her response, while Valorie has been living with diabetes for thirty-nine years. Sarah may not yet have developed the routine recession that Valorie experiences (evidenced when she momentarily forgets she has diabetes), which probably explains why she finds cooking and preparing food so difficult. Valorie reflects on this issue casually; for her, it is merely a bore – at least she is not in pain – and her response suggests a recurring joke that she has with her husband. This routine recession is still, as I have argued, an unachievable ideal of diabetes for even Valorie still has to pay attention to her body; it still dys-appears.

WORK SPACES

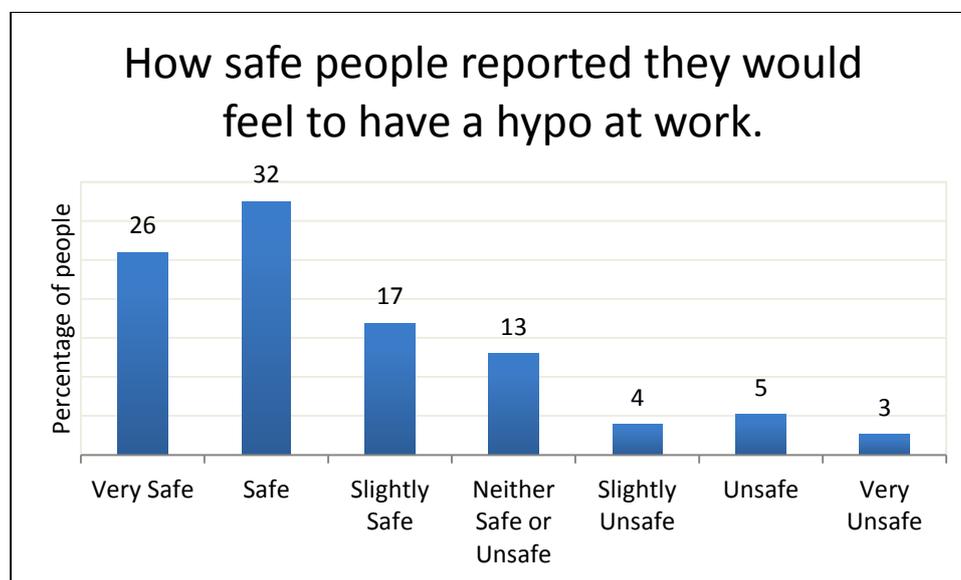


Chart 3: Feeling of safety if having a hypo at work.

Most of my participants reported similar feelings of safety and familiarity at work as they did at home (Chart 3), such as Jennifer who writes: “at home and at work I feel OK in my environment, able to check my levels as and when I need to”. However,

with the presence of work colleagues and myriad others, disclosure of diabetes becomes an issue in the workplace. Charmaz (2008) discusses how disclosing chronic illness – she focuses mainly on those illnesses that are not immediately visible – is risky and often a dilemma for the ill person. Evidence from my participants supports Charmaz’s findings and demonstrates that diabetes can have a profound effect on one’s working life. For instance, Charmaz found that her participants fear colleagues might come to resent special accommodations for managing illness. Similarly, Sophie says that, when working at a department store, she requested an earlier lunch break so that she could maintain her eating routine. This was much to the annoyance of a colleague whose lunch break changed as a result and who felt that Sophie was using her diabetes to get a coveted lunch break time. Charmaz also considers when an ill person should disclose their illness, noting that those who do so on job applications get fewer interviews. Such instances were not prevalent among my respondents, but Richard recalls his anger that, after being offered a prominent teaching job (in the early 1970s), the offer was promptly rescinded when he disclosed his diabetes while accepting.

Charmaz (2008: 10) discusses the fear of a changing self when illness is disclosed which is tied up with an “assumption of moral failure”. Reflecting this fear, Sarah feels the need to conceal her type 2 diabetes at work: “I feel stigmatised for being type 2 and fat. I’ve heard people talking about it at work, with one manager stating he hates fat people and diabetics. I don’t feel comfortable talking to other people about it”. PWD are aware that in work environments their diabetes, perhaps in concert with other bodily attributes, can lead to them being judged or stigmatised, a keen example of ‘felt’ stigma (Goffman 1968). Critiques of diabetes as an ‘easy’ condition are similarly evident, and Emma writes about her work life:

I find it quite hard that people generally do not see the ‘bad’ bits of diabetes (e.g. night-time hypos, nausea with high blood sugar, difficulty concentrating with high blood sugar, having to insert infusion sets). I worry that people will wear out of patience with me making excuses for being ill/not believe me.

Many participants report that their colleagues and employers are often accommodating with regards to their diabetes. However, the above quotes demonstrate that the discursive understandings of diabetes as something minor, easily overcome, still play on the minds of PWD while they are at work and influence their actions. Some people state an unwillingness to bring attention to themselves if they

experienced a hypo, even if they endanger themselves by not treating it promptly. This is perhaps explained as a “keeping safe repertoire”, which Davidson and Henderson (2010: 158) find among people on the autistic spectrum who fear that their relationships with friends, family and work colleagues would be irrevocably changed if they revealed their autism. This repertoire is reflected in the above comments from Sarah and Emma. Additionally, Frederica hints at the negative affect this can have on her diabetes management: “the worst time was in a meeting when I began to have a hypo. I didn’t want people to know about it so I ignored it and did nothing until the end of the meeting. Really bad move. But didn’t want to make a fuss”. Likewise, Kirsten remarks on her busy work environment, a fast food pick-up and delivery outlet:

Well I usually just get on with it and have my Lucozade [when experiencing a hypo at work], and I know that’s maybe not the textbook answer, you should maybe sit down for a while and deal with it but we’re often short staffed. I judge the situation myself; if I am feeling awful I will go and say to the boss that I need ten or fifteen minutes to sort myself out. I don’t tend to tell everyone because ... some of the people there don’t quite understand and sometimes make quite stupid remarks that annoy me so I usually just kind of deal with it myself ... But there has been times where it’s been really, really busy and something needs done and I can’t do it because I’m having a hypo and it’s that feeling of having to explain yourself and it’s like you’re making excuses to get out of doing the work.

There is a belief that one’s work ethic comes under question if a brief break has to be taken in order to manage a hypo. These accounts from Frederica and Kirsten indicate that hypos are not always visible to others (remember Gillian’s remark in the previous chapter) and so claiming a five minute break to deal with a hypo could be interpreted as an excuse for a ‘skive’⁹⁹. Moss and Dyck (2003: 94) consider that women with chronic and unseen illness often avoid disclosing their illness when in the workplace because they do not want to open their bodies to scrutiny and surveillance, nor risk being considered a “slacker”. This reluctance of disclosure is especially true for people with chronic illness, with fluctuating or ‘contested’ (Moss and Teghtsoonian 2008) symptoms. Kirsten acknowledges that enduring a hypo is bad for her health, but she feels that the social expectation of being seen as a productive and problem-free overcomes immediate concern for personal health. For Kirsten, having a hypo is

⁹⁹ A skive referring to an ill-begotten, underserved break from working.

not an adequate ‘excuse’, and she hints at the discursive recession of diabetes when longing for her hypo to be understood, but is reluctant to admit the extent to which it affects her. Ken echoes Kirsten’s discontent about lack of knowledge among colleagues:

The impact [of diabetes] on my previous job was significant and my diagnosis was a major factor in my leaving. Although my colleagues and management tried to be supportive, their lack of knowledge made life difficult and I eventually got tired of having to explain and excuse everything I did. The department I worked in was a very busy call centre environment and it often seemed that there was no time to manage anyone whose personal circumstances meant they had different needs.

Ken picks up on one of Kirsten’s points, noting that he tires of continually having to ‘explain’ his behaviour while at work in order to gain legitimacy as a good worker rather than a ‘slacker’. In the workplace, suspicions of slacker behaviour can increase the surveillance and scrutiny of diabetic bodies, hence rendering PWD as suspicious characters.

As well as bodies being open to surveillance, PWD can be reluctant to expose their bodies as out of control in work environments. Mary said that she prefers the safety of running her blood sugar levels high when she needs to be focussed at work:

If I know I’m speaking in a meeting or something like that I just want to take the whole ‘is my blood sugar low? Is there potential for a hypo?’ Take that out of the equation ... My HbA1c is ... 5.8; 5.9[%], so really well controlled. So I normally don’t let it run high. But for me ... going into a meeting, if I was on a 9 or 8[mmol/l], normally ... at home, I’d be saying ‘my god my blood sugar’s high’, but when I’m out and about I consciously make sure that it’s that bit higher so I’m not worrying.

Mary clearly distinguishes two different standards of control for home and work. Home for Mary is safer where she can run her blood sugars more tightly and therefore risk the occurrence of a hypo, but when at work or out and about she prefers to run high, taking the ever-present risk of hypo “out of the equation”. Mol and Law (2004: 55) note that PWD will inevitably enact such ‘trade-offs’ because the ideal, well-balanced diabetic body is, “unsustainable”. This offers further evidence that the diabetic body is a dys-appearing body. With this example, we are seeing how PWD can adopt strategies to make themselves appear more ‘normal’, expunging the risk of hypo and an out-of-control body. Mol (2008: 40) reports something similar in her study of PWD, arguing that in the space of work/office meetings a person’s body must

be ‘tamed’, otherwise it can become illegitimate: “civil bodies are to be subjected to the agenda of the meeting. Eating, leaving, measuring blood sugars, none of these are in order”. Anxiety does not completely disappear; worry about future health was discussed in the previous chapter and Mary hints at her anxiety in the quote above when she remarks that at home a blood sugar level of 8mmol/l would be undesirable. Mary is therefore enacting a health trade-off, risking long term difficulties for the sake of appearing normal in the short term. Balfe et al (2014) also find that PWD can experience great demands on their time while at work, which can lead to them sacrificing good self-management, such as missing clinic appointments, neglecting to test blood sugars, not eating healthy food or not taking the time to exercise.

Disclosing diabetes in the workplace is a complicated process, dependent on an individual’s personality, type of work and support (or lack of) from colleagues and employers. Mary recounts a work Christmas party where she realised that her diabetes, although often not discussed in her office workplace, potentially marked her out as different:

I remember at my Christmas night out and sitting with my boss and, after a few glasses of wine, I’d gone to the toilet and was probably in there for twenty minutes, talking to people in the toilet – that’s what girls do. I remember coming out and my boss saying to me, ‘I thought you were in a diabetic coma or something’. You know, something that was probably not pre-meditated, it’s just come out and the thought might have crossed her mind in a caring way ... but to me that was ... ‘god that’s a sick thing to say’ ... Moments like that can be quite hard; are people almost always thinking of me as a diabetic before anything else? ... So you’re thinking, who else [is thinking]: ‘Mary the diabetic’. I think it could be worse but ... is that really the first thing that came to her mind, whereas a normal person can go to the loo and not come back for twenty minutes but you know it wouldn’t be considered anything [unusual].

Mary comes to realise that her diabetes may be constantly on the minds of her colleagues, and that perhaps she may be receiving special treatment or extra attention. She comes to realise that she is not considered by her boss as a “normal person”: while her female friends and colleagues can visit the loo, socialise and it be thought of as nothing other than ‘normal’ gendered behaviour, she becomes aware that her behaviour may be more closely monitored. This then comes to have an effect on her identity, for she believes her diabetes is under control and does not affect her work, but her boss and colleagues may think differently. PWD may be under surveillance at work, with colleagues waiting for the moment that the PWD’s body will dys-appear.

Charmaz (2008) notes a similar example of a PWD who felt that his diabetes had negligible effect on his working ability, whereas his colleagues, who knew about his diabetes, attributed his falling behind with paperwork to ill-health rather than any other circumstances such as general stress or difficulty of the work.

While Mary starts to suppose that her colleagues consider her differently, other participants experience more direct challenges to their capabilities. Gretchin speaks of how her body and lifestyle are closely monitored by work colleagues:

I've had problems at work with taking hypos because work [colleagues] think I'm not fit to be at work if I'm taking hypos ... Trying to tell them that this is something that's going to happen, it's happened for years, I've always took hypos and I'm always going to be at risk no matter how well I look after myself, it's never going to go away and, actually, when I try to control more closely, I take more hypos. So they then said to me, 'should you be exercising'? [As exercising can lead to more frequent hypos] I said, 'well do you want me to be obese, do you want me to lose a leg when I'm older'? It's catch-22, you can't be pleasing everybody.

Gretchin works as an occupational therapist in clinical spaces. As such, she can sometimes be responsible for patients who are in her care. Concern about hypos from her colleagues may then be understandable, but she feels that this extra attention is unjustified, it being unfair to call into question her ability to work in this environment merely because she has diabetes. Gretchin is proudly in control of her diabetes after reflecting that, while in her teenage years, she rebelled against paternalistic medical care and experienced serious problems with consistently high blood sugars. At work, Gretchin's body becomes something on which her colleagues feel free to comment, as a public rather than private body – much like in Longhurst's (2001) study of women's pregnant bodies, they feel her body to be a workplace issue rather than a personal one.

Major instances of workplace discrimination were evident as well. Valorie describes one experience:

It [diabetes] never impacted my life at work until 2007 when I'd been at my employer for nine years and everyone knew I was diabetic. We ate our lunch at our desks so I tested and jabbed [injected] as per normal at my desk. In 2007 they told me I wasn't allowed to jab at my desk any more – however, I would be allowed to test. I said 'where then'? They said 'the loo'. I said 'no', I said 'that's discrimination'. They said it wasn't. They were utterly vile to me from then on in and I should have resigned and taken them for constructive dismissal – however, I battled on and had the complete mental breakdown to

prove it. Eventually a cash offer was made for me to go away and keep my trap shut. I was at such a low ebb by that time health-wise, I just took it and went and signed all their unreasonable agreements. I don't regret it because at times I was actually suicidal through all this and I needed to do it if I was ever going to get my sanity back. During this period I found a [online] diabetes forum, who actually, I'm quite convinced of this ... saved my life because 'all this' was having a terrible effect on my blood sugars. [I] used to go from 33 to 1.8[mmol/l] on my meter, several times a day Mon-Fri inclusive¹⁰⁰.

A discursive pressure was at play here, with a belief among her employers that she should test and inject (jab) in the toilet; that this was not discrimination, even if Valorie felt it so. Her employers were 'vile' to her, upset that she would not hide her "destabilising body" (Moss & Dyck 2003: 118) in abject spaces. Longhurst (2001) has written about bodily practices in the working environment, especially about the importance of wearing a suit for people in managerial positions as they present a body which is seemingly guarded from outside penetration and inside leakage. In this way a suited body maintains a professional, clean and untainted façade. Valorie shows how diabetes also disrupts the ideal working body. Diabetic bodies are considered vulnerable in the workplace: Mary comes to realise that her body is regarded by her colleagues as unreliable, vulnerable to a coma. Likewise, Gretchin's body is vulnerable to hypo and so though unsuited for health care responsibilities. For Valorie, her own body's fluid boundaries are perceived as transgressive and not suitable for the working body or environment.

Conversely to concealing diabetes at work, disclosing it was often considered practical by my participants, so that they could establish a 'safety net' should they ever require assistance in the event of a severe hypo. Davidson and Henderson (2010: 164) consider such an act as an "education repertoire" for people with autism 'coming out' to others, where coming out serves to educate others about autism and so lessens the experience of stigma. Many of my participants also note that they take

¹⁰⁰ There are cases of PWD being subject to discrimination in their employment due to diabetes. Wije (2012) reports the case of an employee with type 1 diabetes being discriminated against by his employers, the AA. The AA were found to have intentionally placed unreasonable expectations on the employee, with regards the physical labour of vehicle recoveries, in order to justify his dismissal when he reported being unable or unwilling to complete the recovery tasks. Interestingly, part of the AA's argument was that another employee also had type 1 diabetes and was able to carry out vehicle recoveries. Thereby, the AA indirectly suggested that the inability or unwillingness of the original employee was due to his poor control or desire to 'skive' rather than the embodied symptoms of diabetes (exercise or other physical activity increase the likelihood of hypo, which could be especially dangerous during a vehicle recovery). Under the Equality Act 2010, the AA were found to have discriminated against the employee.

opportunities to educate others about diabetes. Kirsten says that: “I do like to ... talk about it as much as I can and increase awareness ... if you tell one person they might go and tell another. I do like to take the opportunity to educate people”. Kirsten does go on to say that constantly explaining diabetes to others can be exhausting and she wonders whether such ‘education’ could be done on a wider scale, rather than left to individual PWD. It is important to note that for most of my participants who enacted an “education repertoire”, they remark that it is done so, to establish the aforementioned safety net rather than to limit experiences of stigma. At work, Gretchin provides a fact sheet, to her colleagues, containing information about what to do in case she is hypo or hyper and cannot help herself. Likewise, Allison has a notice on the wall at her place of work telling colleagues about her diabetes: “it’s got my name, how I might be, how I might look [when hypo], if I’m conscious or appear conscious and can take something by mouth give me a sugary drink”. Allison does not mind having this public notice of her condition as she works in a nursery and thinks that, in such a workplace where young children are cared for, it is good that her colleagues are aware of her condition.

Disclosing diabetes to colleagues (and others) was certainly a contradiction which recurred among my participants. For example, Sophie recalls attending a lecture for her nursing course:

Although the lecturer knew I was diabetic not everybody in the class did ... So this lecturer stopped in the middle of a lesson one day and said ‘Sophie are you OK, because this lecture’s gone on a wee bit long, do you want to go out for a snack?’ ... There was a whole silence in the place ... I just said to him ‘oh no I’m OK I’m fine at the moment, thank you’. He says ‘well mind and let me know’, and I says ‘will do’ and that was it ... I felt I was totally questioned after that [by her fellow students] ... I don’t like that attention ... It’s somebody being kind to you ... that lecturer stopping and saying ‘Sophie, you OK?’ ... I can’t be rude and say ‘I’m fine’ [said short and sharply as if annoyed], I couldn’t even go and say anything to her after it without [seeming ungrateful and rude].

Sophie remarks that she prefers to keep her diabetes unknown to others as far as possible, not wanting the attention of others who may come to regard her as vulnerable. Sheila echoes this concern: she is a social worker, and she tells of one time when someone came into her office seeking an impromptu meeting. Sheila was due one of her regular tea-breaks, which were important for her in maintaining her eating, blood sugar control and testing routine while at work. She says that ideally she

should have asked one of her colleagues to take the appointment, but then explains how she feels her working environment would be unwelcoming to any bodies seen as different. She admits that she would rather put herself in danger of experiencing a hypo than talk about her diabetes and related anxieties with her colleagues:

I thought, I'm not exposing myself as vulnerable and highlighting that I have a disability ... So I went and saw the person and I came back and I was going into hypo and I was really angry with myself because I thought I really shouldn't have done that, I really should have said, 'look this person needs to be seen by somebody else', but I just couldn't bring myself to do that. So I'm placing myself at risk.

The expectation on PWD is that their body should recede and their diabetes be controlled, but this is not easy to ensure. Nevertheless, PWD will often try to present such an image because they feel there to be no way to express the realities of living with the condition without being considered vulnerable or even disabled, as Sheila mentions. Sheila does, however, fan the flames of contradiction, as she recalls her training course for social work:

I got the timetable for when the classes were and I thought, 'oh there's no tea breaks here'. So we were sitting and the lecturer said 'do you have any questions about your timetable'? ... I just put my hand up and said ... 'there doesn't seem to be any tea breaks' ... I wasn't being cheeky, I was genuinely concerned because of my condition and she was really angry with me. She says 'yes and do you have a problem with that'? ... I says ... 'yes I do', and she says, 'well what's the problem?' 'Well I'm diabetic and I need a tea break' and she just about crumbled ... this wasn't my intention ... [to create] a situation where she was embarrassed and she says, 'oh well in those circumstances [you can have a tea break]'.

In the above situation Sheila was happy to challenge the lecturer, in front of her classmates, for space and time to attend to her potentially dys-appearing body, which speaks to the ever-present contradiction outlined in the introductory chapter. In some cases Sheila prefers that her diabetic body remain quiet – as does Sophie – while in others she prefers to disquiet it in order to gain recognition of some of her difficulties. Indeed, while preferring a quiet diabetic body, Sophie tells of a time trying to enter a football stadium and being challenged by a steward over her possession of bottled water. The steward insisted that she abandon the bottle before entering as it is a prohibited item, but she protested, exclaiming her diabetes as legitimation for entering

with the water¹⁰¹. PWD may well prefer a quiet, recessive diabetic body in general, but as Sophie and Sheila demonstrate, ‘diabetic rights’ may be claimed at certain times and in certain spaces as PWD insist that their different needs be accommodated. It may be unfair to expect others to know about these needs when diabetes is so receded and unknown – as Sheila notes she did not want to embarrass the lecturer, but simply wanted to have her needs recognised in this setting – but it highlights a need to educate others about often invisible and contested illnesses. Employers being more sensitive to “accommodation problems” (Charmaz 2008: 16) in the workplace for people with chronic illness can lead to more accepting environments for PWD where perhaps their disclosure as a PWD would not have such an impact on their identity.

Charmaz (2008: 12) discusses the disclosure of chronic illness at work in spatial terms:

People with serious illnesses have changed relationships with space, time, and timing that impose obstacles and require problem-solving, if they remain in the workplace. They may discover that their experiences are profoundly dislocating and subsequently lose connection with spaces, places, and people at work. Under these conditions, they occupy a liminal space where earlier rules, routines, and meanings do not apply. The ambiguity of being in a liminal space means they likely lack a language through which to understand and express their changed lives.

The evidence here has shown the impact of diabetes at work. Some participants struggle to have the legitimacy of hypo episodes and effects recognised, others try to conceal diabetes entirely, while others still experience severe discrimination due to the condition. My evidence suggests that in work spaces, many PWD still “lack a language” for discussing diabetes. For this reason, the everyday realities of living with diabetes are obscured to employers and colleagues, and PWD then inhabit this “liminal space” where they struggle with the question of disclosing their diabetes. While work may very well be a ‘safe’ space, as Chart 3 suggests, it may only be ‘safe’

¹⁰¹ Eventually she conceded and put the bottle in the bin, but she expressed her anger in a written complaint to the organisation in question, arguing that people with illnesses such as diabetes should be allowed to take in bottled water. Although water does not treat hypo or hyper, many of the symptoms of both (thirst, dry mouth, dizziness) are alleviated by drinking water. Part of Sophie’s complaint was that buying bottled water within the stadium is ludicrously expensive and is decanted into a polystyrene cup (so that the bottle cannot be used as a missile), which is not convenient for keeping in a pocket or bag. This represents another mundane everyday problem for PWD. I have myself, many times, entered stadia or other venues only to be cursorily searched and questioned over my diabetes ‘kit’. I then have to explain diabetes as I hold up the queue. Hannah also recalls going to a concert in Glasgow, only to argue with stewards over her insistence that she be allowed to carry food into the venue in case of hypo, while they insisted it was not allowed.

in the sense that PWD feel that they would not be in acute medical danger should they have an extreme incident of hypo or hyper (as there are usually other people around). Nonetheless, the accounts here show how work is still “dislocating”, since there is a more complex relationship to space than merely being safe or unsafe. The characteristics of this “dislocating” are that PWD are constantly wondering what others think of their bodies and their work performance (Kirsten, Mary) along with frequent clashes with colleagues about best practice for a PWD (Gretchin, Valorie). This means that these participants are never fully relaxed at work, never fully comfortable¹⁰².

PUBLIC SPACES

‘STREET’ SPACE

This tension between revealing/concealing and the public/private nature of one’s diabetes is clearly evident in the responses to the questionnaire question about how safe people would feel if they were to experience a hypo in a busy or quiet street (Chart 4). The two spaces received almost equal numbers of responses from the categories ‘very safe’ to ‘very unsafe’. Comments from participants elaborate on a feeling of either safety at being unseen, and therefore diabetic identity and potentially embarrassing episodes remaining concealed and essentially private, or anxiety over lack of potential help should it be needed during such an episode. For example Julia writes:

I do not want people watching me have a hypo, as it makes me vulnerable. I am unable to function basic skills. I look dammed incompetent. I also feel

¹⁰² It is important to note, though, that many participants also tell of very accommodating workplaces. Hannah, for instance, works as a yoga instructor and says that, even when she has a hypo while instructing a class, her colleagues always help her recover and she praises their understanding and patience. Steven, who works in a university, tells of the network of colleagues who he knows would assist him in the event of difficulties due to their own personal knowledge of diabetes and other illnesses. Wilton (2006) reiterates the social model of disability, stressing that it is often the work environment that disables rather than a person’s illness or impairment. As a further caveat, however, Charmaz (2008) does note that, while people with chronic illness may experience little adverse impact at work, such illnesses are often unpredictable or can become worse over time. Valorie comments at the beginning of her quote above (p. 149), that diabetes had no impact at work for nine years prior to her disagreement with employers; a timely reminder of the potential for the diabetic body, suddenly and unexpectedly, to dys-appear.

ashamed, like I am not in control of my body. This is OK at home but in front of others not so good, as I get afterwards¹⁰³: ‘why do you think this happened?’

Julia fears this loss of control of her body when in more peopled and hence public space. She also comments that, once she has recovered, she feels that she must be accountable for her behaviour, the rhetorical question that she uses in her response suggesting that she is somehow to blame for her out-of-control body. Likewise Jennifer also touches upon this sense of being judged if having a hypo in public: “I would not want anyone thinking I was drunk or stoned or something, or being judgemental about my diabetes control especially if the kids were with me. People just don’t get how tricky it can be at times”! Hansen and Philo (2007) write that the sometimes ‘unusual’ behaviour of people with physical disabilities can be mistaken for drunken behaviour. They argue that people with disability often have to explain their condition in order to have their behaviour accepted. Jennifer fears this lack of acceptance, feeling that even her ability to be a good mother might be called into question if she is seen having a hypo in public. Conversely, Perry highlights the importance of being around others when out and about, “in my teenage years I ended up in casualty as I could not eat fast enough [to treat a hypo] and was found in a park by children who thankfully helped”. This recollection further illuminates the interesting contradiction about disclosing one’s diabetes, for many of my respondents commented on the need to have a safety net in place, such as colleagues, travelling companions, family members who knew enough about diabetes to assist in emergencies.

Linda, talking about various difficulties living with diabetes, says that she often runs her blood sugar levels high to avoid potentially embarrassing episodes in public space:

I think I try to be on the cautious side ... rather than risk having a sudden hypo, I would maybe accept that my sugar levels are quite high for a while, hoping that it will right itself. But then a sort of bad conscience comes in as well: what’s my HbA1c going to be like? Or what’s the doctor going to say?

Running blood sugars high allows PWD to avoid the anxiety of potentially going low, providing another kind of safety net. As well as the long term fears of high blood

¹⁰³ Julia was unclear in her response who exactly asks these questions. Due to this being an anonymous questionnaire response I was unable to ask. Regardless of who she is referring to, friends, family, colleagues or bystanders, the main point is that these questions are asked at all.

sugar, Linda introduces a fear of being judged by clinicians should her decisions to run high be discovered through her HbA1c. While aiming for tight control of blood sugar levels is a worthy aim and proven to be effective for improving the health of PWD (The Diabetes Control and Complications Trial Research Group 1993; Nathan 2014), the accounts here of being fearful about going low in public spaces and the subsequent judgements that may be made about an individual's levels of control demonstrate the emotional toll that such 'gluco-centric' targets take. Indeed, this is the critique of current clinical approaches to living with diabetes that many of my participants express and which will be discussed throughout the rest of this chapter.

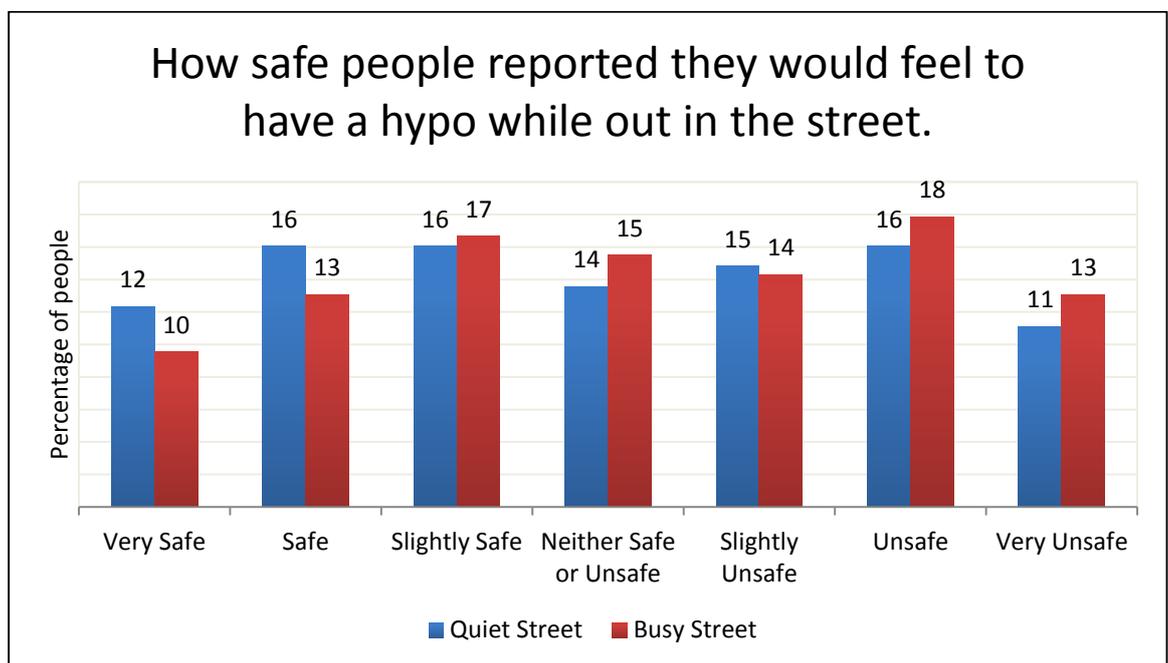


Chart 4: Feeling of safety if having a hypo while on the street.

OTHER PUBLIC SPACES

For the selection of other public spaces included in my questionnaire, the results were almost the same across the board (Chart 5). This reflects the results from street spaces, showing the different attitudes emerging among people with diabetes about concealment (privacy) and safety (being around others). The space of the night club was an exception, with participants feeling mostly unsafe. This finding can be explained as, while the pub, coffee shop and restaurant have broadly similar ergonomics of space, a night club is different due to less sitting room, busy and often messy toilets, dim lights, loud music and an expectation to dance. A common way to

describe the effects of hypo is like being drunk, and so in a night club environment the hypo may not be noticed by others and even by the person experiencing it if they have been drinking.

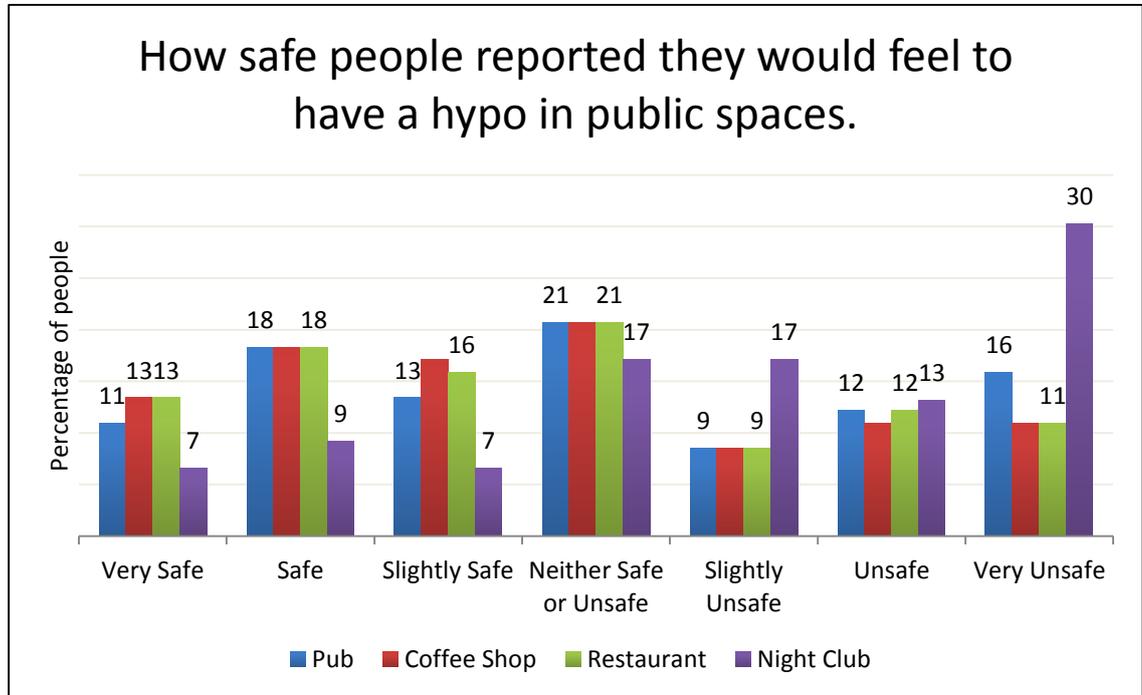


Chart 5. Feeling of safety if having a hypo in various social spaces.

Throughout my data, I started to discover an increasingly diminished geography for PWD. Wilton (1996) discusses a ‘diminished world’ with regard to the activities of men after they had been diagnosed with HIV/AIDS, describing a pattern of relapse (into a diminished world) and partial recovery (into an expanded world), yet with an overall eventual diminishing. While my methods do not allow such a longer-term analysis of PWD’s diminishing and expanding worlds, the data does uncover a general sense of limitation in PWD’s everyday geographical and social worlds. For example, Ken writes that:

Diabetes has had a significant impact on my social life. I don’t go out as often as I used to due to my concerns about having to test or inject during the evening. When I do go out I am constantly aware of how I am feeling and find it difficult to switch off. I also suffer fatigue as a result of diabetes which means I rarely have the energy to socialise.

Because of his dys-appearing body Ken prefers to restrict himself from socialising, entering what Wilton (1996: 79) describes as a social “cocoon”: a period of

introversion. For Wilton (ibid: 79), “the cocoon period may also contain a renegotiation of personal space”. Ken has experienced this phenomenon when he describes a fear of losing control and having a hypo in public space: “I feel very self-conscious if I have hypos anywhere other than at home, or if I am with anyone other than my partner as other people aren’t used to seeing me in that condition”. His fear of the embodied sensations of hypo, of losing control of his physical body and temperament, along with his concern while out in public lead to an overall diminishment of his lifeworld. This situation is supported by his responses to the rating scale questions, in the questionnaire, in which he indicated most public spaces as being slightly uncomfortable for self-management practices and most public places being unsafe for experiencing a hypo. At the time of writing his response, Ken had been diagnosed for ten months and his geography may have been affected more acutely for this reason. He may yet not have developed a sense of routine recession, which would lead to a partial recovery, and so his diabetes is more recent and present in his life.

Ben had been living with diabetes for five years at the time of our interview and his accounts of his social life contrast with Ken’s. Ben shows that that over time he has become more relaxed about his control, and his account continues the comparison with Wilton’s stages. Wilton (ibid: 79) describes a period of “emergence” following cocoon in which the ill person’s lifeworld expands. When I ask Ben if diabetes has affected his social life, he says “not at all, not now. I don’t think it ever [did] really; it’s never stopped me going out; maybe just thinking about [it], being a bit more prepared, I would say it’s made me just think about things a little bit more”. Ben has an active social life and often will drink alcohol on a night out. His response hints at the sense of contradiction so prevalent throughout all of these spatial accounts: while adamant that his social life is unaffected, he reflects that there is still some effect, a lack of spontaneity, a need to be prepared. He elaborates further on his attitude to nights out:

I think to start with it was just the fear of losing control; not [being] completely in control of your own actions. It’s easy to drink too much and not know what you’re doing or where you are ... [At first] I hadn’t really told a lot of people and wasn’t confident; well maybe a lot of people knew I had diabetes but didn’t know what it entailed or what they had to do or look out for [if I was in trouble] ... I do now probably drink too much; I’ve been in a couple of

dangerous situations¹⁰⁴ ... I look back and think I really shouldn't have done that or got myself into that place but it's a bit of peer pressure, you go out and before you know it [you're drinking a lot]. But to start with ... that would never happen to me because I always wanted to remain *compus mentus* when I was out ... I was able to look after myself and then I got myself into dangerous situations not just with drink but with my diabetes and drink. Over the years I got over it but that's probably not the right phrase to use; I probably forgot about not wanting to lose control, sometimes now I lose that element [of worrying about loss of control] and then deal with the consequences later.

Wilton (1996: 80, 82) discusses that there can be "relative recovery" as the men in his study, "spend much of their time living with, and not dying from, HIV/AIDS", during periods of emergence. Similarly, Ben has recovered from an initial knock to his confidence; he does not allow a hyper-vigilant management routine to dominate his life, and nor does he allow diabetes to restrict him. However, this is not a brightsiding narrative akin to Nicola Johnson (remember my critique of her autobiography in Chapter 3), for throughout our interview he frequently refers to knowing this is not best practice, referring to his own laziness as the main reason for not having attended DAFNE, which he knows his employers would support by allowing him time off. Indeed, this material relates to Balfe's (2005; 2007) work, where he discovers that young PWD will often practice risky drinking strategies, putting their health at risk, so they do not appear different. It may be more fitting, though, to consider Ben's account as a "lowering of self-expectations" (Aujoulat et al 2008: 1236), as he is not obviously concerned with appearing 'normal' like Balfe's participants. Aujoulat et al (ibid: 1236) consider this lowering:

Accepting the loss of control [over illness management] is not necessarily an end-point leading to a devalued sense of self, but may be part of a personal transformational process, in which people do not become adjusted to their illness, but in which the illness becomes an element of a person's personal and social identities, thereby allowing the person to develop a new sense of coherence in life.

Ben further explains his attitude in other parts of our conversation, at one point referring to his inexact carbohydrate counting:

It's more a guesstimate than anything, I don't weigh out my food or write down everything I eat or anything like that but I do try to make an effort at it.

¹⁰⁴ Ben later provides an example of such a dangerous situation when he went on a weekend trip with friends and neglected take spare insulin, meaning that he had to go to the hospital when it was lost.

I've still to receive proper structured education on the subject so right now it's carb counting on my own trial and error but it seems to be doing pretty well.

Ben is aware of his non-ideal approach but is still satisfied. He acknowledges as well that, while his blood sugar numbers are not ideal, he still hits his targets 60% or 70% of the time, and remarks: "I think that's as good as I'm going to get it right now". Ben has lowered his expectations; he is content to drink and is content, temporarily, to forget about losing control. He has accepted that his body and blood sugars will never be ideal. Mol and Law (2004: 55) argue that ideal diabetic bodies with permanently well-controlled blood sugars are a fallacy, for "it depends on the ability to assess one's blood sugar level, calculate what one eats and keep track of the energy one uses up in exercise – unremittingly, moment by moment, without ever stopping". Rather than trying to achieve the unachievable, I follow Mol and Law (2004; also see Mol 1998, 2008) in arguing that diabetes management practices must be something of a 'best fit', contingent on an individual's lifestyle and circumstances.

Following Wilton's analysis further, Ben notes that his lifeworld is still diminished in some ways, commenting on the extra preparation and consideration that PWD must have for everyday tasks. Wilton (1996: 80) characterises the "relative recovery" of his participants writing that "overall improvement may be substantial, but it does not remove the cyclical pattern of highs and lows that overlay daily life". In Chapter 5 I discussed the diabetic body as a constantly dys-appearing body because diabetes was never far from my participants' thoughts. Through the examples in this section we can see how this constant attendance affects the social lives of PWD. It is these unreliable bodies that limit social interaction and mobility: it truly is a "relative recovery". Even if Ben is able to enjoy a night out and not worry about his diabetes, the concerns will later re-surface.

A PWD's relationship with food also affects their social life. Participants frequently comment on their reluctance to eat out at restaurants, preferring to stay at home. Kim laments about: "not being able to go out to dinner in a lot of places – Indian or anywhere where the food is 'mixed up' so that you can't tell how much carbohydrate or hidden sugar there is". Likewise, Holly remarks: "it has severely affected my ability to eat out. It makes me very uncomfortable to have to guess the carb content of the meals and test my blood sugar and inject in front of people". Experience of living with diabetes was also a factor, and Hayden, who has lived with type 1 for thirty-five years, says: "it was two years before I plucked up enough

courage to go into a restaurant ... because I hadn't got around to this idea of being able to look at a plate and say that's X [amount of carbohydrates] on that plate, that's Y on that one". Meanwhile, Ken writes: "my diet was heavily restricted while I got used to carb counting and I was reluctant to leave the house unless I could guarantee I'd be home in time to eat". When it comes to eating out, these responses show how public spaces carry with them an uncertainty. It is not only the unreliable and disappearing diabetic body that causes PWD to cocoon in their own homes and shy from public spaces, but also aspects of these public spaces that make it difficult for PWD to feel comfortable. For my participants, restrictions around food cause not just a loss of nice things to eat, but also represent a geographical restriction in terms of a diminished social network. Johnston and Longhurst (2012) describe the strong sense of community and belonging that preparing and sharing food in one's home can foster, but also consider the importance of social networks connected to certain restaurants, cafés and food shops. Similar instances occur throughout the responses in my research, demonstrating the loss of a social network around food. In the following chapter I will discuss in more depth my participants' micro-geographical strategies of managing their diabetes in restaurants and other public spaces.

CLINICAL SPACE

The questionnaire results point to clinical spaces being considered an overwhelmingly safe space (Chart 6). Interestingly, there are number of outliers and comments from participants who note that, when being admitted to hospital for whatever reason, not necessarily to do with their diabetes, it is hard to maintain control over one's own diabetes. The self-management routine is often taken out of the PWD's control and a textbook approach to diabetes imposed by clinicians (Munt and Hutton 2012). Gabriella recalls an experience of being admitted to hospital following a foot injury:

It was a foot injury because something had fallen on me, it wasn't a diabetes related foot injury ... The first thing they did was test my blood sugar level but, when you go on a pump you need to agree ... if you are admitted to hospital and you're not fit to work the pump yourself, that the hospital staff can't be asked to do it for you and you need to be put on a sliding scale drip until you are fit to work the pump yourself, which is fine. But it's kind of like ... they're testing you in that situation and you're left on a sliding scale drip ... [but] if the staff were too busy and forgot to do the blood test, you're going to slip into a bad hypo or if you're too high and it's ketoacidosis [DKA] ...

because in everyday life other people are OK to admit that they don't know anything about diabetes, whereas in a hospital you expect people to know and they maybe don't want to admit 'I need advice here'.

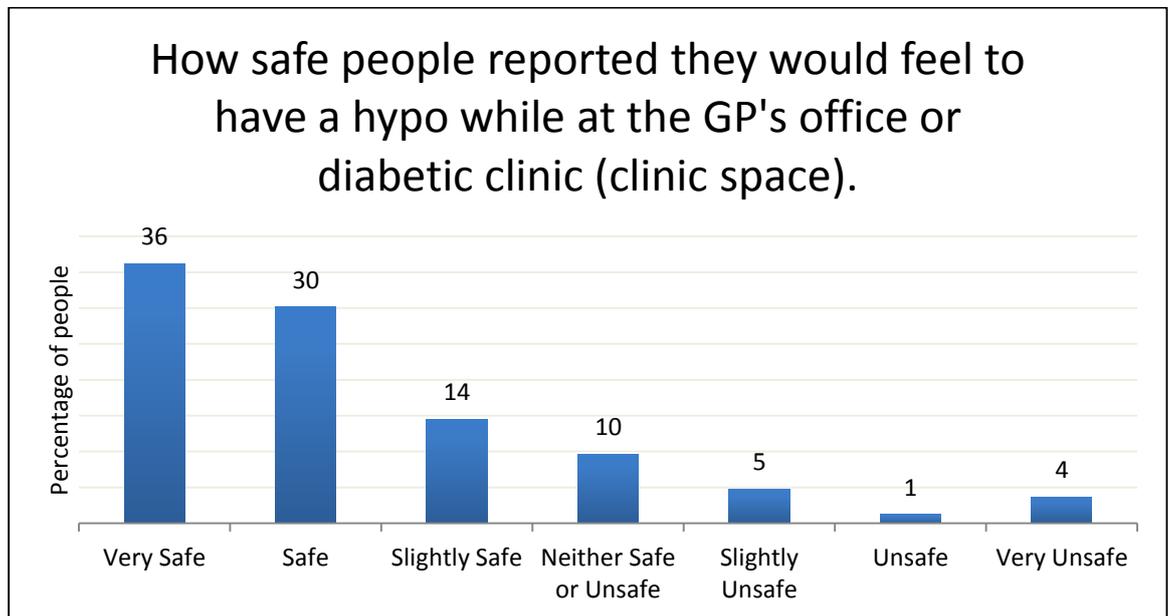


Chart 6. Feeling of safety if having a hypo in clinical spaces.

For Gabriella, clinical spaces – despite (or even because of) the presence of clinicians, equipment and close monitoring of bodies – can become anxious spaces. As Gabriella notes, in everyday life the PWD has control over her or his management¹⁰⁵, but when admitted to hospital they lose control of their body, literally signing it away to hospital staff. Gabriella hints at a distrust of clinical staff, not that they would be malicious; but perhaps that they may forget to manage this care due to being busy. Likewise, Arthur finds hospitalisation an uneasy experience:

The place that I found people's ignorance [of diabetes self-management] the worst was in the hospital ... [After being admitted to the hospital for an undetermined illness] I had to tell them I was diabetic ... I'm glad I wasn't unconscious because they did not have a clue how to treat my diabetes: 'how many units of insulin are you on'? [They said] 'Well it depends on what I eat' [Arthur responds]... and they were quite shocked at it [not having an exact amount of insulin to take at each meal], but it was a busy acute medical ward so they're not experts in everything. I eventually asked them to bring somebody down from the diabetic ward to tell them ... it could have been a scary experience [had he been unconscious and unable to affirm his personal management practices].

¹⁰⁵ Although as we will see in the following two chapters, this control does not exist outside of certain forms of biopower.

As Arthur continues to recall this experience, he suggests the staff in the ward doubted his claim of a flexible insulin regime:

Arthur: They didn't believe me, thought I was making it up. That's the impression I got from them.

Mark: They thought you were making up the ...

Arthur: how I treated [myself] ... because I said, 'it's DAFNE: dose adjustment for normal eating' and I says, 'if you give me so many Weetabix I would take so much insulin but if you gave me this or that ...' ... I think by the time I left the next day they were beginning to actually get it but at that point I was going home so it [their burgeoning knowledge] would be lost.

Munt and Hutton (2012: 191) note a lack of literature concerning experiences of PWD's self-management while hospitalised and they reflect my own concerns about 'gluco-centric' approaches, writing that "research is needed to determine whether the hospital setting focuses too much on glycaemic control as the goal for T1DM [type 1 diabetes mellitus] management without considering the individual as central to their T1DM management". From Gabriella's and Arthur's accounts this certainly seems the case, for the clinical staff perceive diabetes in quantitative terms. They insist on taking over Gabriella's self-management, on their own terms as they have limited knowledge of the pump, while they doubt Arthur's pragmatic, flexible and DAFNE inspired routine, instead expecting PWD to have a simple, fixed amount of insulin to take each day.

The most common way that PWD interact with clinic spaces is during routine check-up appointments where various vital statistics are taken such as HbA1c, blood pressure, cholesterol, which are then used in order to determine a person's level of control over their blood sugar levels. However, many of my respondents expressed frustration at the lack of time that they received to talk about their diabetes rather than just being 'measured'. Linda, for instance, laments the lack of time she has to talk to clinicians about everyday living with diabetes, objecting as well to the paternalistic attitude which she feels she encounters in clinical settings:

I find my regular check-ups utterly dispiriting, I don't get anything from them ... I would love to talk about my diabetes like I do now with you, there are so many useful little tips that I could pick up ... but I never find out anything useful there ... You have to wait for a long time, and then ... all that matters is how your HbA1c is, and there's some stress associated with that. So if I get a good result, it's fine, but then they're trying to get me to use the pump

differently and do things differently ... and I'm finding myself quite non-receptive, because I feel they are not really [listening]. I feel I could benefit from good advice, but good advice ... comes from really listening if it's cooperation rather than imposed ... People want to be listened to, please put that in you thesis! ... I get the impression, for some of them anyway [clinical staff], is just that they are seen as the person in authority; that they get respect.

Linda hints at the power relations at work within clinical settings, and other participants express similar frustrations. Kyle is himself a diabetes specialist nurse (DSN), and shares with me his encounters, as both nurse and patient, with senior clinicians who refuse to give up their authority and dislike having their judgement questioned. Gretchin is also a clinician, and adds her frustration at medical colleagues:

In terms of DAFNE ... I think it is absolutely brilliant, but that educates only one thing, there wasn't enough education on what diabetes was, how it would affect you and how to manage it. It's not just quite as easy as going into your clinic appointment and getting your feet checked and seeing your dietician and she'll tell you how to eat properly. You need somebody to put it all together and say this is how you break it down and this is how you can adjust it to your life, because people should fit diabetes around their lives rather than fitting their lives around diabetes.

Among my participants it was considered all too easy, as Kyle describes, to become a "passive recipient of diabetes care". The hospital is hence not always a space of wellbeing, despite the results in Chart 6 suggesting that it may be, although Kyle is adamant that it can become one. He argues that PWD who feel aggrieved or neglected by clinicians need to stop being passive and challenge the system, and he regards DAFNE as a central example of how this challenge can start to be achieved as it empowers patients with knowledge. Of my participants who attended DAFNE, many reported that their relationship with clinicians was indeed altered after the course. They started to challenge their clinicians when previously they were passive, as Elise observes:

I find the six monthly appointments ... in the past I've found them a bit of a waste of time because they'll ask 'what are your levels and how much insulin do you take'? ... I kind of tell them what it should be rather than what it is ... But since DAFNE I'll be in there with questions and with my book¹⁰⁶ and saying 'look this has gone high here, what can we do'? I think I've got a lot more knowledge now and I'm a lot more confident.

¹⁰⁶ Referring to her DAFNE diary in which she records her blood sugar readings.

Beverly et al (2011) present the other side of this argument, suggesting the issue be part of larger ‘structural’ problem. Interviewing doctors from Boston, USA, who treat people with type 2 diabetes, they discover that doctors are aware of the emotional and social difficulties of living with the condition but are all too often thwarted by a lack of time and resources, meaning that they rarely get to engage with patients beyond the brief dispiriting check-ups that Linda describes.

While many PWD are frustrated with the treatment they receive from clinicians, there were also many who were very happy about their level of care. Julia tells me of suffering a severe hypo and being taken to the hospital by ambulance:

The hospital told me I was taking too much insulin, and changed the time of my *Lantus*¹⁰⁷ from night to morning. This has helped immensely, it has taught me not to be so complacent and learn to listen to my body. [For instance asking myself] ‘Am I tired or am I having a hypo’?

For Julia, the clinicians helped her to become more attuned to her body, stirring her out of a dangerous routine recession where she had become complacent, falling into a bad habit of taking too much insulin, and so she has regained control of her body.

During their regular appointments, for many of my participants, the clinic space is similar to Smyth’s (2005) conception of therapeutic spaces which reinforce medical authority, upholding social divisions and accepted perceptions about specific conditions. Smyth (ibid: 494) calls for “new opportunities to develop landscapes of resistance and activity that challenge exclusionary discourses”. DAFNE is arguably one such mode of resistance in the clinical landscape. Of all my participants who attended DAFNE, only one expresses any dissatisfaction with the course¹⁰⁸. For the others, DAFNE provides an invaluable source of information and has opened up new possibilities for self-management. Perhaps the most significant example is Adam, whose relationship to his everyday spaces was seemingly changed due to the course. A football player, he reflects that previously he has had serious difficulty managing his blood sugar levels during the intense physical activity of the game. After DAFNE, he notes that, “I just feel a lot more confident and comfortable going out to play a game knowing that I’m going to have a level blood sugar”. Likewise, he talks about his changed experience of eating out:

¹⁰⁷ *Lantus* is a brand of long-acting insulin.

¹⁰⁸ This will be discussed more in chapter 8.

The other night there ... going out for dinner ... it was a buffet ... right OK, I'll count that plate, I'll split my dose, something that I would never have done before [DAFNE], just splitting doses or thirthing¹⁰⁹ it throughout the meal as well, or having a pizza and I'm going to have a certain amount now and a certain amount at the end. Just wee bits and pieces ... I've never thought about doing but I think it's stuck in there now.

He is referring to new practices that he learned at DAFNE as being now stuck as habit, making eating a complicated buffet easier. Adam elaborates on the impact for everyday life:

It's making things a lot easier ... I'm a lot more energetic ... it gives you a more comforting outlook, a relaxed outlook as well ... it's one less thing you need to think about when you're going to do stuff, whether it be playing football or going to work or whatever, because you know you've got it covered, which is a big deal for anybody, because me and my brother going out gardening; me and a teammate going out playing a game, maybe I've got one more thing to think about on my mind but ... you feel you are on a level playing field with everyone else ... if I can keep it under control, which, just now, I feel as though I'm doing pretty well, it's plain sailing.

While I consider the lack of a routine recession in the lives of PWD, Adam confounds this notion. He exclaims that, while the increased self-vigilance learned at DAFNE gives him one *more* thing to think about, it is not a burden to him, but rather enables “plain sailing”. He notes that this is a relief from previous experiences when he had serious diabetes-related health struggles attempting to lose weight in order to continue his career as a professional footballer. DAFNE allows PWD to “assign a meaning to their illness experience” (Aujoulat et al 2008: 1236), and Aujoulat et al (ibid: 1237) consider it important for a person with illness to achieve a sense of “wholeness and personal integrity”. This much is clear in Adam's accounts when he notes that he considers the DAFNE course to be a life-changing experience, and he is excited that his next twenty-four years of living with diabetes could be easier and better controlled than his previous twenty-four years. He no longer experiences space so anxiously or with a lack of energy as do some PWD discussed in previous sections of this chapter. He feels that his sense of difference is lessened; previously he felt that he could not

¹⁰⁹ Splitting and thirthing doses refers to taking multiple injections at different points during a meal in order to maximise the efficiency of the insulin. For instance, the best time to take most fast-acting insulins is about fifteen minutes before starting to eat. However, many people find this difficult, especially at restaurants, as they do not necessarily know how large the portions will be or how much of the meal they will want to eat. Therefore, DAFNE recommends that you can take half a dose fifteen minutes before the meal and then take a second dose when you know how much you are actually going to eat.

keep up with non-diabetic others, but now is on a “level playing field”. Adam still acknowledges that this control he is enjoying may only be temporal, “which, just now, I feel as though I’m doing pretty well” but hence potentially subject to relapse as Wilton (1996) recognises.

Crooks and Agarwal (2009) interviewed women with clinical depression and were surprised to discover that the women considered the clinic environment to be crucial in determining the quality of their relationship with clinicians. The women in their study, unprompted by the researchers, talked about the lack of privacy afforded in waiting rooms, the apparent stress of clinic staff and the reliance on computer data by clinicians as shaping the clinical experience. My own participants did not delve into these details when discussing their clinic experiences, but instead, they focussed on the encounter with clinicians and the quality of treatment and advice received. For PWD, the clinical environment is not always so important, although the clinic retains value as a ‘diabetes knowledge network node (DKNN)’ (Cravey et al 2001; Gesler et al 2004). Such a node is a site for disseminating health care information about diabetes. Linda (from her earlier quote in this section) clearly finds her own clinic particularly unsuitable for this purpose, but, with a DAFNE intervention, other participants, such as Adam found clinical space a much better DKNN. Derek also says of DAFNE:

I’ve learned more in the one week of DAFNE than what I learned in the last fifteen years [since his diagnosis] ... Some of the questions I was asking, it had taken me fifteen years to find out [the answer]. [For example] if I’m at 9[mmol/l] and I want to be at 6[mmol/l], how much insulin do I take? I never got that answer until I went to the [Glasgow hospital for DAFNE course] and that’s how vague the information was from then to when I went on the course.

Balfe (2005: 227), using a Foucauldian concept, considers the DAFNE courses to be a “technology of the self”, due to the scientific nature of the course in calculating carbohydrate content and insulin doses. DAFNE as a “technology of the self” is certainly clear in Adam’s account as he talks about using his newly gained knowledge to split doses of insulin and take control of his diabetes. For the women in Crooks and Agarwal’s study the clinic space was clearly important to them as the main location where they would receive treatment for their condition. Of course, these women still have to deal with their condition across myriad other spaces in everyday life, as anyone with a chronic illness must do, but they do not necessarily have the same close

and quantifiable self-surveillance of a PWD. For the PWD, the clinic space is constantly moving, as Lupton (2013: 266) writes: “not only has the clinic moved into the home, it has dispersed to every possible spatial and temporal location. Not only are medical and health-related data now mobile, but so are the bodies/devices that produce these data”. Patton (2010) writes of a ‘clinic without the clinic’. On accompanying two nurses during a home care initiative in a poor neighbourhood, Patton observes the transformation of various street and private spaces into clinic spaces. She recalls one incident where the nurses changed a patient’s bandages in a hallway: “the air of efficiency and privacy transformed this dirty end of a hallway into a ‘clinical space’, or what the nurses have, in more formal moments, called a ‘clinic in a corner’ ” (ibid: 131). The self-management of diabetes, particularly type 1, is a sort of mobile, rootless clinic. Diabetes is everywhere and PWD have no choice but to take it with them. The space surrounding the PWD is a space that can become transformed into a ‘clinic in a corner’ at any time. Unlike these transient clinics described by Patton, the mobile clinic of the PWD does not need the presence of a nurse or any other travelling clinician.

DIABETIC MOBILITIES

DRIVING WITH DIABETES

Travelling with diabetes was often remarked upon by my participants, and Chart 7, below, shows my participants generally feel unsafe on public transport. Shiu and Wong (2002), summarising research done in Hong Kong, note one PWD who reflects on the anxious experience of suffering hypoglycaemia while stuck on a mini-bus in a traffic jam with none of their friends or people who know about their diabetes nearby to help. Most of my respondents had little to say about public transport however, as most of them drove. Kirsten does comment on bus travel becoming somewhat anxious for her if she were not properly prepared, something that happened frequently when she rebelled against her diabetes in her later teens: “I did end up in a couple of situations where I thought oh god I don’t have anything; I’m on this bus it’s going to take ten minutes to get to a shop and I don’t have any money”.

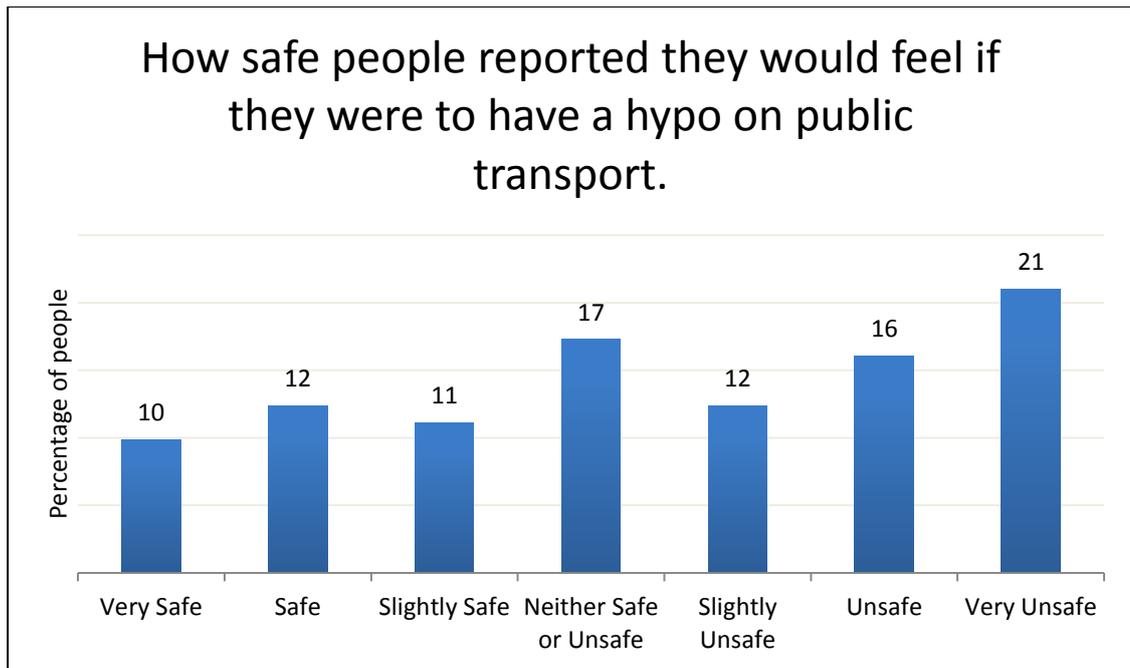


Chart 7. Feeling of safety if having a hypo on public transport.

This demonstrates the anxiety that can exist for a PWD, being enclosed somewhere with no chance for a quick escape, and not having the proper supplies quickly creates a dangerous situation. Driving can also be a problematic issue for PWD. UK regulations insist that PWD must test their blood sugar every time before driving; at regular intervals during long distance driving; and have on hand in their car a record of these tests (DVLA guidelines website). These regulations exist because of the danger of experiencing a hypo while driving. As mentioned in the previous chapter, Richard had one such incident where he was reported by others as driving recklessly. He was stopped by police and escorted to the local police station where he was considered to be drunk. Since this incident Richard has never driven, telling me of how he recognises the danger that he can present to himself and others on the road; he thus agrees with the authorities that he should not be driving and so voluntary restricts his mobility. Others did not have such an uncomplicated relationship to driving restrictions. Mary, for instance, feels frustration at the insistence that she must test every time before driving:

If I had a real serious hypo where I nearly caused an accident or something then yeah by all means get me to renew my driving license but I think there's probably a bit of stigma to that. I'm as capable of driving as anyone else is, but I'm treated as a kind of high risk person by the DVLA, and ... one of the nurses ... when I did the DAFNE thing ... was like, 'check your blood every

time you get into the car', and I just wouldn't do [that] ... I'm not being irresponsible but I know that ... I've got my hypo sweets ... for a backup ... Obviously some people are more risk than others of having hypos when they're driving if they're not controlling it, but personally you think ... why should I have to renew my driving license? There is a bit of a ... stigma attached there.

Mary feels her ability to drive is not affected by her diabetes, proven by her general good control – she distinguishes herself from other PWD who have poor control, suggesting she has something of a superior sense of responsibility – and so, she believes that she is being unfairly treated by the DVLA as 'high risk'. For Mary this is stigma, and she later muses that driving with diabetes is no more dangerous than crossing the road with diabetes: one could easily have a hypo while crossing the road and be struck by a car or cause an accident, but there is, of course, no restriction on PWD crossing the road.

Richard claims that he easily is able to give up driving because he is retired and lives in an area of Glasgow where all his travel needs are easily met by local public transport. Mary though, often needs her car for work and also has two young children. Olivia likewise expresses frustration at the driving requirements:

I think the DVLA have brought out really strict guidelines saying you've got to check your blood before you drive. How practical is that, though? I mean in the morning, for example, I'm up at half-six, breakfast at half-seven and I'm in the car at half-eight. So if I do a blood test at ten-to-eight what's that going to tell me? I'm post prandial¹¹⁰, I'm going to be higher anyway. Really the time I should be doing a test is nine o'clock or half-nine ... then I'm not driving. Then I think, again, it is for our safety, but it's people interfering ... that don't know anything about it.

Olivia also has a young daughter and lives in an area with poor public transport services, so her car is essential to her day-to-day mobility. For Mary and Olivia, the DVLA regulations are not compatible with everyday life; testing before driving tells Olivia nothing, for testing only an hour or so after a meal will usually give a high reading as the insulin bolus for the meal will still be taking effect. The evidence discussed above suggests that, even among those who drive, there can be a sense that

¹¹⁰ Immediately after eating a meal, an insulin-dependent PWD's blood sugar levels will be high. This is because the insulin that was taken for the meal usually takes two to four hours to work fully. For this reason, it is often recommended not to test blood sugar immediately after eating as the reading reflects a blood sugar level that has not yet settled. DAFNE would recommend that blood sugar levels are tested immediately before eating a meal as, at this point, one's blood sugar level will likely have settled from the previous meal.

having a hypo while driving is not likely and that regulations to avoid it are an unwelcome intrusion upon their identity as a well-managed and in control PWD.

That said, driving still caused anxiety among a number of participants. Although Alice said that her not having learned to drive is out of laziness rather than anything else, DAFNE has now caused her some anxiety about learning:

I've never really had to [drive] and now I really ... want to and, not that they've [DAFNE operators] scared me, but I'm worried about it. They told us a few wee stories about the checks if you drive now because there have been accidents. So that for me has not scared me but it's made me a wee bit wary, and I would always be quite conscious if I was alright when I was driving. I think I would be a bit overprotective of myself if I were to drive ... [if I were to] cause a problem; cause an accident.

Reflecting Alice's feelings is a blunt statement from Kim: "I work from home as an author, as I am not allowed to drive and my control is too on a knife edge to cope in the real world". A real sense of a shrinking lifeworld is hence evident in Kim's response, and she elaborates, in a subsequent answer, about how diabetes affects her social life:

Not being able to just go out for the day or to take the children swimming or whatever, as I am not allowed to drive and live in a village with a poor bus service. But also going on a bus is a major undertaking! There are just too many ways to describe them all ...

Kim's responses acutely reflect the major weakness of my questionnaire method¹¹¹. Her final ellipses here are original and end the answer to the question, possibly used by her to express further the vagueness of her final sentence above. Is she referring to the too many ways in which diabetes affects her social life or the too many ways that they can be described, hinting that indeed they cannot ever be fully encapsulated or expressed? While I discussed in the previous chapter how people were keen to represent themselves in particular ways during the interviews, as not being affected

¹¹¹ As discussed in Chapter 4, this weakness of the questionnaire is that, while so many answers are quite powerful statements – "my control is too on a knife edge to cope in the real world" – how I have implemented the method has left no room for elaboration and further probing by myself. I devised this method to inform the construction of semi-structured interviews. If it had been the only method for the research, then I would have selected 'good' responses like Kim's and attempted to arrange further communication to expand on answers. On the other hand, responses such as Kim's, in which she exposes her feelings and sense of self-worth, may not have been obtained if she were aware that I, the researcher, may follow up. The ability to give one-off answers anonymously may be what has elicited this and other such, seemingly, honest and open responses.

greatly by diabetes and managing unproblematically, Kim reminds us of the ineffability that often comes with representing life with diabetes.

Many participants did express fear at the potential of having a hypo while driving and, akin to the fear of having a hypo while they are the centre of attention, the strategy of running blood sugars high emerges again. Gretchin says:

Sometimes the fear of taking a hypo when driving; I used to drive quite a lot, for my work, when I was at university, and when I graduated I had to drive to ... places, long drives for meetings and stuff. I would just run my blood sugars high, I didn't want to have to stop and test my blood ... I've always got a fear of them taking my driving license away.

While driving it was easier for Gretchin to run her blood sugar levels high rather than having to stop frequently and test. Gretchin's response, along with the responses from Mary and Olivia, demonstrate how being able to drive can be so closely associated with one's feelings of independence. All of the participants quoted in this section were aware that their driving competence was coming under question because of their diabetes, a form of governmentality. Richard, due to his circumstances, responds compliantly; Kim responds as demoralised; Gretchin as fearful; while Mary and Olivia respond as resistant. While the previous sections considered the extra preparation for negotiating various spaces that is so often unseen, in this section the realisation is that, when this preparation (for driving) *is* acknowledged, it can seem out of touch with the reality of living with diabetes.

These varying attitudes towards driving with diabetes also highlight the impact on the lives of others that the diabetic body can deliver. In 2006, in Wales, a PWD, while driving and experiencing a hypo, lost control of his car and struck and killed a pedestrian. During his trial the prosecutor claimed that, through not having a sugary snack in his car and general negligence at managing his condition, he was criminally responsible for the death. Indeed, he was ultimately found guilty, the judge agreeing that, had he attended to his condition and tested his blood sugar levels before driving, the accident would have been avoided. He was jailed for four and a half years (BBC news article 2007). In this example, we see how easily negligence of diabetes can affect others. While Olivia and Mary are resistant to the self-surveillance of their bodies, diabetes *is* a condition that can impact greatly on the lives of others, and hence it is not merely the personal health consequences as discussed in Chapter 5 that are at stake.

TRAVELLING WITH DIABETES

Travelling further afield also emerges as an anxious mobility for my participants and demonstrates that it is not only spontaneous activity that is restricted, but also planned activity. One aspect was taking extra supplies, and Gabriella talks about how she prepares:

The last time I was out with the UK I had pump supplies for about four weeks even though I was only going for ten days ... I had four different cartridge pens, the logic being I would need one for short-acting, one for long-acting and what if the pen broke and I got the pump confiscated? [Gabriella is anxious about going through airport security with her pump] ... It's not so much that it's stopped me doing anything, it's more the additional thought.

Gabriella touches on a feeling of potential isolation, of being so dependent on technology that she is vulnerable when away from the safety of familiar territory. Glen introduces another concern about travelling outside of the UK:

I do want to get to India at some point ... but I think I would struggle with the heat ... it does play on my mind sometimes; how do I manage that effectively ... I know the heat will affect the blood sugars, it will just send them through the roof. Same thing if I went to Africa at some point, different kind of heat but still would affect me, so I'm just conscious it's something I have to think about.

Weather can have a big impact on PWD's blood sugar levels. For Glen, he has trouble keeping them down. In fact, my interview with Glen, in Glasgow, occurred during an unusually warm spell in the summer of 2013 and he told me of his frustration at his constantly high blood sugar levels. For others, though, the warm weather causes their blood sugar levels to decrease, increasing the chance of hypo – as insulin will be absorbed into the body quicker at warmer temperature. For this reason, Alice deliberately keeps her blood sugar levels high when on holiday: “so I tend to, when I go on holiday ... just run my blood sugar high for the week. Because to me that's easier; just having it that bit higher and being that bit safer”. She acknowledges that in other contexts, such high blood sugar would not be acceptable, to her or to clinicians, but justifies the decision so that she can enjoy her holiday. Through the various accounts of participants choosing to run their blood sugars high, it is evident that on a day-to-day basis diabetes is something of a conscious burden. The dual relief

and cause of anxiety from deliberately high blood sugar levels is summed up by Gabriella, who says: “in a way, when you’re running yourself high all the time, it’s like the high sugar is hugging you and saying ‘it’s OK, you’re not going to go low’. But it’s developing an understanding that it may well feel like that but it’s also hurting you”. This evidence shows that, a routine recession of diabetes rarely emerges in an everyday context. It may emerge if blood sugars are run high, but such trade-offs do not completely expunge the anxiety of living with diabetes; as I discussed in Chapter 5 there are still long term fears and anxieties with having consistently high blood sugars.

Being away from the familiar home country can cause anxiety among PWD. Emma, a physical geography PhD student, writes:

I think I have been more cautious than friends ... about going out drinking, doing fieldwork in remote places. Especially as a geography student, I have been nervous about working abroad and not being able to obtain insulin, or getting sick. This makes me feel that my condition is very fragile and dependent on being in a developed country.

Most of my participants from the UK, express a sense of privilege that they enjoy from the NHS. Glen reflects on this matter most acutely, being a Canadian who has been living in Glasgow for the past eleven years:

I am delighted to pay taxes in this country ... I benefit hugely from it [free health care from the NHS] ... It’s one of the things that keeps me here because it’s not entirely free in Canada. Insulin is part covered, test strips are part covered, but nothing entirely and so when I was living in Vancouver there was a period when I was not covered by my parents ... and so I estimated I was paying about CA\$600 a month to keep myself alive ... It’d be even more now and that is a significant factor to when or if I go back to Canada, because the money to keep myself alive has to be factored into my expenses.

The availability of supplies for Glen keeps him rooted in the UK. His experience also tells of the vital geographies of living with diabetes: living in Canada, it would cost him money to stay alive. Interestingly, most of my participants did not consider this privilege directly, which is another example of what was possibly missed in interviews between participant and researcher who are both PWD living in the UK. Perhaps we take our ‘free’ (of course it is paid for through taxes) treatment and prescriptions from the NHS for granted. For most of us the experience of paying for supplies and treatment, of needing appropriate medical insurance, is *foreign*. Some

participants, like Hayden, do recognise this privilege: “let’s face it; I have ... forty plus years to thank them [the NHS] for, I feel very, very privileged, not to have to live in that sort of condition [he is referring to living in a less developed country]”. Polly also remarks that, “if I didn’t need all the crap medications (insulin etc) which are expensive; I could move to another country”. While Glen and Hayden feel privileged to be living in the UK, Polly’s comments suggest that possibly this privilege also restricts mobility, contributing towards a rooting of PWD in the UK that is not necessarily desired by all.

Sheila demonstrates this rootedness, with a certain restriction of mobility and sense of adventure, as she discusses her trepidations about travelling far afield from Scotland:

When we were sitting in the DAFNE programme and they asked us that question, has it stopped you doing what you wanted to do? ... I had one goal and one ambition and that was to go to Nicaragua and that was for the Nicaraguan solidarity campaign, because I’m very political ... I wanted to do this; go to this country for political reasons and I thought, to go on my own – because it would have been on my own, my husband wasn’t wanting to go ... I would be vulnerable. I wouldn’t have a back-up ... he’s always my back-up. How would I manage just myself? I worried about having hypos, I worried about my bag, I worried about what temperature for caring about my insulin, was it going to be OK?

Travelling away from one’s familiar home environment caused concern among my participants. Emma previously touches on a sense of vulnerability, reflecting the earlier response from Kim whose lifeworld was even more locally restricted because of her delicate control. Sheila also feels vulnerable without the otherwise ever-present “back-up” of her husband. Having a safety net, in terms of trustworthy and knowledgeable others, is important to PWD, as the responses from Catherine and Frederica revealed in the home space section.

Diabetes impinges on a PWD’s life even when they do travel. Sheila ultimately went on her trip to Nicaragua and enjoyed it with little difficulty, admitting that she did have some “back-up” because, while travelling without immediate family, she was still with a larger group of political campaigners making the same trip who were friendly and understanding of her diabetes. By declaring her diabetes to her fellow travellers, she was also able to be housed with the only family in the village that they were visiting who possessed a fridge, so her insulin could be kept chilled. Denise however, struggled when she went on a trip to Jerusalem with her family:

This is the anxiety with ... diabetes because it definitely impinges on your enjoyment of life because you're frightened to anticipate, at least I find that ... and yet sometimes it turns out fine and I think, 'why was I worrying like that'? I find I enjoy things sometimes in retrospect more than I do at the time.

Further debunking the idea of an easily developed recession of diabetes, Denise struggles to enjoy her holiday, reflecting that it is often the anxiety that diabetes creates rather than any actual, realised problems that mar her enjoyment.

Remote places can also cause anxiety. Few of my participants lived in rural areas, but Sophie had previously lived rurally and she reflects on a feeling of isolation:

I felt very isolated when we lived rurally in Aberdeenshire because the access to getting things is not that easy when you're on a country road, so I got to the point where I always kept things in the car ... because here [west end of Glasgow] ... there's *Morrison's* or a wee kiosk or whatever. I feel better here that way and I think I'm a wee bit more relaxed about it but I felt, up the road, when we lived rurally, it's even more to think about.

The availability of resources in Glasgow helps to put Sophie's mind at ease, for there is a network of safety nets for her to fall into should she require; whereas, when living rurally, she worried more about the absence of these safety nets. Linda echoes this concern when telling of going on a Buddhist retreat:

I think about a couple of months after I was first diagnosed I went on a solitary retreat for two weeks on Skye and I wasn't really used to it all [self-management] then and I went out without having the provisions with me and I was probably about a mile from home when I had a low sugar episode that was so scary. I made it home OK but I was really, really scared and that hasn't happened since.

Linda says that her doctors often question the wisdom of going on such "strange holidays", as they refer to them, raising questions about her security were she to experience a severe hypo again. It is almost as if modern urban places tie PWD into their infrastructure: while the hustle, bustle and plentiful opportunities for poor diets and limited exercise pervade the city, so too does the medical, familial and emotional infrastructure needed to control and live with diabetes. Nagelkerk et al (2006) support this conclusion, arguing that PWD in a rural setting can often feel isolated from the best knowledge and treatment for the condition.

SPONTANEOUS GEOGRAPHIES

These different considerations in different spaces and places mean that diabetes is necessarily an intensely managed condition, and this management in turn greatly affects the everyday mobility of a PWD. Questionnaire responses are littered with remarks about a lack of day-to-day spontaneity. For example, Nina writes that: “I am not as carefree or as much fun ... Nothing is spontaneous anymore”; and Perry writes: “I have led such a regimented life since I can remember that there is zero spontaneity now. Everything I do is pre-planned and I have become to hate anything else”. Interview participants also talked about this everyday restriction, and Alice, who recently attended a DAFNE course, remarks,

I know now they're saying going to DAFNE; it's trying to make your life less restricted but there's still times it is restricted about what you can do; you can't have unplanned exercise. I mean what if you want to go a walk? It's so awkward, and there's times when I used to go to the gym ... I wasn't planning on going and then my friend says, 'do you wanna go'? I can't just [go]; I need to think about it. I need to eat and I'll need to take more insulin and ... it's quite awkward.

Most of my participants who had attended DAFNE commented on how the course had improved their lives, allowing them more flexibility around eating but also clarifying a number of misconceptions and partial knowledges that they previously held. Alice nonetheless reflects that this flexibility does not expunge the extra thought and effort that goes into making everyday decisions; a simple request from a friend to go to the gym carries with it multiple extra decisions and considerations. For Alice, DAFNE's textbook approaches still do not necessarily always apply to everyday life. Gretchin expresses her frustration at the hiddenness of these 'self-questions':

I don't think they [meaning both clinicians and general others] understand the work that goes into it and how much you've actually got to think about it as well. It's not just a case of taking medication especially for people on a basal/bolus [MDI] regime with carb counting. You need to think about every meal. I need to plan ahead for going to the gym ... I wouldn't ever say there's anything I can't do; but I need to plan for it, everything that I do I need to think about before I [then] do it a different way from somebody who wasn't type 1.

Gretchin's necessary different ways of doing things frustrates her, and she is conscious that her lifeworld is, in some ways, restricted by having diabetes. She echoes some of the responses from the previous chapter about the unseen and unappreciated mental labour that goes into managing the condition. This labour means that her body is always dys-appearing, supporting my contention that a routine recession of diabetes is difficult to obtain or sustain.

In Chapter 5 I drew on Leder's (1990a) work to argue that a PWD is constantly distrustful of their body, its susceptibility to hypo and hyper meaning that a PWD must always be aware of bodily states and changes. This extra awareness affects a PWD's experience of place. The evidence throughout this chapter unveils a restriction on easy mobility and an awareness that this is not the same as for those without diabetes: a PWD's spontaneous geographies are curtailed. These spontaneous geographies involve the ability to do things and go places at a moment's notice without significant pre-planning and throughout this chapter there is a keen sense of this spontaneity being missing for PWD. In the section on home participants lamented the predictable routine of preparing food; at work they were restricted by social pressures to conform to a 'healthy' working body; and in public spaces they were fearful of losing control of their body. Even clinical spaces offer little room for PWD to express themselves as, again, they feel the need to conform to clinicians' expectations of a compliant, 'gluco-centric', diabetic body. Lindsay remarks on the keen effect that this complication has on space and mobility: "since having the hypos it has made me re-evaluate my surroundings when I go out, who I am with, what I would do if I had one whilst out, etc". Like Paterson (2014), who studies blind lifeworlds, or Davidson and Smith (2009), who study the lifeworlds of those on the autistic spectrum, I would not like to consider a diabetic lifeworld as 'lacking'. However, my evidence suggests that PWD are aware of, and frustrated by the lack of spontaneity due to their diabetes. Such frustration is not always the case, and for some DAFNE offers a more flexible partnership of care, with the PWD being encouraged to take on more responsibility for managing their own diabetes and thereby enabling an expansion of their lifeworld, as it does for Adam.

CONCLUSION

This chapter has shown that in different spaces and places diabetes is more or less visible. Chart 8 offers a summary comparison of home; work; busy street; clinic; public transport and restaurant spaces (quiet street and the other public spaces are excluded in order to keep the chart simple to follow). It is clear that home is considered the most safe, followed by clinic and work. While these spaces are not entirely safe, as the discussion in this chapter has shown – especially with regards clinic space – they are spaces where PWD know what to expect. Conversely, it the spaces with less predictable occurrences, spaces co-habited with unknown others, where PWD feel less safe – street, public transport and restaurant. While the data confirmed my assumption that the home would be considered a safe space, participants also revealed how isolation when living alone made home an anxious space, while home as merely safe was further complicated when participants told of the drudgery of managing diabetes as a chore. At work and in public social spaces, diabetes became more visible and participants reflected on their strategies for convincing colleagues, friends and family that their diabetes was minor and did not affect their ability to work or to socialise. This finding further reinforces the sense of a discursive recession that exists in diabetes, with participants expressing how they attempted to conform to the expectation of a PWD as responsible and unaffected. While this imperative to conform, to ‘normalise’ oneself, was evident among many of the participants, there was also dissent to this recession. There was open resistance, such as Valorie’s account of the confrontation with her employers, but other resistance was silent, unspoken, such as Mary’s concern about what her work colleagues thought of her. Some resistance was more practical, entailing concerns about being prepared for travel, both short and long distances/times: as Gretchin pointed out, a level of preparedness that curtails spontaneity and reminds her frequently of her difference from people without diabetes.

It is clear that the negotiation of space for PWD is inherently risky, involving situational health trade-offs. Balfe (2005: 133) discusses the risk strategies of university students with type 1 diabetes, writing that students often choose between the risk of consuming copious amounts of alcohol, in order to conform to the expected young student body, or refraining from such consumption and risk, becoming a social

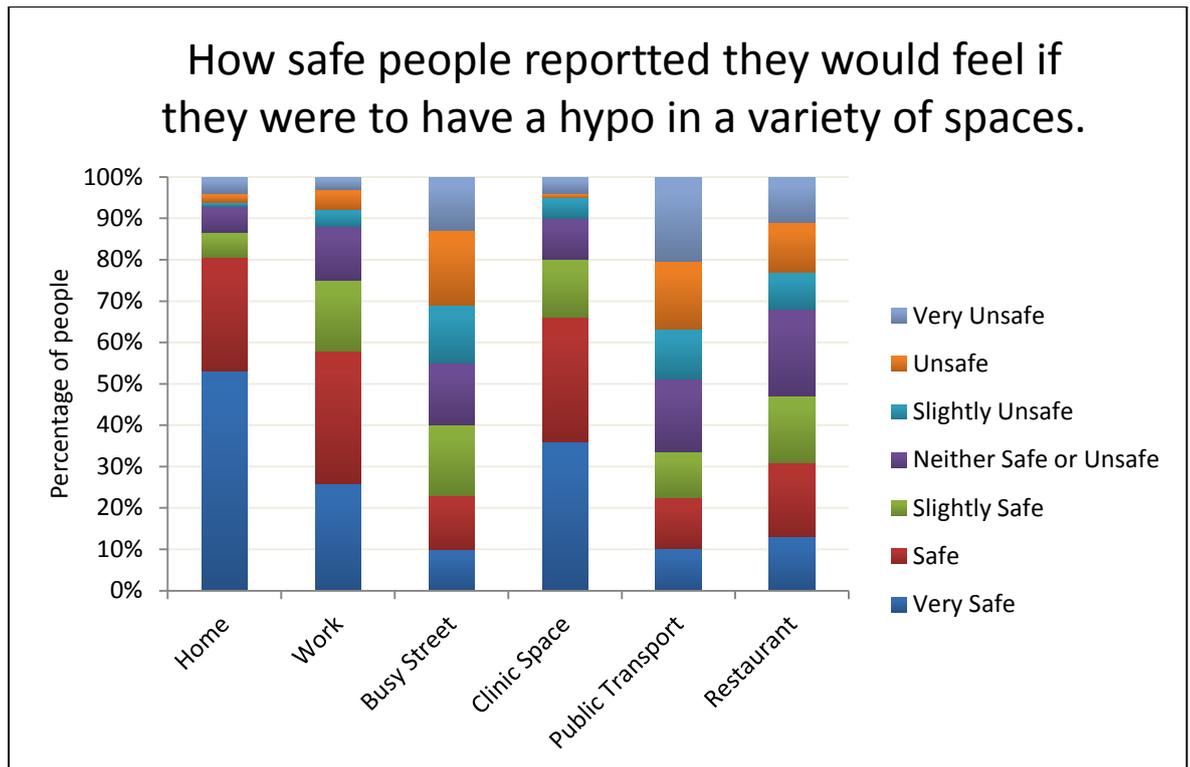


Chart 8. Stacked bar chart comparing degrees of felt safety in different places.

“leper”. While Balfe et al (2014) do consider PWD in the workplace, and they do touch upon issues of having hypos and doing TIM at work, their analysis centres around issues that *all* people, regardless of health and other life circumstance, may face in the workplace (for example: working long hours, eating unhealthy food and not finding the time to exercise) which diabetes exacerbates rather than causes. Therefore I do not find Balfe et al (2014) to be particularly enlightening to the experience of the ‘working diabetic’, whereas my research foregrounds these specifically ‘diabetic’ work related problems (of hypos, TIM and disclosure). The working body must trade-off short-term health considerations, such as Frederica and Kirsten ignoring their hypos at work, in order to perform a reliable working body. Mary, Alice and Gretchin trade-off possible long-term health complications, by running their blood sugar high, to obtain a reliable body. These trade-offs exist in various milieus: for Mary at work; for Alice on holiday; and for Gretchin while driving. As Lupton (1999: 122) argues, people “may move between different risk positions at different times, sometimes attempting to control risk, at other times preferring a fatalistic approach that simply accepts the possibility of risk without attempting to avoid it”. Ben certainly falls into this latter category when he talks about

how: “I probably forgot about not wanting to lose control, sometimes now I lose that element and then deal with the consequences later”. His resigned approach to nights out, as previously discussed, is important to his own diabetes coping strategy, since for him to live with a hyper-vigilant self-monitoring would incur an interminable period of “cocoon”. DAFNE presents a useful way of managing these risks. For Adam, this clearly works, going a long way to marrying the “expert knowledge” of living with diabetes and PWD’s “own risk knowledges [generated] through their own experiences of the world” (Lupton 1999: 110). However, it is still not perfect: as Alice noted, the textbook guidelines of DAFNE do not always work so well in everyday life. I hope, then, to bring forward, possibly for acknowledgment by clinicians, media and the lay non-diabetic public, the multiple spatial contingencies of living with diabetes.

CHAPTER 7

'PERFORMING' DIABETES: TESTING AND INJECTING

"I do not inflict my gear on anyone" (Elliot).

INTRODUCTION

Having now established that living with diabetes is far from an aspatial experience, in this chapter I will discuss the ways in which PWD 'perform' their diabetes. While PWD often lament a lack of understanding that living with the condition can be difficult, and that certain concessions may be needed in everyday life, they also want aspects of their day-to-day management to become normal and unremarkable. Consider Sheila's account from Chapter 6 when she believes her work environment will not be accommodating of her need for breaks, but does not do anything so as to avoid being seen to complain about difficulties experienced with her diabetes. This contradiction leads to the visible management practices of diabetes being performed with consideration to place and company. While PWD are often assertive in their claims that diabetes causes them no great difficulty in life, and claim not to be bothered by who sees them practice TIM (testing and injecting management), they nonetheless often describe strategies of concealment.

I will present my evidence in this chapter with reference to Goffman's and Butler's writings on social interaction and performance, as introduced in Chapter 3. These two authors seem somewhat incompatible, given that Goffman focusses on conscious decisions that people make in order to present and conceal aspects of their identity and body to others, while Butler considers an unconscious adherence to certain norms. However, together they illuminate the crux of the discursive recession: the diabetic body is often subdued by discursive pressures, but also deliberately concealed by PWD. Nelson (1999; 2014) has issues with personal agency being uncritically used in connection with Butler's theory of performativity, although I consider it necessary to use Butler's writings in order to understand the discursive framing for how diabetes is regularly performed¹¹². PWD often unquestioningly

¹¹² Nelson (1999; 2014) reads Butler's earlier work (*Gender Trouble*) as suggesting that there is a 'cerned' subject at the heart of her theory of performativity. This cerned subject is an enclosed subject

conform to a certain way of being diabetic, just as Butler considers that people unconsciously conform to certain gender roles. Nonetheless, much as is true for the geographers criticised by Nelson (1999), my evidence shows that PWD consciously wrestle with, and often struggle against, these expectations.

In the first section of this chapter, I will discuss how PWD can come to feel that their TIM is a performance when in public space. Following this, in the second section I will consider the public display of diabetes through TIM as somewhat 'closeted'. Following from Michael Brown's (2000) consideration of the gay closet as more than just a metaphor for concealing one's homosexuality, and instead as representative of actual closet spaces, I will discuss how PWD often attempt to hide the reality of diabetes and how particular spaces can become diabetic closets where the visibility of TIM is most acute and reflected upon. Before concluding I will discuss the process of coming out for PWD, and then, in conclusion, I will consider how PWD are subject to a panopticism which directs their self-management practices.

PERFORMING DIABETES

Many of my participants are conscious that TIM makes their diabetes visible. For instance Mina writes: "I still have problems with testing and injecting before meals in public because I feel 'on show' ". They are conscious that the public performance of TIM could be regarded as an *excessive* display of one's condition, one which could be interpreted by others as a form of attention seeking. Alice reflects on her own feelings of seeing people with illness or disability: "because I've seen people that ... maybe had something wrong with them ... and I know I've looked at them and thought things like, she's just doing that for attention, to get someone to feel sorry for her". Helping to explain Alice's feelings, Wendell (2013: 170) writes that "someone

who is entirely at the mercy of discourse, with no agency of their own. Butler's later work (*Bodies that Matter*), as Nelson points out, starts to consider the subject as having agency. Nelson argues that this shifting perspective of Butler's has not been critically addressed by geographers who use her work (namely, Bell et al 1994 and McDowell and Court 1994). Therefore, according to Nelson (2014: 90 *italics original*) opportunities to better "rethink the ontology of the subject in ways that would allow us to consider the power of hegemonic narratives and norms to be re-enacted in the context of day-to-day life *and* to be open to questions of critical consciousness" are being missed. Perhaps I am falling into the same trap with my uncritical use of Butler's performativity, but this trap provides an explanation of the discursive framework of living with diabetes. Possibly, this explains geographers' continuing 'flawed' use of Butler's performativity, which Nelson (2014) also laments.

who can pass but chooses not to may be seen as soliciting sympathy and special treatment". As discussed in previous chapters, the relative invisibility of many of the symptoms of diabetes means that PWD are normally able to pass, and so some, like Franklin, are keen not to "make a big fuss about it [TIM] and make it seen and get a lot of attention". Jessica also reflects on this:

In here [work/office] I come into this room [referring to a small conference room] to take my blood testing because ... I just don't think anybody needs to know ... I think why do they need to know I'm diabetic? Why do they need to know that I'm testing my blood? And why do they need to know I'm taking insulin? ... People know I'm diabetic but they don't know I test my blood here [referring to her workplace and, more specifically, the small, private meeting room at her work where we are doing the interview], they don't know I take my insulin here, because they've never seen me.

Although Jessica seeks to keep her diabetes secret, she concedes that her colleagues know about her diabetes, but she feels that exposing them to the full scope of management is unnecessary. PWD may also want their TIM to go unnoticed, not necessarily to keep their diabetes entirely secret from others, but rather to convey an in-control, responsible and reliable body.

Nonetheless, as Franklin elaborates: "at the same time if someone wants to know about it [the practices of TIM and diabetes more generally], I've got no issues discussing it with them". Franklin wants his work colleagues to know about his diabetes, but does not want it to be regarded as a big deal and so he conceals TIM in the bathroom at work. Throughout the interview, he repeatedly asserts that diabetes has no major impact on his life, as do other interviewees such as Steven and Allison (their routine recession is discussed in Chapter 5). Many of my participants hide the embodied aspects of diabetes, through fears of being "on show" or of it being considered an excessive display of illness. Jessica prefers to completely censor all aspects of diabetes, presenting diabetes as an 'abstract' condition: the embodied effects are concealed and discussion of diabetes censored. Franklin, on the other hand, does not censor the discussion, but by concealing the embodied aspects, he likewise presents diabetes as 'abstract': a condition that exists in words and conversation but not in/on his body. We can see how the embodied practices of diabetes, configured in this abstract way, become mystified. I do not mean to discredit these participants' accounts, as (deliberately or unconsciously) omitting more negative experiences of the condition, for they may truly experience something of a routine recession in which

their diabetes impacts only minimally. Instead, I contend that such narratives contribute to the discursive recession of diabetes, reaffirming conceptions of the condition as easy, arguably heightening the possibility of narratives telling of difficulty being perceived as from 'bad' PWD who have not practised good control.

This heightening of surveillance leads to many PWD concealing TIM, and by extension, their diabetes. Gina writes that she will "mainly try to hide the reality. Will inject privately where possible and do sugar tests as discreetly as possible". Mina also writes that "I avoid situations where I might have to test in public". Brianna, likewise writes: "only my partner ever sees me test or inject. I don't let anyone else see on purpose. Some might catch a glimpse, but no-one has ever commented". By 'hiding the reality' of diabetes management practices and by only allowing others, at most, to "catch a glimpse" of TIM, PWD 'screen the real' (Diedrich 2007) of diabetes, and the reality becomes cloaked. Of course mystery leads to curiosity, and some participants who were more open about their TIM being seen consider the interest others often show, going some way to debunking the idea that there will be punitive consequences for visible TIM. As Gilbert states, "colleagues/friends [are] always curious and interested. I've never had any adverse reactions". Likewise, Gary agrees that "some people are curious. Some claim to be horrified, but usually [they] watch and ask questions without passing out". However, even these – more open with TIM – respondents still reflect on being discreet. Gilbert's response continues immediately: "I openly, but discreetly, inject in public". Gary concurs:

I have never felt the need to hide away, though I do try to be sensitive to other people's discomfort around needles ... when 'out and about' a quick jab in the abdomen was all but invisible even in a busy public place. Nowadays, on a pump it just looks like I'm sending a text message.

This hiding (or perhaps even camouflaging) of the reality of TIM contributes to a simulacrum of diabetes, which reveals little of the flesh, blood, penetration and sharp objects that TIM really involves. Instead, a façade is created, the acceptable image of diabetes as easy and unobtrusive. Oudshoorn (2011: 134) proposes that:

Because mobile phones are by now a widely accepted and domesticated technology in many countries, it is almost taken for granted that they participate in transforming public space. In contrast, telecare devices for outdoor use [or perhaps in the case of TIM for use 'out and about'] are a more recent development and thus are not yet accepted in routine practice.

This explains Gary's disguising of his practices as an inconspicuous act of sending a text message. Although stating that he has never felt the need to "hide away", his former ability to inject subtly and now to disguise his pump enable him to pass as someone without diabetes.

The act of TIM, often quick and painless, was mused upon by my participants, particularly due to its visibility in public spaces. Mary echoes Franklin's thoughts; tentatively, she tells of how she does not 'hold back' her TIM from others' gazes, but also does not "broadcast" it:

I've probably never consciously held back ... but again I don't ... go about broadcasting it ... If people are looking at me if I was checking my blood or something I would say [affirmatively, confidently], 'I'm checking my blood, I'm diabetic' ... I certainly don't hide I certainly haven't been in a circumstance where I don't want people to know I'm diabetic.

Goffman (1971) suggests that some people will attempt to dramatise their activities to gain appreciation of complicated processes, or to gain praise for other aspects of their performance/service that are not as easily appreciated. The opposite happens with TIM and diabetes, as there is a clear desire not to dramatise one's TIM but rather to *conceal* any difficulty in thought or action that the task requires¹¹³. The contradiction is stark. Mary asserts her right to test publically: she has diabetes, and it is something she has to do. At the same time she is careful not to "broadcast" the act. There is a careful balance to performing diabetes: people are careful to *under-dramatise* their performances so they are not seen as making a big deal of such an 'easy' condition. This is a mundane form of brightsiding; while not a narrative of overcoming, it still creates a similar "public patient" (Roney 2009: 239). As Goffman (1971: 44) observes, "this constitutes one way in which a performance is 'socialised', moulded, and modified to fit into the understanding and expectations of the society in which it is presented".

Going further, some participants preferred to *hide* the performance completely by seeking private spaces to do their TIM. There is a similarity here with the illicit injecting practices described in Rhodes et al (2007), where the authors found privacy

¹¹³ Indeed, in Chapter 5, I discussed that for PWD, the condition is rarely far from the forefront of their minds; and in Chapter 6, I discussed how diabetes changes one's relationship to space and place quite thoroughly.

to be a key determining factor in where injecting, here of illicit drugs, took place. Lillian tells of finding private spaces:

Lillian: [talking about going away on holiday] Because you could always find a little private place to do what you need to do anyway so it's fine.

Mark: Do you think that's a skill you've developed, always able to find that little private ...?

Lillian: It is really yeah, because you know you've got to do it. I wouldn't say it's sort of forefront of my mind but it's just you are aware of it, that you know you've got to find somewhere at some point.

Finding a private space, for Lillian, is a necessary skill that has to be developed; even if not always at the "forefront" of her mind, it is an inextricable part of living with diabetes. The procedure of TIM, for Lillian, is not understood as a performance at all, but as something *not* to be performed; something to be hidden; located not just out of sight but out of the way. Many participants support Lillian's view, explaining that TIM is conceived not as a performance, but something for which there should be no audience: Daniel says: "if you don't have to do it in front of people then why would you"? These participants, rather than performing diabetes or TIM, are maintaining a performance of being non-diabetic. TIM and, by extension, diabetes are thereby 'closeted'.

TIM can be *non*-performed (completely spatially hidden) or *under*-performed (done confidently in public but still not 'broadcast'). The responses above hint at a "citational legacy" (Butler 1993: 18) where such statements of concealing diabetes are unquestioningly reiterated by my participants, reflecting the "binding power" (ibid: 17) that the discursive recession has on PWD and their bodies. This power stems from those popular opinions of diabetes as easy and the often negative associations of (im)morality that are attached to diabetes (Broom and Whittaker 2004). In previous chapters, I have discussed how, when hypos are seen by others, PWD fear that these negative associations will follow. Perhaps the sight of TIM for others is also too stark a reminder that diabetes is a serious illness, one requiring regular intervention in the form of self-administered injections and blood tests. It disrupts a popular image of diabetes as unproblematic. Proudfoot (2011: 150-151) argues that seeing the excessive enjoyment of an illicit drug user evokes, "unconscious anxieties about enjoyment and excess" in other non-drug users. Although PWD who practice TIM

are not pleasuring themselves, but simply medicating themselves in order to replicate the functions of a normal pancreas, the act may similarly be viewed by others as excessive when done out in the open, perhaps not in the sense of an excessive pleasure but more in the sense of exceeding a social norm.

PWD AND 'THE CLOSET'

Akin to Goffman's (1968) notion of 'enacted' and 'felt' stigma, it is important to note that very few of my participants reported an actual experience of being confronted by people in public space when practising TIM (enacted stigma), but many did mention, as Arthur surmises with some Scottish vernacular, something along the lines of "sleekit glances"¹¹⁴. Such "unverifiable" (Evans and Colls 2009: 1073) gazes serve to create a sense of paranoia, leading PWD to believe that they (like everybody else but perhaps more acutely because of TIM) are being watched for any deviance (felt stigma). Boyer (2012: 556) finds that breastfeeding in public is often policed in similar ways:

The forms of social opprobrium for breastfeeding in public uncovered in this [her] research ranged from gestures and odd looks to a looser, more visceral sense or feeling about the discomfort of others ... Tuts, glares and funny looks serve as indicators that women breastfeeding in public are 'failing' in their duty to maintain public comfort.

This claim links to the idea that diabetes, like breastfeeding, is only publicly accepted when done in particular, socially approved ways. Although not using the concept of the closet directly, Boyer's analysis also resounds with Brown's (2000) ideas of the closet when she discusses the separation of breastfeeding into certain breastfeeding rooms and portable lactation modules which are often dirty, isolated spaces; ones that, rather than providing 'safer' or more comfortable spaces for breastfeeding simply reinforce the idea that breastfeeding should not be done in public.

Brown (2000) considers the closet, with respect to gay men's experiences, as more than merely metaphor but also as a spatial phenomenon, involving not just material spaces and places but also socio-spatial forces that serve 'to closet' gay men

¹¹⁴ 'Sleekit' is Scottish vernacular: in Arthur's context he uses the word to refer to sly or surreptitious glances from others when doing TIM.

in hidden and/or repressed closet space. Sheila tells of one confrontation, which goes some way to help understanding how diabetes is 'closeted' in public space:

Sheila: I was at a meeting one time and this chap sitting beside me took out his insulin pen and he injected and he made some grumblings of 'I've got to take this injection and to hell with anybody else'. I ... had a wee laugh to myself and I said to him 'I might be upset about you and I might be upset about needles ... you're just doing that right in front of me' ... Of course, I had no qualms about this and he went 'I'm...I'm...em', he ... stuttered about it because ... he obviously never thought that somebody else might be having a difficulty with needles.

Mark: You were just winding him up?

Sheila: I was just having a wee wind up and I was having a giggle about it. But I thought it took me many, many years to get to that stage where I could have a bit of fun about it. But I never said to him I was diabetic, it was a wee bit of fun on my part and I just laughed about it. But he takes his injection ... and he just carries on with the meeting. It was just his attitude ... he was arrogant, about no giving a damn, about anybody's thoughts or feelings about him taking this [injection], and I thought, 'hey wait a minute, there might be other reasons why somebody might be upset'.

Mark: The sort of reason you'd thought about for so long?

Sheila: Aye!

Mark: And he's just got this instant confidence of just whipping it out and going for it?

Sheila: Aye!

Sheila 'winds up' this fellow PWD, expressing a frustration about his "arrogant" attitude, "no giving a damn about anybody's thoughts or feelings" regarding TIM, while, as Sheila mentions during her interview, she has struggled in coming to terms with her diabetes and TIM. A sense of the tensions over the ways in which TIM is performed comes through here, and Goffman (1971: 29) writes that:

It should be understood that the cynic with all his [sic] professional disinvolvement, may obtain unprofessional pleasures from his masquerade, experiencing a kind of gleeful spiritual aggression from the fact that he can toy at will with something his audience must take seriously.

It is not evident that the man Sheila teased was obtaining "unprofessional pleasures"; and his performance of TIM was not necessarily a masquerade. Nonetheless, Sheila's account of the situation does suggest that he is able, casually, to "toy at will" with the

act of TIM. Sheila describes his attitude as akin to a “gleeful spiritual aggression”: the man claiming his right to do TIM in front of others, claiming a space to be openly diabetic, being casual even though his audience may have to consider it more seriously than him due to a lack of knowledge about diabetes and/or discomfort around needles. Butler (2006: 187) discusses the “giddiness” of performing drag and challenging accepted gender norms, and replacing drag with diabetes/TIM, hints at what might be a thrill of doing TIM in public: of knowing that people are watching, that your acts have become a performance, and that accepted notions of TIM being hidden and discreet are being challenged. While most of my participants suggest that they seek to conceal diabetes using various strategies, the evidence here shows how easily the act of TIM can come to be understood as a performance, a way of broadcasting one’s diabetes and seeking attention. Sheila’s ‘wind up’, as a fellow PWD, is serving to police this man’s diabetic behaviour as she catches him off guard and forces him to think about something that he may not have thought about before. Indeed in the account from Sheila, she is closeting the other PWD, making him feel guilty for being so open with his TIM. Likewise she is closeting herself, re-assuring herself that TIM *is* something to be hidden, and that this other PWD has somehow transgressed the widely accepted self-closeting of PWD.

Many of my participants effectively closet their diabetes, adopting a docile body in order to conform to this simulacrum, and there was a feeling among my participants that TIM being seen was somehow shameful. Linda describes this:

Linda: I think that becomes a bit more awkward ... a bit more self-conscious [being in enclosed spaces]. I guess that also would have an affect on how one feels long term, there’s a sort of sense of shame I guess.

Mark: Do you feel that sense of shame?

Linda: Sometimes yes ... shame and secrecy have a lot to do with each other. When people feel ashamed of something they keep it secret, so it goes the other way around as well. I don’t want other people ... to know because I don’t want to spark curiosity, I don’t want to stick out as different ... In certain situations I really want to stay anonymous. So I keep it secret and then the feeling kicks in because it’s linked in the brain, secrecy and shame.

Glen also wrestles with this sense of shame. He is adamant that his diabetes is merely an unremarkable part of his identity, and so he does not tell people unless it is

necessary. A comment from myself during our interview sparks an interesting response:

Mark: It's easy to hide as a diabetic.

Glen: Yeah, but your choice of words ... 'it's easy to hide', why did you use the word hide? ... Hide implies that it is something that shouldn't be open or there is a shame to it. It's the same as when, my favourite line from the Levinson Inquiry ... they said, 'privacy is for pedos', one of the most joyous bits of logic ever applied in a court room. The idea that privacy is only for something that you're going to hide and if you have nothing to hide then you don't have anything to worry about ... It's interesting that you chose the word hide ... I don't think you need to apply things like that. Most diabetics, they just live. They just go through the motions and they do stuff like that. It's not about hiding or being more open about it or telling people.

Much like Linda, Glen feels that, by consciously concealing diabetes, it automatically becomes associated with something deviant, something to be shameful about. Instead, he wishes the visible aspects of diabetes to be just done, not hidden or performed or under-performed. Glen talks passionately about this subject of concealing and considers, at times in the interview, that 'coming out' as a diabetic is: "kind of like being gay, which I am. The, who cares on one level and what business is it of people? But in the other sense there's an almost societal expectation that you would tell them". Glen is quite frustrated by this societal expectation to reveal personal characteristics, and as such he guards his personality and personal information closely.

Glen wishes his diabetes to be unremarkable, but he also laments the pressure to make public aspects of one's identity, which others may feel is imperative for them to know, such as sexuality or health. Glen reflects Samuels (2003) argument about passing by stressing that he is passing 'by default', not 'deliberately':

I try to do it subtly [TIM in public] ... I suppose you could view it ... that I am trying to hide it but I don't view it as that [hiding]. I just don't see the benefit of making a song and dance over it. It's the idea that there's either two approaches to it, either you're – again it does seem similar to being gay ... you're either out and proud about being a diabetic or you're hiding it, and no it's neither of those ... I don't need to go up to people randomly in bars and say, 'hi I'm gay' ... I don't need to go around announcing it [talking now about diabetes].

In the previous chapter I discussed how some PWD prefer to have others know about their diabetes in order to establish a 'safety net' should they encounter any serious problems and require others' assistance. Even Jessica, who is very secretive about her

diabetes, acknowledges the importance of her work colleagues at least knowing that she has diabetes (if not knowing *about* her diabetes). Glen also acknowledges that for some this may be important but feels that he is in control of his own body:

I take enough care that I know if my blood sugar's going to crash, I can feel it crashing and I can do something about it and also because I don't trust people to care for me if something goes wrong. The number of friends ... [that say] 'so if your blood sugar crashes I give you insulin right'? I'm like, 'only if you want to kill me'¹¹⁵ ... I wouldn't rely on other people to know ... unless you really think that you need other people to look after you, it's really no big deal. I don't think that it's something we need to announce in that sense.

For Glen, having to acknowledge his diabetes to others renders his diabetic body vulnerable. He resists this disclosure explaining that the possible benefits of others knowing you have diabetes – in the event of an extreme hypo or hyper – are outweighed by the negatives as they may administer medication that makes matter worse.

CLOSET SPACES

Along with socio-spatial processes that serve to closet PWD, there are also physical closet spaces where the hiddenness and secrecy of TIM and diabetes are manifest. The importance of such places for PWD has already been introduced in this chapter by Lillian, who talked about her need “to find a little private place”. Other participants support this desire for a spatial concealment of TIM. For instance, Sarah writes: “I am secretive about testing and do that in my drawer at work – I wish my meter didn't beep”. Brianna remarks about simply shifting her body when out and about: “when out in countryside, it's often easy to face away from group or path [to do TIM]”. The most obvious space where people conceal their TIM is at a restaurant, and they describe how it can be done, under the table. Figure 19 shows myself enacting this ‘under the table’ approach in a café.

¹¹⁵ Giving a PWD insulin while hypo, would only make the hypo worse.



Figure 19: I am injecting insulin into my belly, ‘under the table’ at a fast food restaurant. The photograph is taken by my friend sitting across from me and demonstrates how little another person may see of the act of injecting, but it is still evident to others who may be observing that something, involving injections and exposed flesh, is still happening (author’s own photograph).

Steven says that “I’m quite lucky because I just hook up my shirt and stick it in; I can usually do that under the table anyway”. Derek also says “I’ll just do it at the table, that’s it; job done because normally you’ve got the drapes [tablecloth] ... nobody sees nothing”. Goffman (1971: 34) discusses the importance of “setting” to one’s performance and ‘front’. In the above quotes, it is clear that, when in a public space, most often discussed in these quotes as a restaurant, the setting is indeed very important. While Goffman considers the setting to be a place chosen specifically for the purpose, the setting of the restaurant here is more an example of an everyday setting, one where PWD find themselves, quite often as part of the common social scene of western Scotland. Rather than having prepared tools to utilise, PWD make use of what resources are available to them to conceal TIM adequately: a table with drapes, a convenient toilet or a quiet hallway. However, there is arguably a prepared aspect as well, in that aspects of one’s “personal front” (ibid), such as clothing, become vitally important for ease of concealment and can be determined in advance. To expose his belly for an injection, Richard can “roll up” his jumper, Mary can “lift her top up” and Samantha can “lift her jumper up”. Steven reflects on the clothing issue, saying that it is “quite lucky” that he can “hook up” his shirt, but when talking

about his wife he remarks that “it’s different for Allison you know, if she’s wearing a skirt or if she’s ... really done up to nines, she’s got to be a wee bit more careful” (remember also Olivia’s problems, from Chapter 5, with where to put her pump when she is wearing a tight dress). Strategically, using one’s setting along with other prepared aspects of one’s own ‘front’ allows PWD to maintain the closet.

An even more salient example of a diabetic closet is the toilet (in the context of my following discussion, I am referring to toilets in restaurants/cafés/bars). The significance of this space for PWD has been discussed by others (Balfe 2005, Jenkins et al 2011). Most relevantly, Balfe (2005: 266) notes his participant’s use of toilets for TIM to protect ‘normal’ identities, but also underlines how, for some, toilets were a “spoiled space” and so sometimes negatively affect identity. The space of the toilet also recurred frequently throughout my data, with few PWD considering it to be an acceptable place to practice TIM. Arthur says:

When you’re out, going to a toilet in a restaurant ... they’re not the best places, I would refuse to go to the toilet. If somebody in a restaurant came up to me and said, ‘you shouldn’t be doing that here’, I think I would walk out.

Likewise, Lydia writes:

I used to hide in the toilet and do it. Nowadays, if I had to inject, I wouldn’t out of principle because I don’t see why diabetics should have to inject in an unhygienic place just because other people feel uncomfortable with it.

While Arthur and Lydia find the toilet to be an unacceptable place to practice TIM, others tell of the convenient privacy that a public toilet can still provide. Richard adds:

Because usually you go to the loo, the worst, ... the place that’s heaving with germs and infections, but that’s the one place in a public spot that you can have some privacy and that’s all that’s required, you’re in and out in ... five seconds and that’s it, finished, full stop, no problem, no problem at all.

Even though Richard recognises the filthy environment of the toilet, he priorities the privacy that one can have and the fact that the whole process can be completed in five seconds, keeping time spent in this abject space to a minimum. The convenience of the toilet is further extolled by Lillian: “if you’re at a table that’s quite enclosed ... if it’s a busy pub ... I would maybe be more worried of people seeing things, but I would say most of the time I probably would go to the toilet ... yeah, probably the toilet most of the time”. For Lillian, the toilet is a convenient place when she is already

“enclosed” in a “busy” environment. This is a situational context in which the toilet becomes an acceptable, preferred place of TIM, the relative quietness and privacy of the space overruling its conception as a dirty space. There emerges a sense of clean/dirty, public/private when PWD consider the spaces in which they test. While toilets can be considered dirty, germ-ridden spaces, unsuitable for injecting, they can also be convenient escapes for PWD in busy places.

Some authors contend that “toilets are technologies of concealment. They make waste ‘disappear’ and they ‘provide a literal and moral escape from the unacceptable’ ” (Barcan and Hawkins quoted in Barcan 2005: 10). Focussing on her own discipline of gender and culture studies, Barcan (2010: 40) argues that the gender distinction evident in public toilets serves to reinforce social norms and categories, so much so that:

They enable a kind of subtle cultural homology whereby those who represent a threat to the established gender/sexual (and sometimes racial) order [by using the ‘wrong’ toilet for their gender or identifying as a gender that has no toilet] may themselves come to be imagined as a form of cultural waste – or, if that is putting it too strongly, as a form of troubling category whose presence we would rather conceal.

This discursive construction of toilets and the practices of defecation that take place within them configure toilets as a particular kind of performative space (Gregson and Rose 2000), spaces that perform a purge on those who enter of undesirable traits, practices and matters. Longhurst (2001: 66) agrees, stressing the use of toilets, “as spaces in which bodily boundaries are broken and then made solid again. They are spaces in which bodies are (re)made and (re)sealed ready for public scrutiny”. Coupled with the discursive pressure to escape the gaze of others while doing TIM in public, some people are directed into this space to do TIM, configuring TIM as a practice which, unless concealed in this space, is dirty, transgressive and unclean, set alongside the practices of defecation. The space of the public toilet then sharply exposes the closeted nature of living with diabetes. For some it is an abject space where they feel others may expect them to go for TIM, but they resist, not necessarily flaunting their diabetes, but, as earlier participants said, just doing it as a normal practice. For others, it is indeed simply a convenient space, providing privacy.

Conversely, the space of the restaurant table has its own performativity as clean, hygienic and social. Bell (2007) has considered the ways in which city

consumption spaces such as restaurants and bars have more than just economic functions. Bell argues that hospitality is also an ideal about what it is like to live in a city, or a specific area of a city, or to be part of a certain social/cultural class that dines at a specific type of restaurant, café or bar. Further, Lugosi (2009: 430) has shown how these ideals can be upheld by customers who “conform to particular expectations of patronage”. By electing to do TIM in toilets, or in a broader context seeking out private spaces, PWD are upholding such normative expectations, legitimating a ‘healthy’ discourse where bodily difference and transgression are not welcome. Barcan (2010: 40) conceives of those people who may upset the accepted gender/sexuality divisions of public toilets being “imagined as a form of cultural waste”. Likewise, Butler (2006; 2011) considers the performance of drag to be a subversive act, challenging embedded gender norms. So, continuing the parallel of drag performance and TIM performance, someone who does TIM in public, at a table in a restaurant, is subverting both the performativity of the restaurant table as hospitable and the performativity of the toilet as decontaminating¹¹⁶. Jessica, for instance, would rather use these performative spaces and would be shocked to see someone transgress this discourse: “I think it is a very private thing ... I’m used to it because I’m a diabetic but, if I wasn’t, I wouldn’t want to see somebody sticking a needle in them; honestly, I would ask them to go somewhere and do that, I would. I just don’t think it’s necessary”.

Many others, as already mentioned, assert that they would subvert this discourse, recognising the abject status of toilets and being prepared to challenge any punitive comments that arise. I touched upon Frank’s “disciplined body” in the previous chapters, and his discussion of other body types also emerge throughout the data. Frank (2013: 44) discusses the “mirroring body” which tries to replicate both other healthy bodies and an idealised “picture of health”. This body is evident among my participants who write about hiding the reality of their diabetes in toilets, store rooms and homes. Much like the closet spaces of Brown’s (2000: 28) work, where gay men can feel a sense of “sustained heteronormativity”, PWD can feel a sustained ‘*healthynormativity*’ where they feel the symptoms and treatments of diabetes must

¹¹⁶ Decontaminating in the sense that the toilet is a bounded space where people go to *remove* waste from their bodies before *returning*, now clean, to other spaces, such as a restaurant table. The toilet space itself may be considered dirty and abject, but the process of using this space is cleansing or decontaminating.

be concealed and closeted. Their bodies must mirror, as closely as possible, the non-diabetic bodies with which they share space. Frank (2013: 46) also discusses the “dominating body”: “the disciplined and mirroring bodies turn on themselves. The dominating body turns on others”¹¹⁷. This body can also be seen in my participants, not least those who are assertive about not hiding their TIM:

Never noticed anyone getting offended. Hard luck if they are! (Agnes).

My former work colleague thinks it should be done behind closed doors and out of sight. If I need to test, I will test, no matter who I am with or where I am. They will just have to get used to it (Laurel).

These participants are happy to occupy space with their body even when it becomes a specifically diabetic body when they do TIM. For some PWD, the act of TIM, being imperative to day-to-day life, is not something to hide from others. For example, Allan and Catherine write:

I have always been very open regards my diabetes and always injected in full view of people. I would rather have a discussion regards diabetes and correct myths than hide away. In my view, I need to inject, they don't need to look (Allan).

I will inject or test anywhere in front of anyone. I have never experienced a stranger telling me not to do a test or injection. And if I did, well, to say I'd give them a piece of mind is a massive understatement (Catherine).

Such attitudes are akin to the arguments put forward by Hansen and Philo (2007) that ‘difference’ should be something ‘normal’, while Mol (1998) similarly seeks to establish ‘multiple norms’. The aim of these authors is to destabilise a narrow conception of a ‘normal’ body that acts and performs only in uniform ways, and which thereby makes varied performances more marked by their difference. The above respondents hint at a more pro-active approach to doing TIM in public, in which they claim their right to do TIM in public space and prefer a (productive) confrontation rather than ‘hiding away’. Frank (2013: 51) proposes that real bodies will never fully fit into any of these ideal types: “each of us is not one type or another, but a shifting

¹¹⁷ The final body type that Frank (2013: 48) discusses is the “communicative body”, which he considers as an idealised type of body. The communicative body shares its illness experience with others, fulfilling an ethical responsibility to share its experiences of illness in order to relieve the suffering of others. Essentially all my participants exemplified a communicative body, accepting the benefits to research and understanding diabetes that I outlined in the opening information page of my questionnaire and information sheet for interviewees.

foreground and background of types. The value of the types is to describe the extreme moments of these shifts, thus providing some parameters for hearing the body in the story". I have used Frank's concepts of ideal body types here to demonstrate the various ways in which the diabetic body can be understood as shifting between types, emotions and even performances, indicating the dynamic range of experiences and complexities involved in living with diabetes.

The performativity of spaces, such as restaurants and toilets, is often acknowledged, as people take measures to be discreet, doing TIM 'under the table', under shirts and jumpers or slightly contorting their bodies to create a brief shield. Social context is also particularly important for my participants. When discussing TIM, many of the interviewees made reference to who would be seeing them test or inject. There was a clear distinction between close friends, work colleagues, family and strangers. Allison explains the importance of this: "to be fair, I'm not a public injector ... I'm not worried about it but I wouldn't consciously inject in front of my work colleagues ... if they came into my office when I was injecting. It's very discreet because I've got the pen". At an earlier point in our interview, Allison claims that she is not a "secret injector" but now claims she is also not a "public injector". I ask her about this:

Yeah, I know, that's a kind of contradictory statement. What I mean is I don't have any issues about jaggging because I need to ... If I was jaggging at work, I wouldn't deliberately jag if I knew somebody was going to walk in on that minute, it would be a quieter time when I choose to jag ... But, as I say, [if] we've got friends in; we've got friends who are diabetic ... then we [her and Steven] wouldn't bother about jaggging in front of them because they're used to their husband or wife [injecting] ... So it is a bit of a weird answer, I realise that.

She acknowledges that at times she is a public injector and at other times she is secret injector. She explains this contradiction, saying that timing, along with in front of whom you inject is all important. Allison is remarking on what now emerges as a complex and contingent time/space geography of TIM. One aspect of this geography is how the habitualness of TIM can become an unremarkable, accepted part of everyday life and therefore not a distinct performance. A routine recession develops here, but only in this particular socio-spatial context, for Allison still notes that this relaxation is not experienced in other settings: she still "consciously" decides not to inject in front of work colleagues. Reflecting back to the previous chapter, we can

further see how important one's home space in feeling 'safe' with diabetes.

A relevant incidence occurred during one of my interviews. In a quiet café, while we talk, Samantha decides to test her blood sugar level. I ask her about it and she replies:

Samantha: [I] quite often go to the toilets [to test]. I mean there [referring to her test], because I knew that you knew and that's why I just did it.

Mark: Were you more comfortable to do it here because I do the same thing as well?

Samantha: Uh-huh and quite often I'll be sitting at a lunch table ... and I'll sit there and do it and most of my friends know what I'm doing.

Because she was aware that I knew exactly what she was doing and why she was doing it, Samantha felt comfortable testing in front of me, even though I was not a familiar person. Therefore, it is not necessarily *only* in front of family and close friends where TIM is easily done, but also in the company of people who are aware of what it is. Goffman (1971: 57) considers this "audience segregation", commenting that we present different versions of ourselves to different audiences. At home, in front of family members people can (usually¹¹⁸) be openly diabetic, but in front of strangers the performance of TIM is to be discreet and hidden. Rather than being a seemingly natural and unquestioned performance, my participants were reflective on why they felt that their TIM should be concealed in public spaces. Three themes to emerge from my data to explain this apparent contradiction are: the needle phobia of others; connotations of self-injecting with illicit drug use; and injecting in front of children. I will take each of these themes in turn to show *why* PWD often feel that TIM *should* be hidden.

¹¹⁸ Balfe (2005: 267) found that family members can also pressure PWD to enter hidden spaces such as toilets to do TIM. However most of my participants did not share similar concerns of direct pressure from family members. There are some caveats, though: Hayden tells of how his mother was very unsupportive when he was diagnosed with diabetes and would be upset with him when he 'declared' he had diabetes to others. Although, Hayden was diagnosed when he was thirty-five and did not live with his mother while he had diabetes, so such confrontations have been rare. Hayden's wife was very supportive during the diagnosis process and has been ever since. Sheila said that her family members would refuse to inject her with insulin or glucose in an emergency because they were uncomfortable with the act of injecting another person; and Sheila does remark that this hypothetical refusal of assistance, from those so close to her, has left her quite upset. However, her family were not uncomfortable with her injecting herself in front of them.

NEEDLE PHOBIA

I have previously discussed that, when practising TIM, people are aware that they are potentially on display, exposed and being watched, and so a sense of being sensitive to others' feelings on needles, blood, and bodily penetration is evident. Steven explains this:

I used to have a brother-in-law who, you didn't even need to show him a needle, you just had to say the word and he fainted ... So there are people in the world that are like that, so I'm not trying to make their life any more difficult than it is, so you become quite aware of the sort of type of company you're in, what you can get away with.

Steven is conscious that he must manage his behaviours when in the company of others, and he is careful to ensure that his TIM does not offend or make people uncomfortable. Daniel supports this viewpoint, replying to a question from me about TIM potentially being a burden:

It used to when I was on injections¹¹⁹ because ... I used to openly do my injections. I wouldn't hide away from it because I didn't feel like I had to but there was sometimes I would maybe get a wee comment from someone like: 'you shouldn't be doing that in front of people' ... Just ... always having to check and stuff and sometimes people are a bit squirmy with needles, so it just depends who you're with, but I don't really feel like it's a burden.

Maureen, reflecting the aforementioned assertive attitude to TIM, takes a slightly different approach: "well there's one boy at work who doesn't like blood, but then I just say to him 'don't look', but I wouldn't go up to his face and do it in front of him ... because I know he doesn't like it, but it's not a problem. I'd never be worried about doing it in front of anyone". For Maureen, it is her colleague's responsibility to avert his eyes, and hence to avoid feeling uncomfortable when TIM is happening near him, although she does acknowledge that she takes some measures to stop him seeing.

'JUNKIES'

Related to the sense of needle phobia are seemingly inevitable confusions of TIM with the injecting of heroin and other illicit drugs. My participants generally said that

¹¹⁹ Daniel now uses an insulin pump but previously used injections.

TIM was nothing, of which to be ashamed: "it's not heroin so I'm alright" (Allison). Even so, the possibility of being mistaken for doing something illegal and almost unambiguously deviant (Proudfoot 2011; Rhodes et al 2007) still lingered in the responses of some participants. Derek says:

I mean if the dialogue from whoever it is sees you injecting, they might take it the wrong way because they're naïve ... they might think you are actually injecting some illegal substance and they might have some derogatory comment to make, then that's a different kettle of fish [from someone who is needle phobic].

Derek had previously remarked, when telling me about coming to terms with his diagnosis, that "initially that's what I thought, instantaneous ... I'm going to be like a heroin addict, I'm going to have to shoot up and all the rest of it, it wasn't a nice thought". Derek was quickly able to rationalise these fears and reflect that TIM was much easier than he initially thought, not being intra-veinous: "you just get a bit of fat and that's it, you're in". Sheila was not so quick to arrive at this conclusion, and she tells about injecting in the toilet when out at a restaurant:

Sheila: I would go to the bathroom and inject there, but then I still had to take the needle out in the toilet, in the bathroom and inject, you still had people pass you by and I worried that people would think I was a drug user and so I was always so embarrassed about it.

Mark: Did you actually have any incidents of people accusing you of being a drug user or saying ...?

Sheila: No, I think it was more my own perception and I think it was more to do with ... how I might perceive somebody else injecting.

Much like preferring to hide TIM to spare others the sight of needles, PWD may attempt to hide TIM to avoid being taken as drug abusers, given that the act and imagery of injecting oneself is now so steeped in these connotations. Anna also remarks:

I think it's more to do with junkies and all that, you just don't want to be seen, people going like ... 'she's jaggging over there'! ... I think that's what they take it as ... Whereas before, well years before ... it wouldn't be seen as [that]. But obviously the first thing that comes into my head, if I think somebody saw me, oh my god they'll be like that [thinking of 'junkies' if] they see a jag over there.

Anna parallels Sheila's fear of people possibly perceiving her as a "junkie" or illicit drug user, but she also acknowledges that, like Derek, she is able to bypass these anxieties when reality hits: "but other than that ... if I was sitting here ... and I couldn't go anywhere, I would take my jag". The "here", in this case, referring to the coffee shop where we were talking. Despite this reasoning, the association still remains, not in the back of her mind, but instead it is, "the first thing that comes into my head".

Other participants also made references to these connotations, but in a light-hearted way. George, for instance, says that, when having to inject while with others, "yeah, I just make a joke, I say 'yeah I'm going to shoot up now' ... I don't have any problems telling people, I don't think it's anything to be ashamed of". Likewise, Richard states, talking about his diagnosis, "since then I've been more or less a junkie ... using needles and methylated spirits [referring to cleaning his previous permanent syringe with alcohol]". During our email contact before the interview, Richard also wrote that he may be of help to my research for he is "now forty-five years as a junkie on insulin". The dependency on insulin is here jokingly linked to a drug abuser's dependency on recreational drugs. Of course, there is a major difference between the two dependencies: one caused, in chemical terms, by the pleasurable and addictive qualities of the drugs and the other caused by an inescapable medical condition. George meanwhile is likening the actual act of TIM to 'shooting up'; a phrase usually referring to obtaining an illegal high through injecting drugs. By so doing, he aims to dispel any tension among his immediate company, showing that he understands what his TIM can look like, but, through his joke, making it obvious that it is something removed from the (assumed) grim reality of drug abusers (as described by Briggs 2013) but inevitably not from the connotations. The fact that some of the participants made this connection shows that a subtle discursive linking of self-injecting with illegal drugs is still at play in people's minds.

CHILDREN

The suggestion that TIM, although "nothing to be ashamed of" (George), still carries with it a certain mystery connecting it to something illegal, deviant and disapproved was further evident in some participants' responses when commenting that TIM should not be done in front of children. Steven says: "I wouldn't do it in front of kids".

When I ask Jack if he is comfortable doing TIM in front of people, he responds: "I've done it in public, nobody's ever said anything to me; see the thing is I don't do it in front of kids, in front of wee kids, I always try to do it somewhere else or sort of turn away on the chair". He describes going to restaurants and, if there are children in the area, he will swivel his body in his chair when injecting to prevent them from seeing. It becomes apparent that TIM is still something of an 'adult' phenomenon for my participants¹²⁰, then, not to be seen by children, possibly because of the potentially fleshy, bloody, penetrative nature of the act, but also possibly because of the perceived inability of children to understand the sight of TIM. Anna describes this more directly, talking about her grandchildren:

Anna: I'll not jag in front of them, I don't want them to see it's OK injecting a jag, until they're old enough.

Mark: To understand it's a medical thing?

Anna: Like as you say, granny's a diabetic and she has to take insulin, kinda educate them on it. I feel with the younger ones now it's too much of that about [illegal drug usage] so I do, I just don't let them see me doing it. They know what the test is; they've seen me doing that. But the jag I ... stopped doing because, well I didn't like them seeing me do it just in case they thought, 'it's alright to take a jag'. You've got to teach them, when you see needles lying outside not to touch it¹²¹.

Anna believes it is now more likely for children to encounter instances of injecting in their day-to-day lives than it was in the past¹²². She therefore fears that, if her grandchildren become familiar with TIM, they will be unable to disassociate it with

¹²⁰ As discussed in Chapter 4, all of my participants are over eighteen years of age. Of course, as mentioned in Chapter 1, type 1 diabetes often manifests in childhood, and so diabetes and TIM are certainly not only an 'adult' phenomena. The SDS (2013) reports the age range of 'ten to nineteen years old' as having the highest incidence rate of type 1 diabetes, for all years through 2007-2013. However, the SDS also reports a much higher increase in rate of new cases of type 1 among older populations, year on year.

¹²¹ Anna is also highlighting a key fault of the analysis of my data; that is the lumping together of blood glucose testing and insulin injecting as TIM. The two processes are often done together; for instance, one may test one's blood before eating a meal to inform the decision on how much insulin to take after the meal. If the blood glucose is high, one may take extra insulin, if low, take less insulin. However, the practices are also performed in isolation: one may test blood sugar level when feeling not quite right or as part of a regular schedule without having to take insulin, and likewise insulin injections can often be taken without reference to a recent blood sugar reading. Indeed, some people to whom I have talked will only test their blood sugar levels one day out of the week, at different points during the day, to obtain a weekly profile, but still take insulin every day with each meal.

¹²² This claim from Anna may or may not be true in the context of urban Glasgow, her point of reference, but this is not important: the point is that it reflects her own observations and experiences on the matter.

other forms of drug use to which they may also be exposed and possibly become more inclined to touch discarded syringes.

For the PWD in my study, there are certain ways that TIM must be done. Even those who conveyed an assertive attitude and their right to do TIM anywhere still tempered their accounts by discussing concessions they make because of others' possible needle phobia; subtle connections with drug abuse; and injecting in front of children. TIM is therefore, a thoroughly relational act. Boyer (2011: 433) finds a very similar situation for women who breastfeed in public, writing that, even though some women told of their "bravado" when breastfeeding in public, there was still a "view that there were 'correct' and 'incorrect' ways to breastfeed outside the home". She argues that this view relates to the relative rarity of breastfeeding in (western) public places, so that often others are startled by the act.

COMING OUT

The process of disclosing one's diabetes, or 'coming out' as diabetic, is complex. Recall the section on workplaces in the previous chapter, where I discussed the different attitudes that people held about coming out as diabetic to their work colleagues. Some felt they would be discriminated against or they would be considered differently by colleagues, whereas others felt that they should come out in order to establish a safety net in the event of experiencing problems such as severe hypo. Samuels (2013: 322) argues that the analogy of 'coming out' as homosexual does not easily transfer to coming out as disabled:

Coming out as disabled appears to have more in common with racial discourses of coming out or passing than with queer discourse, since the contingent (non)visibility of queer identity has produced a variety of nonverbal and/or spoken means to signal that identity, while the assumed visibility of race and disability¹²³ has produced an absence of nonverbal signs and a distrust of spoken claims to those identities.

This claim supports Charmaz's (2008: 12) argument, quoted in Chapter 6, that people with illness can "lack a language" to express how illness affects their life. Brown (2000: 37) considers the power of the "performative speech act" for gay men who, by saying "I am gay", can "break down the closet by telling or 'saying' their sexuality".

¹²³ Of course, as Samuels is suggesting, race and disability can be invisible as well.

The lack of “spoken means” for people with invisible disabilities means that any speech act is met with “denial, mockery, and silent disapproval” (Samuels 2013: 323) serving to dissuade people declaring their condition.

Alternatively to a ‘speech act’, the visibility of TIM is sometimes used by my participants as a way of revealing their diabetes to others. Cheryl recalls her netball coach discovering that she has diabetes:

She [netball coach] seen me testing my blood sugar once and she went, ‘are you diabetic’? ... That was her just finding out and she was [saying] ‘you should have told me’! [And I said] ‘yeah because it comes up in conversation quite a lot’ [said sarcastically to coach], and she was ... ‘yeah I suppose, but you should have said something’, ‘what, when?’ [I said] ... It’s easier for them if they catch me doing something different and then they go ‘oh what’s that’? ... Then you can tell them, you don’t just, in the middle of a chat about what you were doing that weekend [say], ‘oh yeah so by the way [I have diabetes]’.

Cheryl reflects the previously discussed ‘passing’ attitude of Glen, noting that for some PWD the visible act of TIM serves as a way to negotiate the ‘coming out’ process, subverting the need for an awkward speech act. Colleen tells of her concealment strategy at work:

When first diagnosed I used to test in the shower room at work as there was a lock and no-one would come in. I needed the privacy as I wasn’t very good at getting the blood out and was still accepting it all. Now I use the loo as I can do the whole test a lot quicker and if anyone comes in mid-way I’m good enough now not to look silly and can hold a conversation without having to concentrate on what I’m doing.

Colleen hints at an experiential dimension to management practices: when first diagnosed she had to retreat to an especially secluded place, a shower room, but now that she is more experienced she can use the communal area of the toilet because her ability to test allows her to converse while also injecting. She notes that she is now more confident in ‘coming out’, and yet her actions represent, still, something of a disclosing compromise. Goffman (1968: 124) explains this:

Fleeting offerings of evidence may be made – purposeful slips, as it were – as when a blind person voluntarily commits a clumsy act in the presence of newcomers as a way of informing them about his [sic] stigma. There is also ‘disclosure etiquette’, a formula whereby the individual admits his own failing in a matter of fact way, supporting the assumption that those present are above such concerns while preventing them from trapping themselves into showing that they are not.

Colleen is practising such a “disclosure etiquette” using a spatial tactic. She is happy for others to walk into the toilet while she is testing and see what she is doing, since she is now able not to “look silly” and to “hold a conversation”, allowing her to show that testing and diabetes are not a ‘big deal’ for her and therefore should not be a big deal for others either. Colleen’s tactic nonetheless exists in a careful balance. Goffman considers that tactful acceptance by others of one’s stigma can sometimes be taken too seriously by the ‘stigmatised’ individual, leading them to believe that they are fully accepted, when in fact, they are not. Colleen is happy to let others see her testing but still only in the toilet, therefore only acknowledging it while in an already abject space so as not to infringe on the more ‘healthy’ and ‘normal’ spaces of the office or lunch room.

Lewis (2012: 226) argues that “coming out journeys are not just unilateral ‘quests’ for identity formation or self-actualisation, but also contextual, relational processes”. Consider Allison’s self-confessed contradiction of being both a secret and public injector, in relation to which her self-actualisation as a PWD is evidently context-dependent. Lewis (ibid: 227) continues:

‘Moving out to come out’, then, is not a unilateral quest for sexual fulfilment or identity affirmation, but a relational means of negotiating landscapes – including home, workplaces, and social networks – that are rendered (or expected to be rendered) uneven by the disclosure of sexual non-normativity.

Lewis is describing how gay men will often migrate to live in different areas to facilitate their coming out, something that they may not be able to do so freely in their home context. My participants are not exactly the same, since they do not migrate to come out, but the idea that coming out is highly spatially dependent does resound in their accounts. Being a PWD is indeed a “relational means of negotiating landscapes”, and the PWD in my study perform diabetes differently in different spaces. In Chapter 6, I discussed how being a PWD affects people in different spaces and places, sometimes creating feelings of difference and anxiety. In this chapter I have shown that diabetes is differently performed in relation to context. As Lewis explains, it is not always the case that gay men experience landscapes differently after disclosure of their sexuality, but that they expect or feel that they will, due to their now altered relationship to a perceived heteronormativity. My participants remark on the same feeling. For example, Shiela feels she will be regarded as a drug user and Alice feels

she will be regarded as attention-seeking. These points reflect the idea of a discursive recession of diabetes, where a sense pervades that, while in public spaces, one's body should conform to a certain 'healthynormativity'. This is especially the case with diabetes due to its conception as a condition that is easy to hide and which impacts minimally on a person's day-to-day life.

CONCLUSION

The accounts throughout this chapter have shown how the performance of diabetes, as almost overlooked, unimportant, unmarked – positioned this way both internally (a willingness of PWD to hide TIM) and externally (the discursive pressure of diabetes to be invisible) – is complex, significant and changing depending on spaces, times and company. Seeking private spaces, doing it discreetly and not 'broadcasting' when in public space all demonstrate how diabetes is understood by PWD 'to be performed' as a subtle/unremarkable part of one's identity; for them, this is where and how it *should* fit into one's time/space geographies. As Foucault (1991: 202-203) writes:

He [sic] who is subjected to a field of visibility, and who knows it, assumes responsibility for the constraints of power; he makes them play spontaneously upon himself; he inscribes in himself the power relation in which he simultaneously plays both roles; he becomes the principle of his own subjection. By this very fact, the external power may throw off its physical weight; it tends to the non-corporal; and, the more it approaches this limit, the more constant, profound and permanent are its effects: it is a perpetual victory that avoids any physical confrontation and which is always decided in advance.

What I have described in this chapter is the "perpetual victory" of dispersed relational panopticism to create 'docile diabetic bodies'. As I have noted, few of my participants actually noted any sense of direct confrontation or instances of stigma regarding the sight of their TIM by others; rather, they registered an awareness and fear that they may experience confrontation or be otherwise noticed as unsettling the norms of diabetes. It is this 'felt' stigma (Goffman 1968) that configures TIM as a 'deviant' practice when done visibly. Figure 20 pictures this "perpetual victory" in the sense of a 'vicious cycle' with an unverifiable beginning or end.

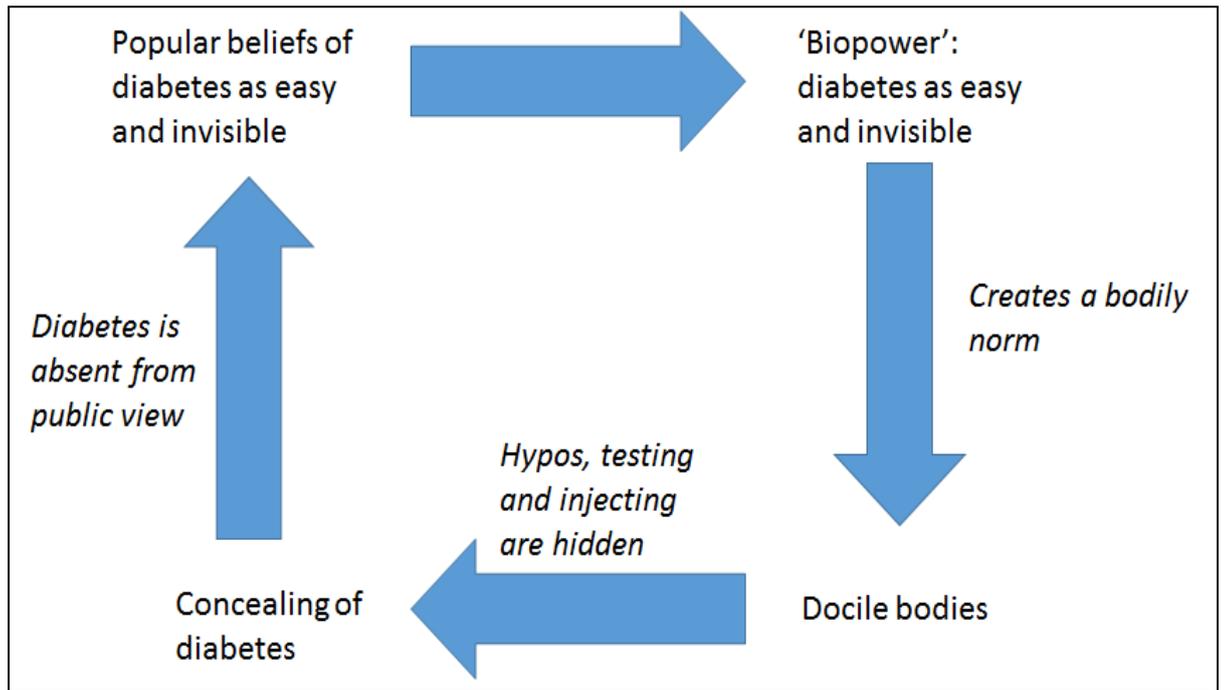


Figure 20. This is my own visualisation of the “perceptual victory” (Foucault 1991: 203) of panopticism, which can lead people to internalise the disciplining of their bodies towards docile diabetic bodies. There is no clear starting or end point of the process.

The validity of panopticism in explaining modes of surveillance has been questioned. Yar (2003) writes that panopticism is not created only by the introduction of a ‘gaze’ (he uses the oft cited example of CCTV in urban environments) but also, as Foucault describes in *Discipline and Punish*, from ‘drills’ and other regulatory practices that establish norms. Panopticism only works to discipline if there is a norm to deviate from. Yar also points out that the disciplining power of panopticism relies on people knowing they are are/could be watched, when in practice, many people are unaware (and/or perhaps uncaring) of surveillance technologies. He (ibid: 262) writes that, to apply panopticism, to any given study, one must provide a “burden of proof” that people are aware of surveillance. I have done so throughout this chapter, demonstrating that many of my participants are aware of being under surveillance, from the gaze of others, when conducting TIM. Indeed, while many insist TIM is an unremarkable part of living with diabetes, they still take care to conduct TIM with regards to their surroundings. Therefore TIM is still configured as something of a ‘deviance’ from a norm, especially when done in public.

Yar also contends that despite Foucault’s acknowledgement of power also being productive, Foucault, and others that use his concepts, often configure panopticism as a normalising force, giving little attention to the ways in which this

gaze can be productive or, when it is a repressive gaze, effectively resisted. Sheila's account of her colleague, 'whipping out' his insulin injection when in the company of others perhaps demonstrates this resistance, as he pays no mind to who may see him conduct his TIM. Of course, as Yar may suggest, the man could simply be unaware of the potential surveillance from others. Yar calls for more consideration of the productive power of the panopticon, such as in situations where people may benefit from, or even enjoy, being 'gazed' at¹²⁴.

I join Boyer in arguing that such health-promoting behaviours should not be concealed in closets. Instead, they should be unremarkable acts that may signify *difference*, but not *deviance*. Perhaps such an idealistic aim of "marking everything" (Brekhus 1998: 45), so that nothing is rendered more or less remarkable than anything else, is unrealisable. It cannot be denied that other people do have genuine needle phobias, itself an often contested condition that creates a considerable amount of anxiety (Andrews 2011). Maybe illicit drug use in public should be challenged by responsible citizens and that any ignorance that confuses TIM with illicit drug use is here understandable, given that PWD often perform their TIM so subtly that it becomes mysterious and unknown to others. Perhaps because of these connotations, TIM *is* best obscured from more impressionable members of society such as children, who may not be able immediately to understand the difference. Nonetheless, these are difficult, open questions to which easy answers are hard to reach, all bound up with further complex issues to do with diabetes and citizenship, which is the focus on my next chapter.

¹²⁴ Yar (2003: 257) also considers responses to panopticism that suggest the concept is outdated, with "dataveillance", that is all the collected pieces of information about an individual's or population's life characteristics (health statistics, shopping preferences, leisure preferences and so on) replacing a 'top down' panoptic view. This is an interesting avenue of research for diabetes as dataveillance is not dissimilar to the 'gluco-centric' view and, to a brief extent, this dataveillance is discussed throughout my thesis as PWD consider their own and others' responses to their blood test numbers (the following chapter touches on this as well). As Yar suggests some people may enjoy being gazed at, disrupting the dominant idea of panopticism as mostly disciplining. In human geography Kitchin and Dodge (2011) discuss such *sousveillance* (empowerment through surveillance and feedback) and *scopophilic* (the pleasure of being looked at) methods and technologies (for example through blogs or *Facebook*). Some of this 'co-opting' of surveillance is evident in my thesis as well: consider Radford's claiming of a cyborg body/identity (Chapter 5, Figure 18), while others watch on in awe. However, I feel the disciplining and normalising power of panopticism is a fitting explanatory model for my participants' responses.

CHAPTER 8**PWD AS 'BIOLOGICAL CITIZENS'**

“As the medical profession know FA¹²⁵ about diabetes, how do you expect the general public to know anything?” (Elliot).

INTRODUCTION

The previous three empirical chapters have disrupted ideas of diabetes as a non-imposing factor in a PWD's life. I have argued that diabetes is far from a recessive condition and that, for most if not all PWD, it needs to be attended to constantly throughout everyday life. Social conventions reinforce the perceived invisibility of diabetes, making it difficult for PWD to talk about the condition with others or to attend freely to their diabetic body through the visible signifier of TIM. This discursive recession of the condition means that the experience of living with diabetes can be an anxious one, characterised by incessant worry about future complications, travelling through space and being marked as different. The discursive recession stems from an assumption about everyday life with diabetes, which is that control is easily attainable thanks to advances in medical science and the availability of supplies and medical care from the NHS. This understanding is maintained by a perceived surveillance of diabetic bodies in public space; as with Foucault's (1991) discussion of panopticism, PWD feel monitored and internalise self-surveillance and self-discipline in order to conform to an idea of 'docile diabetic bodies', thereby sustaining the discursive recession of diabetes (as pictured in Figure 20). In terms of behaving as a proper PWD, such docile bodies can be described as 'biological citizens', a term introduced by Rose (2007) in order to explain how certain populations or groups within populations can come to be defined along biological lines.

Throughout my thesis there has emerged a keen sense of PWD feeling that they have to conform to moral standards of being diabetic, which, I have argued, reflect a particular 'diabetic' biological citizenship. In this version of biological citizenship, an openly diabetic way of being is often unattainable. Mol (2008: 35) explains this dilemma best, writing that:

¹²⁵ FA meaning 'fuck all'.

'By definition' a citizen is someone who controls his [sic] body, who tames it, or who escapes from it. 'Citizens' owe the ability to make their own choices to the silence of their organs. But this implies that you can only be a citizen as far as your body can be controlled, tamed or transcended. Diseases interfere with this. Thus patient-citizens have to bracket a part of what they are. As a patient, you may only hope to be a citizen with your healthy part.

Mol's argument is particularly salient for Chapter 5, where Merritt and Radford's organ (the pancreas) may be silent in reality, but internally and imaginatively is it riotous. I have also shown how PWD often need to bracket that part of themselves which is diabetes (for example talking about it, or doing it through TIM) in order to partake fully in society; ironically, to be accepted as a PWD they need to convey that their diabetes is under control, that they are responsible biological citizens who have not let such a 'manageable' condition overwhelm them. In this mode of biological citizenship, a configuration of PWD as merely having a different way of being and regulating their body is denied. It also creates a tension among PWD, and in the final section of this chapter I will explain why, in this thesis, I have grouped type 1 and type 2 diabetes under the umbrella category of diabetes: in order to prioritise the similarities between the experiences of people with different types of diabetes, rather than stressing the differences.

I argue for a more pragmatic approach to understanding what it is like to live with the condition, based on research that attends to the voices of PWD. I hope that this can lead to a better understanding of life with the condition so that, when PWD fail to adhere to such narrow expectations, they may not feel guilt and shame. Writing of guilt and shame, Longhurst et al (2012: 307) discuss how these feelings are experienced by single mothers who pursue further education:

Guilt is relational and about societal expectations. It is about how a good mother 'should' behave and what 'should' take priority in her life. It is important, therefore, to think beyond the emotions of individual single mothers to consider their discursive construction and relationships as a group with other groups.

Literature on motherhood has proven a useful parallel for discussing life with diabetes in my thesis (recall Chapter 7 and my discussion of breastfeeding and the work of Boyer). Both mothers and PWD are subject to highly prescriptive norms from wider society, as their situation is considered to affect the entire population (in the case of mothers, birthing and raising the next generation of citizens; in the case of living with

diabetes, ensuring the continuation of healthy citizens who do not burden the NHS). As such, they are judged harshly when they are perceived to have failed. Continuing this useful parallel, I will draw from the geographical writing on motherhood, and in particular I will discuss the stresses of deciding to have children who may develop diabetes, the experience of diabetic pregnancy and ongoing difficulties of being both a parent and a PWD. Following Longhurst et al (ibid), I argue that “we need to think not just about individual emotions but about relationality, collectivity, social groups, affects and politics”, when it comes to creating a more accommodating space for those living with diabetes.

The last chapter ended by portraying the “perpetual victory” (Foucault 1991: 203) of panopticism in which PWD internalise practices of diabetes discretion. However, as aforementioned, panopticism is not entirely oppressive but also has productive effects. Vaz and Bruno (2003: 278), note that the internalisation of self-surveillance is not entirely imposed from external factors:

Individuals ... fear potential abnormality not only in others but also within themselves, and thus refrain from doing what would characterize them, in their own eyes, as abnormal. The norm becomes the object of individuals' desire instead of being only externally imposed.

In Chapter 7 the visibility of management practices were a focus. However this management still takes place even if the embodied practices are kept on the margins of visibility. Simply put, self-management must be carried out or ill-health and embodied complications, as discussed in Chapter 5, will swiftly develop. Following Vaz and Bruno's point; fear of abnormality, of the uncanny body with amputated limbs and diminished sight is somewhat separate from the social stigma of being exposed as a (failing) PWD. The 'gluco-centric' approach, gets a reprieve, when configured as a form of internalised self-surveillance which works to *improve* personal health. Dyck (2010: 257) encapsulates this uncertainty writing: “one dimension of divided opinion [in disability research and activism] is the difficulty of distinguishing between therapeutic intervention and enhancement of the normal”¹²⁶.

¹²⁶ Philo (2007: 92) believes that medical processes, practices and other actions of clinicians have often been sidelined in health geography, so that this 'medical stuff' is “critiqued for what it is *not* (not for what it actually *is* and *does*)”. There is, perhaps, a distrust of all (or most) things 'medical' in health geography, when, in fact, medical approaches such as 'gluco-centrism' are not as unsympathetic as first thought.

Therefore there is a balance between keeping TIM discreet and still maintaining optimal blood sugar levels. This perhaps explains the lack of distinct 'diabetes activism' among my participants (as Balfe 2005 also found among his participants). While many of them demonstrated a degree of assertiveness (remember Sheila's and Sophie's fluctuating feelings of discretion and assertiveness in Chapter 6) there was little evidence of what could be deemed activism along the lines of what exists for other disabilities and illnesses (Chouinard 1999; Edwards 2010). While the 'gluco-centric' approach may be critiqued as focussing *only* on the numbers, the numbers still need to be focussed on.

The first section of the chapter will discuss the focus on 'gluco-centrism', under the title 'Care of the Self', and extrapolate that, while the state espouses a 'relational self-management' the social reality suggests that this form of relational care is tied up with issues of guilt and dependency. The second part of the chapter is based on "biosocial groupings" (Rose 2007: 134) identifying online forums, diabetes support groups, DAFNE courses and a more empathetic diabetes community to examine the relational forces *between* and *among* PWD. The final sections briefly explore issues of biological responsibility and the intriguing self-distinctions between type of diabetes that emerges among my participants.

CARE OF THE SELF

In Chapter 2 I wrote about the aim of the Scottish Government to move towards a more patient/person-centric model of care when it comes to diabetes and other long-term conditions¹²⁷. This is an admirable aim, of course, founded on ideals of patient empowerment and the establishment of partnerships with clinicians, themselves core themes of much diabetes research in social and nursing studies (also reviewed in

¹²⁷ In Scotland, the public health programme *mydiabetesmyway* (www.mydiabetesmyway.scot.nhs.uk) represents a push towards this patient-centred approach. When registering with the programme PWD receive access to their medical records, such as HbA1c results. The programme has been found to be beneficial to PWD as it leads to greater information about their own condition and better relationships with clinicians. However, as Cunningham et al (2013) point out, challenges still remain, particularly with patient access to letters between clinicians, which many clinics restrict access to on the basis of data protection. The website resources themselves are aimed towards encouraging better management of diabetes, providing numerous links to lifestyle and diet as well as providing awareness of complications.

Chapter 2). A more circumspect reading of these literatures is nonetheless possible, since a sense of governmentality, here led by the state to create responsible and active biological citizens, simmers under the surface. The name of the *Gaun Yersel'* (2008) document even suggests that one should be self-sufficient, confident and not rely on the state. These documents promote biological citizens who only impose upon the state when they absolutely must. While still acknowledging the idea of health care 'partnerships' (see Chapter 2), the *Gaun Yersel'* (2008: 51) expects certain levels of *efficiency* from citizens. In a section concerning the 'individual's responsibilities', the document reads:

Self-management is not about having to do everything yourself. It can be broken down into four distinct aspects:

- Working out what you want to achieve.
- Working out what you want to or are able to achieve alone.
- Working out what you might need intermittent or occasional help with.
- Working out where you need ongoing support.

Coveney (2006) notes that there are two models for people to enact 'proper' health care. An individual, scientific model, in which people make rational choices based on an availability of information (similar to Mol's 2008 'logic of choice') and a community model in which people make decisions as part of a collective with common beliefs and goals (not dissimilar to Mol's 2008 'logic of care' or from Rose's 2007 'biosocial communities'). However, rather than focus on the difference between these two models (as Mol 2008 does), Coveney (2006: 19) argues that "in each, the subject, or the collective subject ... is required to be self-reflective and self-regulating in order to make 'proper' and informed decisions". Even in the ideal of health care partnerships, patients are still expected to be responsible, knowledgeable and to take the lead, through a fair amount of 'working out'. This is not necessarily a bad thing; such expectations on individuals can be productive, creating more personalised care strategies and so improving their health. Indeed, as Mol (2008: 42) writes: "yes, health care meddles with every detail of our daily lives. And indeed, it tries to normalise our bodies. But it does not despise them. Care has little to do with repressing and all the more with cherishing our bodies". Following Mol, and like Sharp et al (2001: 20), I agree with a:

Broadly Foucauldian reading of power as a thoroughly entangled bundle of exchanges dispersed 'everywhere' through society, as comprising a 'micro-

physical' or 'capillary' geography of linkages, intensities and frictions, and as thereby not being straightforwardly in the 'service' of any one set of peoples, institutions or movements.

These documents suggest a productive form of biopower, improving the health of the individual and population, while at the same time decreasing the financial cost to the state. What I write here is not intended as a simple dismissal of the message in these policy documents, but rather as a *reminder* that such partnerships need to be realised, not only in clinical encounters, but also in *everyday* encounters. Many of my participants clearly still struggle to achieve this outcome: they experience pressure to control their diabetes within certain discursive ideals; often denying a messy and unpredictable reality. This is not to say that such a messy and unpredictable reality is the preferred choice of PWD, as many – most notably from my research, Jessica – still wish their diabetes to be clandestine. Even so, my aim is to dismantle these rigid discursive ideals so that PWD can build up – or, following Rose (2007), 'make up' – their own way of living with diabetes. Establishing partnerships with clinicians is key, but so too is disrupting the discursive recession of diabetes, a recession that exists within clinical encounters but also beyond in the spaces and places of a PWD's everyday life.

GUILT

My participants talk about feelings of guilt around caring for themselves. They are fearful that others will judge them for not properly adhering to a commonly held belief of how a PWD should care for themselves. This can be expressed with reference to food and consumption. For example, Lydia writes that: "people often go 'how can you eat that if you're diabetic?' and I get so annoyed and angry! But it's not their fault; that is the way diabetes is perceived [as having a restricted diet]". Lydia's comments echo a belief among many of my participants that PWD are under a constant surveillance of their bodies, as was discussed in Chapter 6 with regards to employers and work colleagues monitoring diabetic bodies in the workplace. There is a latent wider imagination that PWD have to conform to a strict set of practices, particularly around diet. There is much truth in this projection, and I have previously discussed how PWD need to adhere to certain routines in order to enable good control, but the imagination of the healthy diabetic body as *necessarily* a routinised body,

without options, is a rigid one, denying the flexibility for many PWD to enact openly their own preferences in multiple ways.

Kirsten talks about this sense of surveillance which she feels to be present in her everyday life because of her diabetes:

Sometimes that's ... nice to know that people [talking about work colleagues] are interested and they're trying to take an interest but at the same time ... they'll chum [accompany] you to the toilet to see if your poo is the right consistency! It's just one of those annoying things that people are just being nosy, so you think you are under pressure to produce a good [blood sugar] result ... I used to get like that with my mum; you know what mums are like: nagging you all the time ... 'oh my god it's 10.5[mmol/l], you have to get it under 10'! 'Oh mum, calm down, I'm OK'.

For Kirsten's mother, there is an imagination that one's blood sugar levels are poor if they are above 8mmol/l and so, for her, a reading of 10.5 causes panic and worry, whereas in Kirsten's experience a reading of 10.5 is not such a big deal and she is realistic that her readings will not always be perfect: this is a 'natural' part of having diabetes. Even her work colleagues expect her to produce a "good result" and are seemingly unaware of the pressure and discomfort that this expectation puts Kirsten under. Mol (2008: 53) notes the difficulty for PWD to obtain a satisfactory balance of blood sugar levels and suggests that 'perfect' management not necessarily desirable. She writes: "within the logic of care, a good target value is one that may be achieved in practice. One that is technologically possible and doesn't spoil people's daily lives too much". Alice also notes that her mother's anxiety about her diabetes management can be smothering:

With my boyfriend, I feel like I depend on him quite a lot because I'd rather tell him things [about diabetes] than my mum and dad because he doesn't worry. Not that he doesn't worry ... it's not as bad. My mum is really, really awful for worrying about it and with her worrying it makes me feel really bad. So I don't tell her. Plus it's easier to tell someone that's a little less your mum and dad ... The thought of telling my mum stuff scares me because she would just end up a wreck.

Alice provides another salient example of how others can easily become implicated in the care of diabetes, suggesting perhaps that it is not necessarily the diabetes itself that causes stress for the PWD but the misguided expectations and beliefs of others about what entails 'good' control. While PWD often want their diabetes to remain unremarkable for these reasons, they also commonly desire acknowledgement of the

difficulties of living with the condition and appropriate levels of help when needed.

Linda expresses the importance of having a partner who provides such a balance:

I'm quite lucky in that I have a partner who is quite cool about it; he doesn't really want to know too much about it either ... He never interferes with my diabetes management; he helps me of course when I need help ... he empathises when I have to stop [for hypo or blood test] when we're walking somewhere ... So he's very easy going ... he doesn't question my management, so that's really good.

In Linda's relationship diabetes features as normal, merely a fact of her life to which her partner neither over- or under-reacts. Establishing such an equivalent acceptance of diabetes in everyday life would certainly lead to the condition not being so spatially segregated, as discussed in Chapters 6 and 7.

Nonetheless, judgment evidently comes from those without the condition. Alice notes that she fears people will judge her should she have any other illnesses, even if they are not associated with her diabetes:

Basically you've failed to take care of yourself ... That's a worry ... what other people think, if you do end up in hospital, that you've not done something right. It's not necessarily that. Like I got food poisoning once and ended up in hospital. That's not really my fault and I came out thinking 'what are people going to think'? They're going to think I've not taken care of it [her diabetes].

In a more direct encounter, Jennifer recalls being met with a judgement attitude about her level of self-control when she experiences problems with her eyes due to diabetes:

[When going to an eye 'casualty'] I almost without fail got the snotty, dismissive & contemptuous comment [from staff] – 'Retinopathy? Uh, you MUST be badly controlled then' ... Me [Jennifer]: 'Er, no, actually, just had diabetes for thirty plus years ... Right now my HbA1c is probably better than yours'!!! Grr. A judgmental and utterly unhelpful attitude!

Wendell (2013) discusses how, while people with stable disabilities are often considered less to blame for their disability as time passes (even if they were 'responsible' for their disability, such as loss of mobility through reckless driving), people with chronic illness are often considered more to blame as time goes on because of unstable and possibly progressive (and deteriorating) symptoms. This blame is particularly evident with diabetes; for instance, in Chapter 5, Denise is pessimistic about her future due to diabetes being a progressive condition, and she

continues to lament that she often feels blamed for having type 2 diabetes, with any complications that she suffers being somehow deserved:

It's just ... ingrained in popular perception, not only is it mild diabetes but you've only got yourself to blame. So there's really no sympathy for people with type 2 ... You certainly won't get [someone saying]: 'oh what a shame, you've got a progressive disease, that, worst case scenario can do really nasty things, you could lose your eyes' ... because the press says: it's self-inflicted.

Other participants note a similar lack of expectation of sympathy for diabetes: as Lisa writes, "I feel ashamed of my diabetes, as I have the opinion that it is my own fault". This sense of guilt and shame can also impact on a PWD's family life when some are attributed guilt, for the impacts of diabetes, on family members. Heather writes that: "diabetes had a big influence on my divorce. Husband did not want to deal with a 'sick' wife and felt his life was limited because of my illness". Similarly, Hayden tells of his mother's reaction to his diagnosis of type 1 diabetes:

'Well you didn't get it from my side of the family' [is what she said]. At the time it hurt very badly ... After I became diabetic, there were family parties, I was never invited [to many of them]... We were at a wedding and my nephew said to me, 'I'm sorry but you're at the same table as the duchess'. That's what he used to call her [Hayden's mother], and when they came round with the sweets and I said 'no thanks, nothing for me' and the lady beside me said 'are you on a diet'? I said 'I'm on a permanent diet, I'm diabetic' ... She [Hayden's mother] said 'I wish you wouldn't keep telling people'.

For Hayden's mother, his diagnosis is unforgivable: "she never, ever forgave me ... for becoming diabetic. Although I am pretty sure that's the side of the family it came from". It is an embarrassment for her. A moral stigma comes with diabetes, especially type 2, in that a PWD is often quickly assumed to have brought it on his/herself, as possible genetic factors go unacknowledged. Additionally, the PWD is implicated in a rhetoric of personal responsibility to manage the condition, while those without diabetes can deny any sense of social responsibility.

DEPENDENCY

We know, particularly through Mol (2008), that the care of the self is not solely an individual endeavour, but is relational. Many of my participants felt that the NHS carries a significant responsibility in this relation but that, around certain issues,

particularly the ready supply of diabetes 'kit', PWD's 'rights' – and thereby their ability effectively to take care of themselves – could be curbed. Jennifer shares her anxiety:

[She is concerned about] the NHS and its future – the current cuts feel like another Damocles' sword. It feels like the only way to avoid complications and have a healthy productive life is to test, check and correct and do it all by the book. However with the cuts it feels like the tools I need will almost certainly be rationed, with dire consequences. It feels terrifying.

In Scotland, the NHS provide free healthcare and most diabetes supplies can be obtained through prescription. Even so, many PWD experience confrontations with clinicians and GP staff over how much of their supplies they should be using. Jennifer highlights that these restrictions take a mental and emotional toll, as PWD can become anxious and terrified at the thought of rationing.

Daniel recounts his frustration when trying to secure an adequate amount of supplies for his pump:

I did have a bit of hassle when they said I was spending too much on the equipment I needed ... They ... [said]: 'you've double spent; we can't give you this anymore' ... They were saying, because of me, they couldn't put someone else on ... I was saying to them, because of the exercise and the amount I'm eating, this [referring to a pump insert, which is the piece of apparatus that connects the pump cannula onto the body] is only lasting me about two days ... So I'd have to change this [every two days]... For the pump they've got ten inserts [per re-supply] so ... if this [each insert] only lasts me two days that's only twenty days, that's not even a month ... They were saying 'that should be lasting you a month', but I'm like, 'it's not'.

One aspect of Mol's (2008) logic of care is 'managing versus doctoring'. Here Mol compares the lived reality of living with diabetes with the expectations of clinicians. She provides examples of people with type 1 diabetes who labour to implement the advice of clinicians into their everyday lives, such as one man working in road construction who struggles to test the advised five times a day because of the nature and location of his job. Daniel here describes another tension between managing and doctoring that he experiences when trying to order the various consumables needed to keep his insulin pump active. Using as much of the equipment as he requires for his day-to-day life, which involves frequent participation in sports, specifically swimming, he is told that he has 'spent' more than double his personal budget. He is then made to feel guilty, being told that someone else is missing out on supplies

because he is using too much. Daniel continues, describing the reasons why he needs to order more: there are not enough inserts in each cache of supplies that he receives each time he renews his prescription, but they cannot be ordered individually (all the various pieces need to be ordered at the same time). So when he needs more inserts, he has to order everything even though he does not necessarily need it all (meaning that he may have a permanent excess of one thing along with a precarious supply of another). Additionally, certain bits of apparatus can be easily wasted by accident. Daniel occasionally has an insert come out, which he then cannot put back in for various hygienic reasons, and so has to use another one, meaning that an insert that was supposed to last two days may only last two hours.

Linda has similar problems and she tells of a confrontation with a DSN about her usage of test strips:

I have had a really horrible confrontation with a diabetic nurse about that [availability of test strips] and she was awful; she said 'would you rather we don't give you any strips at all'? ... Sort of threatened me ... But I mean they are there to provide for me ... Basically I said to her my own feelings, she said I was over anxious ... and I said 'well I'm basically taking care of myself'.

Linda is expressing what she feels is her right as a diabetic biological citizenship to access readily available supplies, so that she can effectively take care of herself. The clinicians in the accounts of Daniel and Linda seem unaware of the acute sense of dependency that a PWD can feel with regards to ensuring a reliable supply of kit. Instead, the clinicians follow a prescribed idea of what it takes to manage diabetes effectively, wishing the diabetic bodies of Daniel and Linda to be 'docile bodies'. Conversely, Daniel and Linda desire a more pragmatic approach to the availability of supplies that reflects their flexible lifestyles. Foucault describes this conflict (1991: 156) as ideals of disciplinary power over bodies being disrupted by actual bodies in practice, writing that "the body, required to be docile in its minutest operations, opposes and shows the conditions of functioning proper to an organism". Daniel and Linda are showing their own personal 'conditions of proper functioning', but are being denied this 'reality' by a rigid prescriptive ideal of diabetic bodies and their management¹²⁸. Such reports are disappointing considering the aim of the DAP

¹²⁸ Harkening back to the discussion in Chapter 5, Daniel and Linda are attempting to enact a BwO. In order to achieve the "plane of consistency" (Deleuze and Guattari 2003: 158) they must re-organise their organism (their body), prioritising the sustenance of their cyborgian organ surrogate (the pump). Unfortunately, their encounters with clinicians and GP staff, present obstacles to this aim, and instead

(2010) and the *Gaun Yersel*' (2008) document to encourage people to take the lead in their own health care relationship. Linda and Daniel are doing exactly this: through practice they are "working out" (*Gaun Yersel*' 2008: 51; see earlier quote from this document which places a lot of expectation on people to 'work things out' on their own) what help they need to enable good control of blood sugars, but also of their mental and emotional health by ensuring that they are able to take part in their preferred activities. In response though, Linda feels threatened by a DSN and Daniel is perceived as an irresponsible biological citizen, to the point of being accused of "selling this stuff" by his GP surgery, which, although said jovially, still carries with it connotations of illicit behaviour: of dealing drug paraphernalia (echoing associations explored in Chapter 7). Their bodies are not 'docile' and manipulable enough, and so they become subject to a disciplining by clinicians for their transgressions. Considering the lack of spontaneity discussed in Chapter 6, such restrictions on supplies further serves to create an anxious lifeworld for PWD.

BIOSOCIAL GROUPINGS

Rose (2007: 134) identifies biological citizens formed around "biosocial groupings – collectivities formed around a biological conception of a shared identity". Such groups were in evidence among the communities from which I recruited my participants (online forums, support groups in Glasgow and DAFNE participants). These groups provide an opportunity for PWD to express their biological citizenship in various ways. As a PWD myself, I have often heard, and firmly believe in, the rhetoric that a PWD is the expert on his/her diabetes, not the GP or even the diabetes specialist nurses/doctors/clinicians encountered in a hospital clinic. Although I recognise that this rhetoric is now being echoed by clinicians in NHS Scotland through the increasing availability of DAFNE courses. In this section I will discuss each biosocial grouping in turn, along with discussing another empathic group of PWD which emerged among some of my participants, to demonstrate more of the complexity of life with diabetes, and to argue that emotional well-being is extremely important to PWD but is often unacknowledged in clinical settings.

they experience a body-*with*-organs, as their 'supply chain' is unreliable and so they cannot fully enjoy their activities.

ONLINE FORUMS

The online forums provide an informative and supportive space for PWD. For instance, Colleen writes: "I use the diabetes support message board regularly. I feel I am on the same page as them and they have a lot of knowledge. We talk about different food, experiences and support each other". Jennifer also writes: "[I go online for] mainly the practical stuff but also for some much needed moral support that isn't available from HCPs [health care professionals] and often even family, who can struggle to 'get it' like someone who has, in fact 'got it' ". For these respondents, it is important to identify with others who have similar experiences. As Jennifer suggests, this contact is especially needed when people do not have adequate support in offline environments. However, a small number of other responses indicate PWD's reduced use of forums, coinciding with a reduced identification as 'diabetic'. Perry writes: "sometimes I post on message boards but rarely. I don't see my life revolving around diabetes, I have no choice, so I just live with it as best as possible", while Smith writes: "I used to post on the forum [where] you posted your questionnaire but I stopped because I now have more important things to worry about". Through limiting their participation in online forums – allowing them to come and go as they please to seek information as and when they need it, rather than sustaining any permanent contact and sense of community or friendship¹²⁹ – these respondents demonstrate a "flexible intimacy" (Parr 2008: 142).

This flexible intimacy is echoed by Mazanderani et al (2012: 551), who describe how some people with motor neuron disease prefer not to share knowledge in face-to-face support groups, precisely because seeing others with serious physical symptoms can be upsetting. Instead, some people prefer to use online forums because they can "foster a sense of distance ... 'distance' in this case is not the antithesis of empathy, but precisely that which enables particular forms of computer-mediated

¹²⁹ An overview of the forums in question does in fact reveal that many of those who post on the forums initially, often seeking help for a particular problem, are newly diagnosed people looking for some basic information. Senior members of the forum are always happy to help but, often once the necessary information has been imparted, people will rarely frequent the forum again. Of course, many of these people may return to the forum as 'visitors', and peruse the discussions without logging in and revealing their presence.

distal empathy". The importance of this "distal empathy" for PWD is evident in a response from Caitlin:

They [other forum users] have experienced it, seen it and got the t-shirt. Marvellous and immediate support when down, confused or you just want to moan. Local diabetes group chairman – good initial support in early weeks but they only meet quarterly. A couple of neighbours are also type 2 but as they are being managed with one tablet and diet ... they have little sympathy for me where things have just stopped working properly.

The online forum and its users are important for Caitlin: she can expect the support and understanding of other experienced users. Conversely, in face-to-face meetings, due to the irregularity of meetings and the 'controlled' bodies of her neighbours, her 'problematic' and unpredictable body is not understood. Madge and O'Connor (2006: 210) discuss, with reference to new mothers, how online forums are:

Advantageous in allowing the women some temporary relief from the power dynamics played out between new mothers and medical experts in material space ... The anonymity of virtual space thus provided the women with an active route to bypass dominant health discourses and power relations. In doing so the virtual realm was important as it enabled the women to temporarily transcend local moralities of mothering, in which the romanticised ideal of motherhood and the day-to-day reality of the conduct of motherhood were often divergent, leaving women feeling inadequate for not being the 'ideal mother'.

The questionnaire responses suggest that online forums work in a similar way for PWD, with the absence of face-to-face 'visual' and perhaps 'material' bases for judgement arguably creating a more accommodating space for PWD.

SUPPORT GROUPS

Selena describes these face-to-face power dynamics outlined by Madge and O'Connor (2006). At a recent diabetes support group meeting that she attended, the guest speaker asked if anyone in the room, consisting mostly of PWD¹³⁰, smokes and, if they do, to put up their hand. Selena smokes, but fearing judgment from other PWD

¹³⁰ There were also a few family members of PWD who did not have diabetes.

she did not put up her hand; in fact, no-one did¹³¹. Selena reflects on this incident during our interview the following day:

I'll bet I wasn't the only person in that room last night that's a smoker. I don't know for sure but I'd bet my boots on it ... You get judged as a smoker but you're judged more severely if you're a diabetic smoker ... Many of whom [referring to other PWD] are ex-smokers ... ex-smokers are the worst, they're generally very, very sanctimonious.

Perhaps it is feelings like these that explain why the support groups which I attended and recruited from in Glasgow were not always well attended. Usually only the first and last meetings of the series were well attended with around twenty-five people, while other meetings ranged from five to fifteen people.

That said, the support groups were still beneficial to the people that attended, with many, like Hannah, noting that they obtained useful information about living with diabetes: "when you go to those meetings you see more and more people that are worse than me and you think: 'you're not alone'. A lot of other people there as well ... have the same problems with doctors and consultants". Contrary to those who dislike face-to-face groups due to encountering the possibly worse symptoms of others (Mazanderani et al 2012), Hannah gains a sense of community and support from discovering there are other PWD facing the same problems.

DAFNE

The DAFNE courses were also an effective, face-to-face, biosocial grouping. I have already discussed, in Chapter 6, the benefits that the courses provide for participants as a "diabetes knowledge network node (DKNN)" (Cravey et al 2001; Gesler et al 2004). Lillian further reflects on the sense of community that the DAFNE course created for her:

¹³¹ In the summer of 2012 I attended a 'meet-up' event, in Glasgow, for one of the online forums on which I posted my questionnaire. Also attending this meet-up was a young woman from Glasgow who had only recently been diagnosed with type 1 and had heard about the meet-up online. I did not have much of a chance to talk to this person during the meet-up in a city centre pub but, as I left, she said she would walk me out to get some fresh air. In fact, she was using my departure as an excuse to get outside and smoke a cigarette. We chatted briefly as she smoked and she admitted that she had come outside because she was so scared that the other PWD at the meet-up would judge her for not having yet given up smoking.

The biggest thing ... is just being able to talk to other diabetics as well ... I've got one friend that's a diabetic, but I don't see him that often. It was just to be able to sit down and just chat to them ... I was the newest diagnosed out of all of them there, so to learn from their experiences I felt was invaluable really, because a lot of the people you're dealing with at the hospital they're not diabetic and all the specialists are not diabetics themselves. So they're working to the theory of it, if you like, so actually speaking to other diabetics I thought was great.

Proximity to other PWD is important for Lillian and is something to which she would not otherwise have access, even if she does have a fellow PWD as a friend. Derek also considers the proximity to other PWD on the course:

I knew a few people with diabetes, but that's it, you're not in a room with them ... speaking about day-to-day and how they cope ... It just opened your eyes and then you're saying, 'oh I thought my sugars were bad'. But just listening [to others], my sugars are actually brilliant compared to the rest of them, maybe even need to let them get up a bit because maybe I'm a wee bit too tight.

Derek shows the importance of "downward social comparison" (Mazanderani et al 2012: 549) that the DAFNE course can create. For Derek, this comparison helps him to realise that his blood sugar levels are not as bad as he thought they were, although, much like Hannah who also touches on this downward comparison in the previous section, he does not convey any sense of feeling superior or judging others in comparison to his own good control.

Jessica was the only participant recruited from the DAFNE courses who was not entirely satisfied with the course. She says:

I thought if my HbA1cs are quite good ... why am I in with a room full of people who are the opposite from me? ... I just thought 'what am I going to get from them'? To be honest I can say, safely, from every single person who was there I learned nothing but I did from [the organisers] ... Before I went on it, they had said to me it would be good to meet other diabetics and to meet other people, hear the stories and you'll learn a lot from them. I was just appalled by their stories and absolutely appalled that they would tell anybody their stories ... I think I might have got more out it had I been with a group of people that I maybe had more in common with ... I mean the first morning we were there, honest to god, I thought, I cannot believe these stories ... they're telling you these horrendous stories that at the end of the day come down to stupidity, ignorance and bad management. Why would you want to announce that to people?

Jessica is frustrated by the other PWD on her course, feeling very strongly that they are not adhering to a certain level of biological citizenship that she does. Jessica laments that those who, she believes, are more poorly controlled than her received most of the attention from the DAFNE organisers: "I think a lot of the time was taken up on a few people who were really poorly controlled for whatever reason, and too much time was spent on their issues". Jessica illuminates an interesting point that strikes to the heart of one of my main arguments. She clearly wants to learn more about her condition and effective self-management, but feels that her experiences may have been somewhat dismissed during the DAFNE course because of her, seemingly, more accomplished self-management. To the DAFNE organisers it may seem as if she has figured it out and so there is little left for them to address in her case, when in practice she still has serious anxieties about long-term complications, as reported in Chapter 5. Indeed, Lawton et al (2009) note that many PWD considered to have good control often feel annoyed that those who are poorly controlled receive more attention and resources from the NHS. It is important to acknowledge that diabetes education and learning is never complete, and there is always something more to be learned. Jessica's frustration with her fellow DAFNE participants is perhaps not necessarily (or only) a reflection of her wanting to feel superior to other PWD, but also of her knowledge gaps not being addressed by the course.

While Jessica was the only person in my study to express such dissatisfaction with DAFNE, others did express some annoyances. Lawton and Rankin (2010) discover that people on the DAFNE courses can be subject to surveillance and judgment about their habits, and Alice recalls how she felt about 'gaze' from her fellow DAFNE participants when she talked about drinking alcohol:

The only bit I felt bad talking about was the drinking because a few of them didn't drink and I think a few of them were looking at me as if I was judged a little bit, and that was probably the only bit I wasn't totally happy talking about ... The other two girls, younger girls, said that they had drunk, but I ... wish it was a room where everyone had drunk. I felt like I was being a bit silly saying 'I've done this and should I have not done that'? ... They were sitting there thinking, 'just don't drink, then you don't need to worry about it'.

In this case the DAFNE course is creating 'diabetic biological citizens' in which PWD are encouraged to conform to a practice of little or no alcohol, Alice fearing that her more 'regular' consumption of alcohol may configure her as deviant among this group. Alice muses that she may have been more comfortable on a course where there

were more PWD who drank, so that her anxieties about drinking could have been discussed with less fear of being judged as an irresponsible PWD. She feels that in the DAFNE course which she attended the only response to drinking issues was, simply, not to drink. The perceived 'dos' and 'don'ts' of living with diabetes are not only configured by those without the condition but also by PWD. Indeed, Rose (2007) talks of how some biosocial communities, based around a particular health issue, come to govern the conduct of people with that condition, regardless of others' potentially differing preferences.

AN EMPATHIC DIABETES COMMUNITY

A final type of biological community evident in my research is a number of younger PWD who are involved with the charity, *Diabetes UK* (Ben, Gretchin, Kirsten, Gabriella). These participants had frequently attended young people's events and retreats and they note the friendships and community that have arisen because of this involvement. In particular, Ben says:

It's a support network ... Diabetes gives you an instant bond between you and other people [PWD] that [you] wouldn't otherwise ever have met ... It is that kinda instant bond. When someone tries to empathise with you that's not diabetic, you kinda get pretty cynical, but as soon as someone with diabetes empathises with you, you're completely open and they understand completely where I'm coming from and I understand where they're coming from, so I think it's quite unique.

Similarly, Gabriella comments on the instant empathy shared with other PWD:

When you were doing that [being involved with *Diabetes UK* and attending events] you had contacts with people who automatically knew what it was like to live with diabetes, even things you do automatically, like interpreting your blood sugar reading. It's trying to explain to people, too high's bad but too low's also bad and kinda worse at times. Trying to explain as well that you do everything to control it but there are sometimes days when it won't happen and there are going to be days when ... you've counted your carbs accurately, you've done tests, done whatever with the insulin, but you're still going to be having a hypo; and getting people to understand it's not something you've done irresponsibly, it's just the phase of the moon.

While many PWD, as previously discussed, fear judgement from others if they somehow 'fail' in their diabetes management, Gabriella is able to relax and feels safer, when around other PWD. I believe that, if there was more sensitivity to the experience

of PWD by others without the condition, then the sense of being under surveillance and judged that so many of my participants reported would be lessened. However, the discursive construction of diabetes as easy and unimposing means that talking about such issues is still curbed; and, until this construction is disrupted, these experiences cannot be properly shared and the gulf between PWD and people without diabetes will remain.

In Chapter 5, I discussed how my questionnaire respondents considered diabetes to have a negative impact on their identity, but, as that discussion also showed, a small number of respondents do consider diabetes to have a positive impact. Bill writes: "if anything, though, it's been positive. I know I can deal with a chronic condition with relative ease which is actually quite a strong thing to do". Bill does not perpetuate the discursive recession of diabetes directly – because he acknowledges that diabetes is a difficult condition with which to live – but he still takes pride in having done so for so long. Kirsten also reflects on the positives of living with diabetes:

Sometimes you think, oh well, it's a rubbish condition to have, but if you do look at the positives there's a huge list of them ... I think the most important one was it ... gives me a sense of humour to look at things and I go it's not so bad or try to take a bit of a light hearted approach on that. Yeah that is shit, but let's just laugh it off ... a lot of people don't have a sense of humour and I think that's something I've got from it: patience, kind of persistence, dealing with problem solving on a daily basis, and these are all things that I think have helped me in my career, so yeah definitely a sense of humour that's a good thing to have.

Wendell (2013: 171) discusses how accounts from people with impairment and disability attesting to their condition being beneficial to their lives are often doubted by others due to illness and impairment being configured as inherently bad. Being able to be proud of one's diabetes is spatialised, in the context of the *Diabetes UK* youth groups, through being co-present with similar others; these participants are able to talk about and enact their diabetes without fearing the punitive consequences which might follow in a restaurant, café, workplace or other public place. For this reason, their diabetes can be considered a positive in their life, opening up avenues for friendships, career options and positive character traits such as confidence and a sense of humour. Such 'diabetic pride' is productive and communal pride stems from

sharing 'failings' with other PWD, rather than a sense of pride that comes from *fewer* 'failings'.

BIOLOGICAL RESPONSIBILITY AND GUILT

Rose (2007: 147) claims that a good biological citizen "is obliged to conduct life responsibly in relation to others, to modulate decisions about jobs, marriage, and reproduction in the light of a knowledge of his or her present and future biomedical makeup". Some of my participants reflect on this obligation; in particular Kyle, who talks at length about his two sons:

I felt incredibly guilty that I had now fathered ... two children, both were boys and both whose risk of diabetes was far greater. I think that did hit me at the time because I felt that I was responsible ... any parent would probably feel 'oh god I've created an imperfect child sort of thing' ... I felt I'm responsible and ... I've lived with this and I've got a way of living with it, but what right have I got to [possibly pass it on to his sons] ... But ... I do fear: what if they get signs of diabetes? ... Neither of them actually have it but I know as male offspring of a diabetic father their risk is slightly greater ... So I think [that] I would have to deal with it if it occurs but I think, I would feel emotionally, it would test me then.

Kyle struggles with the possibility that his sons will develop diabetes. Some PWD will even not have children in fear that they may develop diabetes. While Olivia and her husband have one child, who was diagnosed with type 1 diabetes at a very young age, Olivia reflects that they would not have another:

I've been able to have one child ... I don't think we could go through having two children and the devastation we felt when one child was diagnosed ... So I feel that diabetes has taken away my choice and dictated the size of my family ... I don't know that I could do it to another child. There's no guarantee but there was a 4% chance that my child could have diabetes and my child got diabetes; despite the fact that I was so well controlled, the gene was so strong it came out when she was really, really young ... I remember saying, at the time when we were up at the hospital when she was being diagnosed, I would never have had a child if I'd known this was going to happen ... It's not as if I want to erase [my daughter] from my memory ... She's the most wonderful person in the world but to subject your child to something like that, I don't think I could have done it. But then could I have lived with making that decision? I don't know because I've got a really strong maternal drive. I don't know, I don't know.

Olivia does not regret having her daughter but does wonder if, had she known her daughter would get diabetes, she would still have had the child. Olivia and Kyle express a sense of guilt that they could potentially 'inflict' diabetes on their children. This guilt comes from personal experience of living with the condition and their acknowledgment that it really is *not* a 'minor' condition, so much so that they seriously consider not having children based on the probability that their offspring may develop diabetes.

We know from previous chapters and arguments in this thesis that 'healthy' is socially and culturally defined, and so, if Olivia and Kyle were able to feel more comfortable with their own diabetes, then maybe they would not be so anxious about the possibility of their children developing the condition. DAFNE goes some way to addressing these concerns. Adam and his partner do not have children but he considers the possibility of having children in the future. Explaining that the DAFNE course and the operators gave him confidence should he ever have a child with diabetes, he says: "if it is the case that I had a child that had diabetes then I would like to think that my experience with DAFNE would stand me in good stead ... I've got the experience to let them have a healthier lifestyle than I have now". Of course, Adam would not have the experience of being both diabetic and pregnant, and neither would his non-diabetic partner. Diabetic pregnancy is particularly stressful and many of my female participants told me of their experiences. Gail reflects on the impact that her diabetes had on having a family. She wanted to have children but, because of being unable to get her blood sugar control to the ideal level, she was unable to do so:

We have never had children and this is due to having tried to get my control really good before trying and then not quite managing it. I think I still hold a grudge (though I am not sure against who/what) about this ... I feel I have never really had the opportunity to become a mother – and that still bothers me ... I thought my diabetes didn't really bother me until I started answering your questions; I now realise that although I tell everyone it hasn't stopped me doing what I wanted to, it did stop me having children and I think that bothers me more than I thought.

This extract from Gail's questionnaire response highlights not only her disappointment and anger at not being able to have a child, it also suggests yet again the impacts of the discursive recession of diabetes. Until being asked to reflect on her life with diabetes, she would tell others that diabetes has had little impact on her life,

denying the truth that she is actually upset and angry at diabetes impeding her desire to be a mother.

Indeed, the imperative for PWD to be good biological citizens is perhaps most acute for women during pregnancy. In order to limit possible complications, for both themselves and their children, pregnant women must control their blood sugars more tightly than they would have to otherwise. Sophie says:

The difficult years I felt with my diabetes were probably when I was pregnant and the reason I say that is because I had another life to think about, not just myself ... They tell you the most horrific stories of what can happen, what could happen to your baby. Until [my daughter] was born ... I still had all this [worry], she's going to have a cleft pallet, she's going to have a curved spine, she's going to have a hole in her heart, she's going to have this and that. Now with the best will in the world it's quite difficult to keep your diabetes [right] ... you've to keep this [blood sugar] down at 4[mmol/l] ... it was horrendous ... So from that point of view, it was hard but I think it was hard because I had to think about somebody else, not just myself.

Jennifer also describes the increased scrutiny experienced by pregnant women with diabetes: "diabetic pregnancy is really, really tough – there's a massive feeling of responsibility and massive guilt any time your levels aren't perfect". Likewise, Julia writes about her pregnancy: "the consequences were terrible: [a] lot of vomiting and a six month visit to hospital. I never thought I was good enough to have a family, was conscious of never getting pregnant". Longhurst (2008) addresses the feelings of anxiety that disabled women experience if they become pregnant. Women with diabetes have similar feelings, many reporting that, like Julia, they did not feel "good enough" to have children. None mentioned any experience of being told they should not have children because of their diabetes, although, upon diagnosis at age thirty-three, Mary was advised that if she wanted children she should have them as soon as possible while she still had good control over her blood sugars. Nonetheless, diabetes clearly creates a heightening of anxiety during pregnancy, not least as the already regulated body of the PWD becomes hyper-regulated.

This anxiety continues through to parenthood. Jennifer has already reflected, in Chapter 6, on her fear that people will judge her ability as parent if she has a hypo while out with her children. The biological citizenship ideals of being a good parent can clash with the biological citizen ideals of being a good PWD. While some PWD, like Kyle and Olivia, worry about their children developing diabetes, others may feel guilty over the amount of time that attending to their own diabetes takes away from

the time spent with their families. Edna writes: “I have small children and they don’t understand why mummy can’t eat chocolate and cakes and ice cream like they do. My little girl worries about me all the time and that makes me feel sad and angry that this has an impact on my family”. Similarly, Jennifer writes that:

Hypos are a real pest. I have two small kids and can get tired and ratty with them if the sugar levels have been bad (high or low). I then feel bad that the diabetes is adversely affecting how good a parent I am. I sometimes feel like I don’t have enough space/time/capacity to give my diabetes the attention I feel I ought to when wrangling the kids too.

Sardaki and Rosenqvist (2002: 605) argue that in western societies women assume (or, of course, can be coerced into) the role of family caregiver. They argue that women often put the health and well-being of the family unit before their own and, as a result, women’s own management of diabetes can suffer: “thus, traditional gender role expectations in families and the fact that diabetes is not always perceived as a ‘real’ illness with an appropriate social response may limit women’s ability to cope with the demands of self-management in diabetes”. Longhurst (2008) concludes that the difficulties faced by mothers with disabilities are rarely considered by others (such as service providers and clinicians), meaning that the social construction of these difficulties is not taken into account. Jennifer notes a similar occurrence for parents with diabetes and suggests, in her quote above, that mothers with diabetes may sacrifice the potential long-term health benefits of tight control in order to appear as ‘good’ mothers in the short-term. We see again more environments and further contexts where diabetes is *not* to be present, creating further difficulties for those PWD with other major demands on their times and attention, whether it be work, children or anything else.

(NOT) DISTINGUISHING BETWEEN TYPES

Much like Balfé et al (2013c), I found that many PWD were aggravated by the lack of distinction between type 1 and type 2. Indeed, for most of my preceding analysis I have, deliberately, not distinguished between types, and I will explain why shortly. Franklin relays his view on the matter:

I think people tend not to know the difference between type 1 and type 2. Given the fact that type 2 tends to be down to weight management issues ...

That can be a little annoying ... [Other people think] I've invited it upon myself and that's completely the opposite to the actual situation [of being diagnosed type 1].

Linda also comments: "interesting that, isn't it, how you feel a little bit better if you say, 'I'm type 1 but not type 2' ". Cheryl also explains how she talks about her diabetes to others: "well I used to just say I was diabetic and now I've changed to put 'type 1' before it ... I seem to get a bit more defensive and I start talking about type 1 and just go 'it's not type 2' ".

Having type 1 diabetes is commonly considered beyond an individual's control and so, for some PWD (type 1), is not supposed to reflect on compliance of good biological citizenship. Although type 2 is regarded seriously by most of my participants, there was a distinct wish among PWD (type 1) to distance themselves from PWD (type 2). For example Arthur says:

Diabetes to me is if you're insulin dependent. I feel there should be another term for [those who are not insulin dependent] ... people [who] manage it by diet or tablets ... To me ... type 2 is more of a lifestyle thing that's caused it, type 1 is more often, something that you've inherited through your genes ... I don't think there's anybody who's type 1 diabetic goes out to say, I want to be diabetic, that's just ludicrous. But if you're [type 2], if you manage your weight better and this and that, well it might be they put you on a tablet for six months but if you can keep it [weight controlled] you don't need to be treated [by insulin], so you've got a lifestyle choice there. There's a chance that you can maybe redeem yourself ... if you try.

These responses suggest that those PWD with type 1 do experience something of a 'diabetic privilege' in terms of escaping certain moral judgements of their lifestyle, as compared to those with type 2. Arthur believes poor lifestyle is a major cause of type 2 and suggests that this is a moral failing for which PWD (type 2) can "redeem" themselves. The concerns of many PWD (type 1) about being associated with type 2 indeed reflect that, although the conditions may well have separate aetiologies, the experience of misconception and stigma is common. Perhaps both conditions, being progressive and chronic, explain this fact. While those with type 1 may wish to shake off associations of blame over the condition, they will unlikely ever be regarded as having a "stable" condition or disability (Wendell 2013: 157, argues that such stable conditions involve less blame being applied to the individual), due to inevitable hypox and unfortunate progressive complications. The insistence on separation from those with type 2 only exacerbates the public perception of type 2 as brought on by 'oneself'

through poor life choices, without necessarily then relieving the same connotations for those with type 1.

Balfe et al (2013c) report similar findings from their cohort of PWD (type 1), noting a sense of 'stigma' at being mistaken as type 2. Unlike Balfe et al (2013c), my research also includes the perspectives of PWD (type 2) and so illuminates the oppressive impacts this 'stigma' can have on those with this form of the condition. Charlotte responds to the perception of many PWD (type 1), writing that she is frustrated by a "lack of understanding and also pillorying of type 2 diabetics in press – we are all fat lazy slobs – even said by some type 1s". The division in attitude and identification between the two types is clear. Other participants reveal the assumptions made by others about their lifestyle because they have type 2 diabetes. Denise tells me:

That's the annoying thing that they make these sort of assumptions, but ... even the medical consultant who ... obviously had read my notes ... When I said to her 'oh dear I wonder how this has come about'? Now she didn't say to me 'well, did it run in your family'? She just said 'it's your weight' ... I thought, yes I'm certainly not slim but I don't consider myself obese ... but for her to turn round and just say to me, 'it's your weight', it just made me feel terrible. I felt so guilty.

This is a common frustration for PWD (type 2) and Rachel even writes that: "people told me it was all my own fault, caused by my diet, including GPs and nurses, and it made me blame myself ... I avoid telling people I have type 2 now, I just say 'insulin dependent diabetes'. People are less rude to me about it then".

While I argue for a collapsing of the two types to understand everyday life with diabetes, Rock (2005) advocates for greater distinction to advance treatment for rising incidences of type 2 diabetes. She argues that the imperative for many first world countries to improve access to medical treatment in combating the rise of type 2 diabetes configures the condition as preventable, and hence obscures the underlying social, economic, cultural and historic inequalities that mean type 2 prevalence is higher among disadvantaged populations. I do agree with Rock's convincing argument, but prefer, for the purposes of my thesis, to establish a common diabetic experience without necessarily focussing too strongly on the biological differences of the various types. One of my participants helps to inform my approach. Hannah was told that she had type 2 diabetes when she was diagnosed and prescribed oral

medication (metformin)¹³². When this treatment had little effect on lowering her blood sugar levels, she was put on to insulin injections and quickly started on an MDI regime, the same as many PWD (type 1). Her experience represents the disadvantage of a rigid biological separation:

They [clinicians] said it's type 2 ... I think it should be type 1. I've tried to go on a DAFNE course as well, they didn't take me ... I think I should be [allowed], they should let me go on. I even asked my consultant and he said 'you're OK you don't need to go on'.

Hannah feels stuck between type 1 and type 2 diabetes. Although 'technically' having type 2, she feels that she would benefit greatly from a DAFNE course, which is designed with MDI in mind, but the DAFNE course is only open to PWD (type 1) and so Hannah is denied access. Further to this, Hannah is extremely frustrated by paternalistic and condescending experiences with doctors who attribute her high blood sugar levels to her indulging in sweets, despite her insistence that she has a very healthy, controlled diet and regular exercise routine. Hannah believes that her fluctuating control may have more to do with other health issues which she has experienced, such as previously being diagnosed with cancer and recurring migraines; but in the incredibly short appointments which she has with doctors, these possibilities are dismissed. Rock's (2005) argument is towards a re-appraisal of how diabetes epidemiology is interpreted at a policy level. My arguments are aimed at the policy level as well, but not the epidemiological: instead, I wish to illuminate the everyday experiences of being diabetic to inform a greater sensitivity toward PWD like Hannah, who feels that she is falling through the cracks by being denied access to a potentially life changing education programme on the basis of a 'technicality'.

CONCLUSION

The findings in this chapter show that there is a clear pressure from society for PWD to adhere to the ideals of a diabetic biological citizen. This pressure creates unpleasant conditions for many of my participants, who often feel that their behaviour and diabetes management is monitored, for compliance or transgression, by others,

¹³² Hannah was diagnosed aged fifty-one, and so it would likely have been assumed to be type 2, often formerly known as 'adult onset diabetes'.

including friends, family, work colleagues, clinicians and even other PWD. Rose (2007: 140) writes about how state-led attempts to disperse scientific knowledge to the public is an attempt to “make up citizens” into different categories which “organise the diagnostic, forensic, and interpretive gaze of different groups of professionals and experts”. PWD have been ‘made up’ in a certain way, constructed through assumptions of the condition as easy, but also, playing on the term, they are ‘made up’ from mistaken beliefs that are not based on research that heeds the voices of PWD.

Diabetic bodies are not easily “tamed” (Mol 2008: 35). In fact, Philo (2012) has recently advocated for a rejuvenation of Foucault’s work stemming from his series of lectures at the *Collège de France* from 1970 to 1984. Philo argues that these lectures reveal a ‘new Foucault’, who thought more about the messiness and unpredictability of lived bodies than ‘old Foucault’s’ attention to discourses, derived from his well-known published texts, would suggest. Philo (ibid: 509) writes that of the lectures that Foucault is:

Returning to an earlier construction, the lens here has arguably alighted upon a collision between the Apollonian and the Dionysian within the individual (self-aware, self-constituting) human subject: to a collision where the battleground remains the body, just as much as in relation to the other forms of power previously discussed, but now the body as struggled over by those aiming to practice a ‘care of the self’ in which the body’s (negative) passions are held down and its (positive) potentials released.

This quote resounds loudly with the experience of living with diabetes. The body is a metaphoric, or in some cases quite imaginative (considering the sketches of Merritt and Radford from Chapter 5), battleground where a peace must be sought between the forces of high blood sugar and low blood sugar. The best outcome is a tentative, fragile peace, so easily disrupted by the simple processes of living. While I want to encourage such a ‘holding down’ of the negative and ‘releasing’ of the positive, there has to be space for the negative as well¹³³. To hold down such negative passions can easily give rise to brightsiding. Although the extreme forms of brightsiding (of Johnson 2001 perhaps) are not evident among my participants, it still exists in mundane forms, directed by the discursive recession of diabetes.

¹³³ Indeed, these are aims, not dissimilar to the pursuit of an ideal BwO, as discussed in Chapter 5.

My hope is that by going some way to loosening the expectations of this 'made up' diabetic biological citizen, PWD can have freedom from the discursive recession of diabetes to be more open, physically (in the way of doing TIM more openly), socially (in being able to talk about their diabetes and obtain a level of understanding and empathy from non-diabetic friends and family) and emotionally (in being able to talk about problems without fearing judgment of having failed or poorly managed the self). In this way, others without diabetes can also become more sensitive to the experience of living with the condition, creating a more accepting environment where, for instance, the prospect of bringing a possibly diabetic child into the world does not seem so cruel. This move goes some way to establishing diabetes as unremarkable, merely another way of being, that can elicit empathy and understanding from others. As Ben and Gabriella describe, this way of being, is perhaps, currently only attainable with other PWD, with whom diabetes and its effects are not considered a personal fault, either brought on by oneself or exacerbated through poor lifestyle choices. Of course, it must also be acknowledged that PWD are not passive victims of such unfair ideals, and there exist divisions within PWD around 'proper diabetic behavior' and the stigma of being associated with type 2 when one is type 1. However, such internal tension would also be alleviated should external understandings be directed on to more empathetic paths.

CHAPTER 9

CONCLUSION: A PERSISTENT CONTRADICTION

SUMMARY

My thesis adds to the understanding of life with diabetes, and below I offer a bullet point summary of the main contributions.

- PWD are subject to a form of biopower.
- This biopower is mutually reinforced by both discursive and routine recessions.
- This biopower assumes a disappearing diabetic body which makes reappearing (*dys*-appearing) diabetic bodies problematic both materially and socially.
- Dys-appearing bodies are inevitable for PWD, but because of the opprobrium of an out-of-control body, space is experienced problematically.
- Parts of this dys-appearance can be controlled (TIM) and so PWD attempt to conform, performing as docile bodies which keep diabetes discrete and minimal in public space, if not entirely invisible.
- Notions of responsibility position PWD as the masters of their own diabetes; as such, when ‘deviances’ do occur, even if they are minor or not caused by diabetes, PWD can be configured by others as irresponsible, failing citizens.

These conclusions reflect the four research objectives outlined in Chapter 1, firstly, of examining how diabetes effects a person’s negotiation of space (research objective 1) and, secondly, how this is interlinked with social and emotional aspects (research objective 2). Thirdly, I have also argued that some PWD feel subject to a panopticism which influences how they perform their everyday practices of self-management (research objective 3). Finally I have also demonstrated the sense of personal responsibility that is often placed on PWD to conform to ‘good’ diabetic biological citizenship (research objective 4).

I argue that the disciplinary landscape of diabetes research is missing a sustained body of work that deals with the geographies of the condition. As discussed in Chapter 2 there is already considerable work on the geography of diabetes by Balfe and Jackson (Balfe 2005; Balfe and Jackson 2007; Balfe 2007a; Balfe 2007b; Balfe 2009a; Balfe 2009b; Balfe 2011), but this work is bounded to a particular time and space (of students and campus). Balfe and various co-authors have continued their studies of life with diabetes (Balfe et al 2013a; 2013b; 2013c; 2014), but mostly without a geographical perspective. With my research, I have continued the exposure of life with diabetes to geographical scrutiny, in particular, contributing to health geography. Following from the three facets of the sub-discipline outlined in Chapter 2, I have shown that, first of all, PWD's understanding and negotiation of space and place are different because of the condition. While home spaces may be construed as somehow 'safe', as the questionnaire data, 'at a glance' suggests, this safety is often understood within a dreary 'chore' space, the necessities of maintaining the diabetic body creating a monotonous and cheerless routine. Work spaces, meanwhile, are strewn with anxieties about disclosing diabetes and how this disclosure will affect how colleagues view a PWD's work ethic. Diabetic bodies were further unveiled as often anxious bodies (Chapter 6), for which spontaneous geographies are curtailed as a sense of adventure and freedom – particularly when travelling, but also in more mundane everyday movements – is replaced with a sense of dependency and anxiety.

Second of all, experiences of (health)care have been much discussed throughout the thesis. Following Mol's 'logic of care' I have shown that diabetes *self*-management is a relational process which implicates others in myriad ways. In Chapter 7, the daily necessity of many PWD – TIM – is considered as a performed practice, responding to an "unverifiable [and sleekit] gaze" (Evans and Colls 2009: 1073) of often indistinguishable others in public space. This performance often conceals the material, fleshy and bloody practices of diabetes in everyday space and, in so doing, obscures the social and emotional realities of living with the condition from others' view. This "unverifiable gaze", is thereby cultivated and progressed, so that it becomes a disciplining regulatory gaze creating docile diabetic bodies. While I argue that panopticism creates unwelcome environments for PWD where they must present a docile diabetic body, other forms of 'gluco-centric' panopticism, can lead to improved blood sugar control, better long-term health and lower the cost to the state of treating PWD. Some PWD also prefer their 'diabetic' identity to be as

minimal as possible – Jessica being the most notable example from my research – although, arguably they are feeding ideals of diabetes as minor and easy, therefore sustaining its discursive recession. My aim is not to critique PWD such as Jessica – as PWD who are somehow oppressed and do not realise it – but, rather, my aim has been to dismantle these rigid discursive ideals so that PWD can build up – or, following Rose (2007), ‘make up’ – their own way of living with diabetes. The trouble arises when this ‘gluco-centrism’ is too narrowly defined and overrides other aspects of life with diabetes (consider the example of driving regulations in Chapter 6: Olivia recognizes the need for regulation but is upset by considered as having a precarious body). I hope my thesis then, perhaps distilled in academic papers and/or informational booklets, can raise awareness among people without diabetes, including clinicians, about the everyday issues faced by PWD, thereby creating more ‘caring’ environments.

In Chapter 8, I found that “biosocial groupings” (Rose 2007: 134) of PWD can provide positive ‘care’ spaces of reassurance and information sharing (especially in online environments). They can also be negative care spaces, however, where differing levels of ‘success’ with the condition can form quiet hierarchies of ‘good’ and ‘bad’ PWD. Online environments are particularly helpful in establishing informal and possibly anonymous caring networks. Positive experiences also came from those PWD who spent time with other PWD as part of the charitable organization *Diabetes UK*. They say that being diabetic around other PWD serves to unmark the condition, so that the opprobrium reported by others is non-existent. This is in contrast to Selena’s comments regarding the face-to-face support group which suggested that this opprobrium is present in these environments. Most of my participants who had undertaken DAFNE report that not only did it improve their blood sugar control and provide them with a more optimistic outlook on the future, but also helped them to establish, often for the first time, a support network of other PWD. Others describe the DAFNE courses as more uncomfortable, however, noting their unease at the behavior and opinions of fellow participants; the “shepherding” (Lawton and Rankin 2010: 490) of behaviours and DAFNE’s occasional lack of real world application.

Third of all, I contended that diabetes could, in particular times and spaces, be considered a disability. Following Chouinard et al’s (2010) call to broaden the definition of disability, I have demonstrated how embodied and environmental factors can combine, in particular times and spaces, to disable PWD. Chapter 6 showed the

range of difficulties that PWD face in their home, work and social lives – in part caused by the embodied vulnerability of diabetes (hypos, fatigue, TIM) and in part by the social context (insensitive work colleagues or family members). These material and social difficulties lead to a restriction of a PWD’s life-world. Following recent insights from psychological research (Gonzalez et al 2011) the disabling aspects of diabetes could be termed ‘diabetes distress’. Balfe et al (2013c) extrapolate some of these ‘distresses’, and as discussed in Chapter 2, many of their findings overlap with my own. This overlap represents the uniqueness of, but also similarity within, life with diabetes. The assembled literature from Balfe et al (2013a; 2013b; 2013c; 2014) is aimed primarily at clinical/nursing journals for the reference of clinical staff as they aim to increase their understanding of PWD’s lifeworlds. I also intend my own research to contribute to clinically-facing intervention in diabetes care. As stated in Chapter 4, this research was, in part, borne out of a desire by clinicians to appreciate, more completely, everyday life with diabetes. Forefronting concepts of space and place my research can achieve this aim, hence supporting and building upon Balfe et al’s (2013c) work.

Chapter 5 represented a close look at the diabetic body. Following ideas of a ‘cultural model’ of disability (Wilton and Evans 2009), I discussed some of the inherent bodily experiences of having diabetes. Uncanny feelings of potential bodily difference, partially losing control during hypo and having an agentic internal other, ‘territorialise’ the body creating an imbalanced and ‘distressful’ *body-with-organs*. As a case study, I considered two PWD who personalise their “internal émigré” (Mazzio 1997: 58), the pancreas, by carrying out an ‘extimacy’ (Kingsbury 2007), which, if not ‘beating’ the pancreas, at least challenges its territorialising effect by exposing its antics to their audience of, mostly, PWD. The other uncanny forces can be challenged through advancing self-management technology, particularly insulin pumps (and possibly in the future a ‘closed-loop’ bionic pancreas system), which can result in fewer hypos and limit future complications. The *body-with-organs* therefore develops towards the ideal *body-without-organs* (BwO) for which these uncanny forces are less prominent. Of course, the new technologies are not to everyone’s liking, and some PWD prefer their familiar self-management techniques, feeling that the pump could actually regress from a BwO, by being a prominent, bodily reminder of illness and difference.

At the heart of this analysis is a persistent contradiction: I argue that PWD need more recognition of their diabetes and how it impacts on their life; at the same time, I want to establish ‘diabetic difference’ as mundane and unremarkable. This contradiction is embodied by my participants, who at times prefer their diabetes to be *unknown* (in order to avoid a ‘diabetic identity’) and/or materially *unseen* (so as not to intrude on ‘clean’ public/work spaces with TIM), and yet at other times prefer it to be *known* (as a safety net or in order to gain accommodation for difficulties in certain spaces and places) and materially *seen* (by not retreating to hidden spaces for TIM). Sheila presents a particularly contradictory body in Chapter 6; preferring to keep her hypo susceptibility secret at work, but recalling her social work course when she publically declared her diabetes as she challenges the lecturer on tea-breaks. Allison also embodies the contradiction in Chapter 7, remarking on her switching between a “public injector” and a “secret injector”, depending on social and spatial context. In fact, many of my participants suggest that examining this contradiction is unnecessary; they tell me that diabetes has become a routine part of their life, that it is not a big deal, perhaps realising an argument from Canguilhem (1989: 186) that “disease is not a variation on the dimension of health; it is a new dimension of life”. Even so, while not denying the accounts of these participants, much of the evidence throughout my thesis has demonstrated that such a mundane and everyday acceptance of diabetes is still far from a reality. Many aspects of diabetes have become “stylised repetition of acts” (Butler 2006: 191), creating a “mundane and ritualised form of their legitimation” so that, I argue, the frequently employed phrase ‘it’s not a big deal’ is something of an ingrained refrain to ward off ideas of failing biological citizenship.

But, as Butler (2011: xxiii) writes, the agency of individuals still does exist: “although this constitutive constraint does not foreclose the possibility of agency, it does locate agency as a reiterative or rearticulatory practice, immanent to power, and not a relation of external opposition to power”. The forms of resistance seen throughout my thesis are not grand displays challenging the norms of living with diabetes. For example, while some PWD may resist the idea of TIM being hidden in public space, they still generally reflect on performing TIM to conform to expected norms, in what may be interpreted as a compromise, doing it assertively but discreetly. The everyday resistance to the “constitutive constraint” of diabetes is instead seen in the seemingly minor grumbles and complaints of my participants, often little heard, and seldom acknowledged, by others. Hence, I see the possible excessive displays of

diabetes management – perhaps most obvious in my thesis in the example of Sheila and her encounter with another PWD during a meeting in Chapter 7 – as similar to Butler’s (2011: 181 italics original) take on “hyperbolic” displays of drag:

Hence it is not that drag *opposes* heterosexuality; on the contrary, drag tends to be the allegorisation of heterosexuality and its constitutive melancholia ... drag brings into relief what is, after all, determined only in relation to the hyperbolic: the understated, taken-for-granted quality of heterosexual performativity.

Drag serves to unveil the unquestioned norms of a heteronormative society, hopefully leading to reflection and improved tolerance: it takes an extreme deviation from these norms to make space for small, progressive changes.

In many ways I have argued that my participants live in a ‘healthynormative’ society where their diabetes experience is suppressed, since it does not fit with discursive and embodied norms. At times, some of my participants hint at what could be considered a ‘drag’ of diabetes, of ‘hyperbolically’ performing, or as my participants refer ‘broadcasting’, their diabetes when in public space. However, as seen in Chapter 7, they often stop short, acknowledging their own accepted norms; that injections and finger pricks, involving blood and penetration of flesh, might provoke visceral reactions in others not necessarily connected to a discursive recession of diabetes. Likewise they feel that others, especially children, might misunderstand and connect TIM to illicit drug abuse, which among my participants was an unquestioned deviance¹³⁴.

While an extreme deviation from diabetic norms is not evident among my participants, there are still commendable efforts such as DAFNE which aim to improve knowledge of diabetes and self-care among PWD (albeit DAFNE can also be considered as part of a regulatory framework to produce ‘efficient’ PWD). Although, perhaps more focus should be afforded trying to rework the imagination of diabetes in the wider public. This imagination configures PWD as “healthy disabled” (Wendell 2013: 163), wherein any deviation from this ‘norm’ signifies PWD having failed to enact good control and discipline of their bodies. This situation creates an oppressive environment for PWD, where they feel unable, freely, to enact TIM,

¹³⁴ This unquestioned deviance, is itself something perhaps misunderstood and needing to be challenged: see McPhee (2012), in which the author argues that drug ‘users’ are too quickly assumed to be drug ‘addicts’.

causing further melancholy at this persistent performance of acting healthily and unaffected. The linkages here are represented in Figure 20 in Chapter 7, and I hope with my research to contribute to breaking this cycle and to acknowledge that living with diabetes cannot be reduced to a societal norm. In this way, my thesis is doing something of an ‘ontological politics’; Mol (quoted in Greenhough 2010: 154) explains:

Ontological politics is a composite term. It talks of ontology – which in standard philosophical parlance defines what belong to the real, the conditions of possibility we live with. If the term ontology is combined with that of ‘politics’ then this suggests that the conditions of possibility are not given. That reality does not precede the mundane practices in which we interact with it, but is rather shaped within these practices.

Mol therefore suggests that changing practices may lead to a change in discourse and therefore create a more welcoming environment for ‘difference’. I am suggesting, in the case of diabetes at least, that a discourse (of recession) precedes practices (of performing TIM). I have shown that living with diabetes can often be reduced to a norm and that, because of this norm, PWD can feel repressed and unable to talk about problems that they may be experiencing because of their diabetes. By acknowledging this discursive recession, in which the reality of diabetes is hidden, and by instead intervening to destabilise what Philo (1997: 74) would call the “ontological tricks” of how discourse programmes realities, we can create a more accepting environment for PWD where the misconceptions of living with diabetes are debunked. Despite my points here, I do not mean to suggest one thing (discourse or practice) precedes any other but that, as demonstrated in Figure 20, there is not clear point for intervention, whether of mundane practices or recessive discourses, to destabilise the ‘docility’ of life with diabetes. Perhaps intervention must be dual-pronged, with attempts to change attitudes towards embodied difference (whether it be diabetes or anything else), through ‘awareness’, working alongside attempts to change practices, possibly through forms of ‘activism’ (such as public assertions of difference or performances of previously concealed practices: such as Boyer’s 2011 discussion of breast-feeding ‘lactivism’ events¹³⁵).

¹³⁵ My participants did not mention taking part in similar events. The (in)visibility of TIM, is perhaps more accepted and less discussed than (in)visibility of breast-feeding which may explain this difference. However, ‘diabetic activism’ could be considered as those mundane moments when PWD

I hope then to have demonstrated the geographical contingencies of living with diabetes, which have so far, been underexplored. I feel this is an important contribution to the disciplinary landscape of diabetes research as recent policy about diabetes self-management in Scotland can benefit from understanding the challenges that a PWD may face in different space, places and times. This policy (DAP 2010) has focused on improving care for PWD, especially through establishing more relational care practices with clinicians. However, by applying a more geographical lens, we can see how these relation care practices also exist beyond the clinic in the spaces and places of a PWD's everyday life.

BODIES OF COMPROMISE

I introduced the idea of a dys-appearing body in Chapter 2, arguing that it is one that rarely recedes but instead exists on the margins of PWD's lives. As I discussed the bodies of my participants throughout the chapters, I have referred, at times, to 'docile bodies': bodies that are subject to manipulation by biopower and forms of governmentality; that are coerced in subtle ways to conform to an ideal of PWD and their bodies as being in control, unproblematic and largely unseen. But, crucially, docile bodies are not fixed and permanent, and so there remains the possibility for resistance. Frank's (2013) 'disciplined bodies' on the other hand are fixed, regimented bodies; as Franks explains, they lack desire and so therefore perhaps they lack the desire for resistance. Disciplined bodies, following Frank's definition, are the extreme extent of biopower, bodies so compliant that the possibility for resistance is absent. Perhaps a flash of such disciplined bodies does exist among my participants, those who comply with the opprobrium of visible, public TIM. Entrenched neo-liberal beliefs assemble PWD as having a 'minor' condition that can be overcome by responsible self-management and self-discipline in conjunction with a brightsiding attitude. It seems harsh to critique programmes such as DAFNE, which undoubtedly improve the lot of PWD, but this neo-liberal undertone persists, insisting that PWD have the means to improve themselves and, therefore, possibly constricting even more, the space for PWD to acknowledge fully their problematic bodies.

'flaunt' their difference, such as Sheila's colleague in Chapter 7 and Radford's sketch of her bionic self in Chapter 5.

This outcome, I argue is the danger of an unrestrained and unchallenged biopower which completely subdues diabetes in public space, so that, eventually, docile bodies become disciplined bodies and there exists no flexibility in this rigid body for ‘deviance’ or freedom from a now entrenched norm. Such disciplined bodies are akin to the closed-off, bodies described by Deleuze and Guattari (2003) when they talk of failing to achieve the BwO: they are dreary, lacking the desire to change, bodies that have given up. While I do not necessarily disagree about the pressure of being a good diabetic biological citizen, I argue that such concepts can oftentimes be too narrowly focussed, when room for ‘difference’ – often misunderstood as ‘deviance’ – must be built in. Moreover, I contend that a greater acknowledgement of the everyday aspects of living with diabetes could keep docile bodies as, at least, the *status quo*. I say the *status quo* as many of my participants had no real problem with a docile body: it seems to be an accepted balance between the contradictions that pervade my thesis. With a docile body, PWD are subject to a biopower which directs compliance with a diabetic body presented as ‘easy’ and barely visible, but a docile body still has the capacity for resistance to this biopower – as PWD exert their rights: to do TIM in public, for instance, or to acquire as many supplies as they need to manage their diabetes in concordance with their lifestyle. It is not on big instances of stigma, discrimination or disablement that I want to bring the exigency of the geography of diabetes to bear, but rather to check the quiet creep of a docile body into a disciplined body.

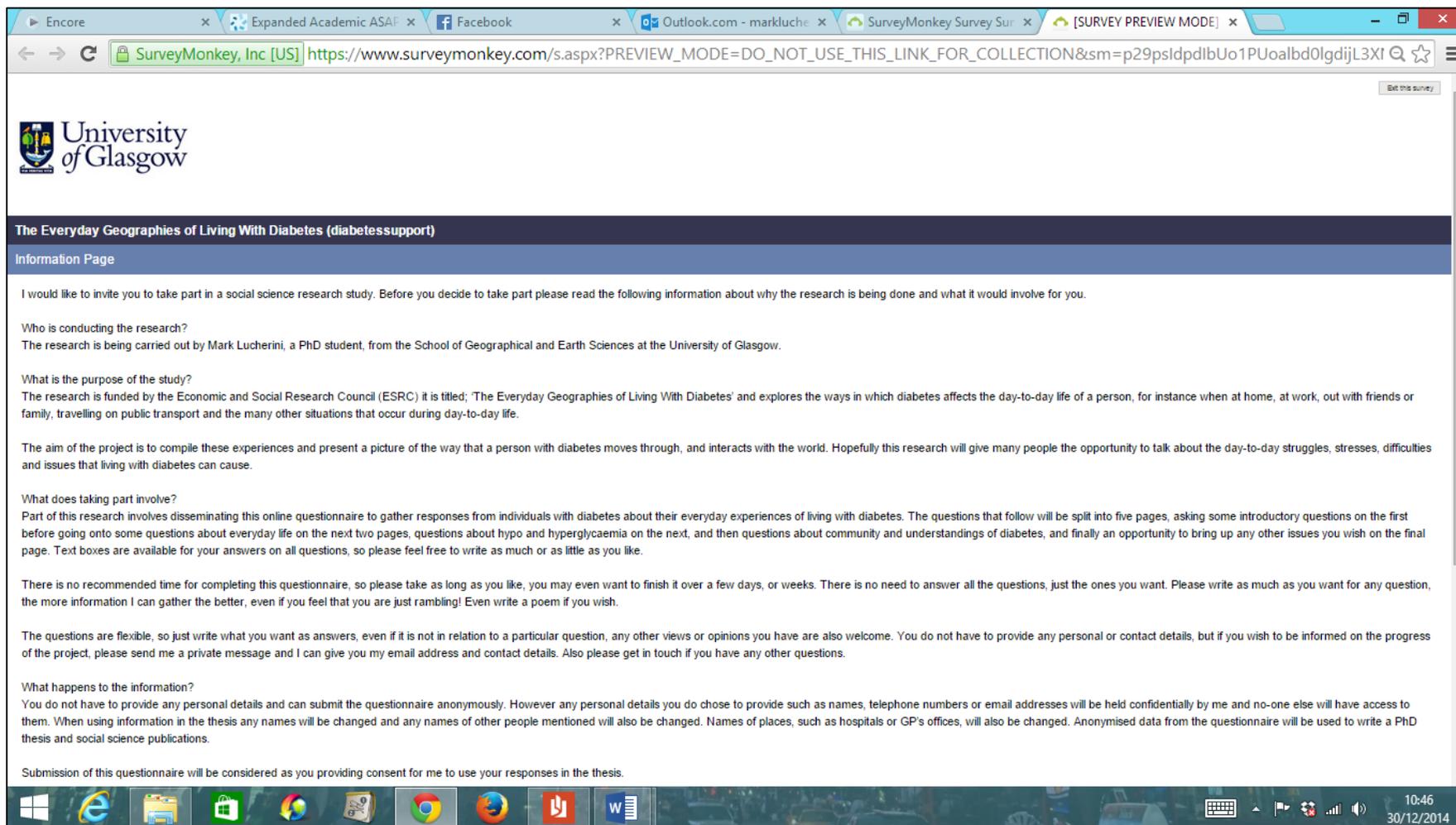
In Chapter 4 I discussed my own positionality when researching the lives of PWD. Having diabetes myself, I suggested that I was able to benefit from a “relationship of sameness” (Rose 1997: 313) when approaching and talking to PWD. Of course, it was not always this simple and a “relationship of difference” (ibid) was still, at times, apparent. Regardless, I feel justified in my analysis, which only at times considered other identity intersections (of gender, for instance), as, although I may have missed out on some insights into such intersections, I have instead forefronted the common experience of living with diabetes: showing how the geography of PWD can be restricted (following Wilton 1996); laden with a hidden labour of choices, measurements and injections; and subject to surveillance which ensures adherence to diabetic norms.

Elspeth Probyn provides some useful conceptual pivots to summarise my aims. She quotes Moreton-Robinson (Probyn 2005: 105 italics original) while

discussing the idea of shame with regards to race relations in Australia: “to *know* an indigenous constructed social world you must experience it from within; to *know about* such a world means that you are imposing a conceptual framework from outside”. Probyn (ibid: 104) argues that there are “profound incommensurabilities between white and indigenous women that radically disturb the possibility of connection”. I argue that there is a similar incommensurability between PWD and others without the condition, and of course between people with any type of illness, disability, impairment and those without. While Probyn’s larger political project is convincing, I use her concepts more mundanely in the case of diabetes. I am not arguing that people without diabetes should be considered as ‘shamed’ due to a history of exploitation, oppression and dispossession of PWD, but I do argue that her “challenge to *learn*, and not to *know*” (ibid: 106) applies poignantly to diabetes given the evidence presented throughout my four empirical chapters. People without diabetes are quick to know and so quick to judgment, quick to shame PWD without attempting to be “emotionally interested in people” (ibid). This is particularly evident in the ‘gluco-centric’ approach which reduces PWD to a series of ‘good’ and ‘bad’ numbers. Probyn’s larger political project is calling for those who shame others (either intentionally or somehow indirectly) to respect those they shame, in a similar vein as Davidson and Henderson (2010) implore us to ‘travel in parallel for a while’ with those on the autistic spectrum. Through such attempts at empathy and understanding, the affects produced by shaming will be less likely to cause division and entrenchment, and more likely to cause introspection and re-evaluation for both the shamed and shamer. Such a connection can help to reconfigure diabetes in the popular imagination less as something ‘to be hidden’, demonstrating Probyn’s (2004) ideas of how shame can be positive and productive. Therefore, I hope not just to loosen the rigid understanding of life with diabetes among those who do not have the condition, but also amongst PWD themselves. Frank (1998: 334 italics original) writes that he wants to “protect the care of the self as a power-free zone in which people can *be*”. By just ‘being’, people may divulge more of the chaotic elements of living with diabetes, establishing less narrow representations of life with the condition and moving towards a more ethical society in which there is a more recognised space for PWD.

APPENDIX 1 ONLINE QUESTIONNAIRE SCREENSHOTS

These are select screenshot from the online questionnaire. The first is the opening information page. The second shows some of the questions.



The screenshot shows a web browser window with the following tabs: Encore, Expanded Academic ASAF, Facebook, Outlook.com - marklucl..., SurveyMonkey Survey Sur, and [SURVEY PREVIEW MODE]. The address bar shows the URL: https://www.surveymonkey.com/s.aspx?PREVIEW_MODE=DO_NOT_USE_THIS_LINK_FOR_COLLECTION&sm=p29psldpdlbUo1PUoalbd0lgdijL3Xf. The page content includes the University of Glasgow logo and the following text:

The Everyday Geographies of Living With Diabetes (diabetessupport)
Information Page

I would like to invite you to take part in a social science research study. Before you decide to take part please read the following information about why the research is being done and what it would involve for you.

Who is conducting the research?
The research is being carried out by Mark Lucherini, a PhD student, from the School of Geographical and Earth Sciences at the University of Glasgow.

What is the purpose of the study?
The research is funded by the Economic and Social Research Council (ESRC) it is titled; 'The Everyday Geographies of Living With Diabetes' and explores the ways in which diabetes affects the day-to-day life of a person, for instance when at home, at work, out with friends or family, travelling on public transport and the many other situations that occur during day-to-day life.

The aim of the project is to compile these experiences and present a picture of the way that a person with diabetes moves through, and interacts with the world. Hopefully this research will give many people the opportunity to talk about the day-to-day struggles, stresses, difficulties and issues that living with diabetes can cause.

What does taking part involve?
Part of this research involves disseminating this online questionnaire to gather responses from individuals with diabetes about their everyday experiences of living with diabetes. The questions that follow will be split into five pages, asking some introductory questions on the first before going onto some questions about everyday life on the next two pages, questions about hypo and hyperglycaemia on the next, and then questions about community and understandings of diabetes, and finally an opportunity to bring up any other issues you wish on the final page. Text boxes are available for your answers on all questions, so please feel free to write as much or as little as you like.

There is no recommended time for completing this questionnaire, so please take as long as you like, you may even want to finish it over a few days, or weeks. There is no need to answer all the questions, just the ones you want. Please write as much as you want for any question, the more information I can gather the better, even if you feel that you are just rambling! Even write a poem if you wish.

The questions are flexible, so just write what you want as answers, even if it is not in relation to a particular question, any other views or opinions you have are also welcome. You do not have to provide any personal or contact details, but if you wish to be informed on the progress of the project, please send me a private message and I can give you my email address and contact details. Also please get in touch if you have any other questions.

What happens to the information?
You do not have to provide any personal details and can submit the questionnaire anonymously. However any personal details you do chose to provide such as names, telephone numbers or email addresses will be held confidentially by me and no-one else will have access to them. When using information in the thesis any names will be changed and any names of other people mentioned will also be changed. Names of places, such as hospitals or GP's offices, will also be changed. Anonymised data from the questionnaire will be used to write a PhD thesis and social science publications.

Submission of this questionnaire will be considered as you providing consent for me to use your responses in the thesis.

The Windows taskbar at the bottom shows the time as 10:46 on 30/12/2014.

The screenshot shows a web browser window with the following tabs: Encore, Expanded Academic ASAF, Facebook, Outlook.com - marklucl..., SurveyMonkey Survey Sur..., and [SURVEY PREVIEW MODE]. The address bar shows the URL: https://www.surveymonkey.com/s.aspx?PREVIEW_MODE=DO_NOT_USE_THIS_LINK_FOR_COLLECTION&sm=p29psldpdlbUo1PUoalbd0lgdijL3XI.

The survey title is **The Everyday Geographies of Living With Diabetes (diabetessupport)**. Below the title is a section header **Everyday Life**.

The survey content includes the following text and questions:

Everyday Life
 These questions will ask about some of your everyday experiences of living with diabetes and will be continued on the next page.

7. How do you manage your diabetes?

8. Does living with diabetes feel burdensome or difficult to you or does it come more easily?

9. How does your diabetes impact your life when you are at home?

10. How does your diabetes impact your life when you are at work?

11. Do you feel diabetes has affected your social life?

12. Has diabetes affected your relationships with friends, family or work colleagues in any way?

13. How do other people react to your use of diabetes management equipment such as needles and blood sugar testing equipment?

The Windows taskbar at the bottom shows the Start button, taskbar icons for Internet Explorer, File Explorer, Mail, Chrome, Firefox, and Word, and a system tray with the date 30/12/2014 and time 10:51.

APPENDIX 2

MESSAGE TO ONLINE FORUM MODERATORS

Hello

My name is Mark Lucherini and I am a PhD student from The University of Glasgow.

I am conducting human geographical PhD research on the 'Everyday Geographies of Living With Diabetes'.

This research explores the ways in which diabetes affects the day-to-day life of a person for instance when at home, at work, out with friends or family, travelling on public transport and the many other situations that occur during day-to-day life.

As part of my data collection I have constructed an online questionnaire, which I wish to post on a number of diabetes forums and support sites. I was hoping you would allow me to post a link to the questionnaire on your website as you seem to have a good number of users and an interest in academic research. The questionnaire has been constructed with surveymonkey.com questionnaire service.

I have included a link to the questionnaire with this email for your perusal. I know it is quite lengthy and looks quite demanding of written responses but I am still hoping that people will respond to it well and, as I say in the information page of the questionnaire, there is no need to answer all the questions. I am at a fairly early stage of rolling this questionnaire out so I may get a lot of responses saying it was too long, too demanding, too boring so I do plan on refining and adapting the questionnaire as time goes on. I have done questionnaires like this for previous projects and received really good responses so I am keen to keep it longish for the moment and maybe adapt later in response to feedback.

To provide you with a bit of further context I am also conducting interviews with people with type 1 diabetes in Glasgow, having come to an arrangement with various diabetes clinics for the recruitment of interviewees, and asking them also to complete research diaries, diaries of their daily experiences with diabetes, over a period of time. I also have type 1 diabetes myself, which it what inspired me to research the subject, and will sort of use my own experiences as a resource as well.

With your permission then I may also ask if any of your users are from Glasgow or surrounding areas and would be willing to meet for an interview with me at some point? This might be unlikely but you never know. Anybody that would agree to an interview would be sent an introductory letter and information sheet first so they can decide whether or not to take part.

This study has been approved by the University of Glasgow's College of Science and Engineering Ethics Committee.

The first page of the survey, link below, is an introduction page with more information and contact details for myself and my academic supervisors.

<https://www.surveymonkey.com/s/X5SZKNP>

Sorry to lay such a big email on you! Please email me if you have any questions about the questionnaire or the project as whole.

Yours Faithfully

Mark Lucherini

APPENDIX 3
MESSAGE TO FORUM USERS

Hello

I am a human geography PhD student from The University of Glasgow and I am conducting research on the 'Everyday Geographies of Living With Diabetes'.

This research explores the ways in which diabetes affects the day-to-day life of a person for instance when at home, at work, out with friends or family, travelling on public transport and the many other situations that occur during day-to-day life.

As part of my data collection I have constructed an online questionnaire, link below, and any responses would be a great help.

The questionnaire is quite lengthy and most questions ask for written responses, but there is no suggested time limit so please just spend as much time as you wish on each question and you do not have to answer every question.

The link below will take you to the questionnaire, which has more detailed information on the first page. Please read this before answering any questions.

<https://www.surveymonkey.com/s/NWTF6RR>

If anyone has any questions or wishes to know more please send me a private message or ask a question on the thread and I'll get back to you a.s.a.p.

Thank you for your help and I hope you find this interesting!

Mark

**APPENDIX 4
INTRODUCTORY LETTER**



The Everyday Geographies of Living With Diabetes

Introductory Letter

Mark Lucherini
Room 303
East Quadrangle
The University of Glasgow
G12 8QQ
m.lucherini.1@research.gla.ac.uk

You are receiving this letter as you may be interested in taking part in a research project titled *The Everyday Geographies of Living with Diabetes*. This research explores the ways in which diabetes affects the day-to-day life of a person for instance when at home, at work, out with friends or family, travelling on public transport and the many other situations that occur during day-to-day life. My interest in this subject comes from my own diagnosis with type 1 diabetes in 2008.

I am hoping to conduct interviews with people with diabetes and I am hoping you would agree to be interviewed. If so please read the attached information sheet for further information and contact me using the details above.

Thank you for your interest.

Yours Faithfully
Mark Lucherini

APPENDIX 5 INFORMATION SHEET



The Everyday Geographies of Living With Diabetes

Information Sheet

I would like to invite you to take part in a social science research study. Before you decide to take part please read the following information about why the research is being done and what it would involve for you.

Who is conducting the research?

The research is being carried out by Mark Lucherini from the School of Geographical and Earth Sciences at the University of Glasgow.

What is the purpose of the study?

The research is funded by the Economic and Social Research Council (ESRC); is titled; 'The Everyday Geographies of Living With Diabetes' and explores the ways in which diabetes affects the day-to-day life of a person, for instance when at home, at work, out with friends or family, travelling on public transport and the many other situations that occur during day-to-day life.

The aim of the project is to compile these experiences and present a picture of the way that a person with diabetes moves through, and interacts with the world. Hopefully this research will give many people the opportunity to talk about the day-to-day issues of living with diabetes. My interest in this subject comes from my own diagnosis with type 1 diabetes in 2008.

What will taking part involve?

This will involve interviewing individuals with diabetes, about their everyday experiences of living with diabetes. The interview, rather like a structured conversation, will be about 60-90 minutes long. The interview can be at a place and time convenient and chosen by you, such as a cafe you often visit or your own home. The interview will be audio recorded with your permission. You will be able to talk about things that you feel are important and that are not necessarily asked by me. However there will still be some guidance to the interview, with themes including:

- The experience of being diagnosed.
- Routines, such as management, eating, testing etc...and how you fit these into your life.
- Experiences of hypoglycaemia or hyperglycaemia.
- Identity and diabetes.
- Places and living with diabetes.

- Talking about diabetes
- Public awareness of diabetes.

These questions are simply guidelines so you do not have to discuss them if you do not want to and if you feel there is something else you want to talk about please feel free to bring it up during the interview.

Your participation is entirely voluntary, and any interview or meeting with me will occur at a time and place of your choosing: for instance after your work at a nearby café you often visit. These interviews are intended to be informal and relaxed so please do not be apprehensive about them. Nobody will pressure you in to taking part and it is entirely up to you to contact me if you wish to be involved and you can withdraw from the interview at any time.

What happens to the information?

Any personal details you give during the interview such as names, telephone numbers or email addresses will be held confidentially by me and no-one else will have access to them. It is intended to record interviews, with the interviewee's permission, and any recordings or written transcripts of interviews will be held confidentially by the researcher and stored securely on password protected computers or locked filing cabinets. When using information in the thesis, all names of interviewees will be changed and any names of other people that interviewees mention will also be changed. Names of places, such as hospitals or GP's offices, will also be changed. Anonymous data from the interviews will be used to write a PhD thesis and social science publications.

You must be over 18 years of age to take part in the study.

Formal University ethics regulations will require you to sign a Consent Form before conducting an interview.

If you would like to meet for an interview please contact me using the contact details below. If you would like to be informed of the progress of the project or have any other questions, please do not hesitate to contact me and I will be more than happy to oblige.

Please also contact my supervisors at the University of Glasgow if you have any queries about the project.

Professor Chris Philo – Christopher.Philo@glasgow.ac.uk

Dr Hester Parr – Hester.Parr@glasgow.ac.uk

Thank you for taking the time to read this information sheet.

**APPENDIX 6
CONSENT FORM**



University
of Glasgow

The Everyday Geographies of Living With Diabetes

Consent Form

I would be grateful for your consent to allow me to interview you and to use the interview material for my PhD thesis. A pseudonym will be used to protect your identity. Any other contact information you give me will be held securely and accessed only by me. Information will only be used subject to you giving your permission with this Consent Form.

- | Yes | No (<i>please tick</i>) | |
|------------|----------------------------------|--|
| [] | [] | I have read and understood the Information Sheet. |
| [] | [] | I have been given the opportunity to ask questions about the study. |
| [] | [] | I now feel I have enough information about this study. |
| [] | [] | I understand that my participation is voluntary. |
| [] | [] | I understand that I am free to withdraw from this study at any time without giving a reason. |
| [] | [] | I agree that the interview may be audio recorded. |
| [] | [] | I understand that these recording may be transcribed by the researcher. |
| [] | [] | I agree to be part of this study and have my information used in the thesis. |

You may contact me at any time to withdraw your consent for your information to be used.

You will receive a copy of this consent form for your own records.

Signed:

Date:

APPENDIX 7 INTERVIEW GUIDE



The Everyday Geographies of Living With Diabetes

Interview Guide

Research Aims

- How is the time-space geography of an individual is affected by diabetes.
- How do people with diabetes fit the disease into their everyday life?
- What are people's experiences of hypoglycaemia and hyperglycaemia?
- How do people understand the wider public perception of diabetes?
- Have people experienced instances of stigma and discrimination because of their diabetes?
- Do people with diabetes have any sense of community?
- Does participation of a DAFNE course make people reconsider any of these questions?

Interview Questions

1. Introduction

- Introductory questions such as age, occupation, type of diabetes, time of diagnoses with diabetes to establish a baseline and rapport.

2. Diagnosis

- What led you to contact doctor/A&E/GP?
- Can you tell me about when you were first diagnosed?
- What impact did diagnosis of diabetes have on your life at the time?

3. Everyday Life

- What is it like to live with diabetes?
- How does diabetes fit into your home life?
- How does diabetes fit into your work life?
- What about when you are out and about, socialising?
- Are there any particular aspects about living with diabetes that stand out for you?
- What's the most annoying thing about being diabetic?
- Does being diabetic make you feel different?

- What kind of things do you carry with you?
- What routines have you developed with regards to your diabetes?
- Have there been times in your life when you have found it difficult to manage your diabetes well?
- Has diabetes affected your relationships in any way?
- How do you manage your diabetes?
- How do you decide how much insulin to take?
- How do you record your blood sugar levels?
- Do you think this is important?
- What blood sugar levels do you like to maintain?
- Is there anything you do, day-to-day to help you manage your diabetes? For instance do you keep spare insulin in a fridge at work?
- Do you like to have privacy when doing an injection or testing your blood?
- Are there places you avoid testing or injecting in?
- When you are out and about and you need to inject or test where will you do this?
- Why will you do it in these places?
- How will you do it in these places?
- Can you pretend you are taking an injection now and show me how you would do it?
- If you are in the company of others, say in a meeting at work or having coffee with friends, how/where will you take your injection?
- Do you find it hard to accommodate these management practices into your everyday life?
- Does diabetes stop you from doing anything, you would otherwise wish to do?
- Do you do anything differently because of diabetes?
- Does diabetes make you think differently about anything in your day-to-day life?
- What about travelling?
- What about driving?

4. *Hypo/Hyperglycaemia*

- What do you understand by these terms?
- What experiences of either have you had?
- How often will you experience hypo/hyper?
- What do they feel like, what are the sensations?
- Can you describe these experiences?

5. *Temporal*

- Has having diabetes for a long period of time changed your day-to-day life, opinions or experiences in any way? (Only asked if interviewee indicates that they have been long diagnosed).
- What changes (if any) have you experienced in your diabetes management?
- How do you feel diabetes has impacted on your appearance?
- How do you feel diabetes has impacted on your identity?
- Do you have any worries or concerns about diabetes?

6. *Community*

- Who do you talk to about your diabetes (for instance friends, family, health professionals)?
- Are there any aspects of diabetes you find particularly hard to convey to others?
- How do you feel about the care you receive for your diabetes?
- What sources of information do you use to find out about diabetes?
- Do you feel you are able to find the information you are looking for easily?
- Do you ever go online to talk about diabetes or to find out information?

7. *Wider Perception*

- How do you feel diabetes is understood by other people who do not have the condition?
- Do you feel that people without diabetes understand diabetes and what it is like to live with the condition every day?
- Are there things about having diabetes you find hard to convey to others?
- How do you feel diabetes is understood in the media, newspapers, television etc...?
- What do you think diabetes is and, what do you think caused your diabetes?
- Have you ever experienced any sort of stigma, discrimination or embarrassment about your diabetes?

8. *DAFNE*

- Does participation on the DAFNE course make you reconsider any of these issues? (Of course only applicable to those interviewees recruited through DAFNE).
- Has DAFNE changed the way you think about your diabetes?
- Do you find the DAFNE principles hard to follow in certain situations?
- What, for you, was the most important thing you learned?

9. *Concluding*

- Have you any other aspects of living with diabetes you wish to discuss?
- Have you any opinions about the interview process?

Reminder Themes

- Experience of diagnosis – change, illness.
- Managing diabetes – routines, testing, injections, HbA1C, diet, exercise.
- Places and living with diabetes – home, family, work, colleagues, travel, driving, public transport, urban, rural.
- Socialising – pubs, clubs, alcohol, romance, appearance, dating, having fun, limitations, concealment.

- Hypoglycaemia and hyperglycaemia – fears, frequency, causality, warning signs, experiences.
- Identity and diabetes – illness, disease, weakness, concealment.
- Stigma – misunderstandings of diabetes, concealment.
- Temporal – change, adaptation, experience, opinions, new technologies
- Talking about diabetes – friends, work colleagues, family, doctors, supportive, understanding.
- Community – forums, blogs, books, friendships.
- DAFNE – helpful, effective, worth the time.

APPENDIX 8 PARTICIPANT BIOGRAPHY

In total I received 127 responses to the online questionnaire and conducted 41 interviews. The table below does not represent every single participant, but only those whose responses feature in the thesis. Occupation was ‘unknown’ for many of the participants. This was particularly true for the questionnaire respondents as I did not ask directly what their occupation was. However some respondents make reference to their employment at points in their answer (some were specific about their occupation while others were more vague) and so I have completed this column for as many participants as possible.

Name	Age	Age at diagnosis	Length of time with diabetes (years)	Occupation	Type 1 (1); Type 2 (2) or LADA	Interviewee (I) or questionnaire respondent (Q)	Notes
Adam	27	3	24	Footballer player/coach	1	Q	
Agnes	66	57	9	Unknown	1	Q	
Albert	68	67	1	Retired (former foreman)	2	I	
Alice	23	14	9	Student/retail worker	1	I	
Allan	44	20	24	Unknown (former police officer)	1	Q	
Allison	65	38	27	Secretary at nursery	1	I	Married to Steven
Anna	57	37	20	Home helper/mobile creche worker	1	I	
Annette	66	57	9	Unknown	1	Q	
Arthur	30	16	14	College teacher	1	I	
Bella	63	63	0	Unknown	1	Q	
Ben	23	18	5	Accountant	1	I	
Brenda	62	59	3	Unknown	2	Q	
Brian	67	61	6	Unknown	2	Q	
Brianna	46	30	16	Unknown	1	Q	

Name	Age	Age at diagnosis	Length of time with diabetes (years)	Occupation	Type 1 (1); Type 2 (2) or LADA	Interviewee (I) or questionnaire respondent (Q)	Notes
Caitlin	67	64	3	Retired	2	Q	
Carly	54	52	2	Unknown (part-time)	LADA	Q	
Catherine	29	5	24	Unknown	1	Q	
Celia	49	34	15	Unknown	1	Q	
Charlotte	56	53	3	Unknown	2	Q	
Cheryl	20	6	14	Student/retail worker	1	I	
Clare	56	46	10	Unknown	2	Q	
Colleen	28	28	0	Unknown	2	Q	
Daniel	21	16	5	Student/bar worker	1	I	
Denise	66	65	1	Retired	2	I	
Derek	45	30	15	Fitness/sports instructor	1	I	
Douglas	70	59	11	Retired (art teacher)	2	I	Insulin dependent
Edna	39	34	5	Unknown	2	Q	
Elise	48	32	16	Primary school teacher	1	I	
Elliot	Unknown	Unknown	50	Unknown	1	Q	Elliot was first questionnaire respondent and aforementioned negative reviewer. Elliot gave no sex, age or age of diagnosis. Elliot did respond that she/he is type 1 and has had it for 50 years.
Emma	24	19	5	Physical geography PhD student	1	Q	Emma being a geography PhD student was coincidence! She came across my questionnaire on a diabetes forum, not through our 'geographical' connection.

Name	Age	Age at diagnosis	Length of time with diabetes (years)	Occupation	Type 1 (1); Type 2 (2) or LADA	Interviewee (I) or questionnaire respondent (Q)	Notes
Franklin	25	5	20	Office worker	1	I	
Frederica	39	29	10	Unknown	1	Q	
Gabriella	32	9	23	Primary school teacher	1	I	
Gail	46	9	37	Teacher	1	Q	
Gary	43	22	21	Unknown (self-employed)	1	Q	
George	28	4	24	Bar manager	1	I	
Gilbert	47	14	33	Retired	1	Q	
Gillian	28	11	17	Teacher	1	Q	
Gilly	56	49	7		2	Q	
Gina	56	22	34	Unknown (works from home)	1	Q	
Glen	35	18	17	Journalist	1	I	
Graham	41	35	6	Unknown	1	Q	
Gretchin	23	Unknown	Unknown	Occupational therapist	1	I	Undisclosed age of diagnosis but Gretchin has had diabetes since childhood.
Hannah	67	51	16	Yoga Instructor	2	Q	Insulin dependent
Hayden	79	35	44	Retired (former dock worker)	1	I	
Haylee	53	49	4	Foster carer	2	Q	
Heather	51	20	31	Unknown	1	Q	
Henry	51	10	41	Unknown	1	Q	
Holly	20	19	1	Student	1	Q	

Name	Age	Age at diagnosis	Length of time with diabetes (years)	Occupation	Type 1 (1); Type 2 (2) or LADA	Interviewee (I) or questionnaire respondent (Q)	Notes
Jack	28	26	2	Sheet metal worker/ bar worker	1	I	
Jennifer	33	1	32	Development engineer in the aerospace industry	1	Q	
Jessica	52	20	32	Office worker	1	I	
Julia	41	11	30	Unknown	1	Q	
Ken	27	27	0	Administration	1	Q	
Kim	53	12	41	Author (home based)	1	Q	
Kirsten	23	11	12	Unknown (previously worked in catering)	1	I	
Kyle	53	9	44	Nurse	1	I	
Laurel	64	62	2	Unknown (retired)	2	Q	
Lillian	41	35	6	Office worker	1	I	
Linda	45	40	5	Yoga instructor	1	I	
Lindsay	36	34	2	Teacher at special needs school	2	Q	
Lisa	33	33	0	Unknown	2	Q	
Lydia	24	7	17	Pharmacy technician	1	Q	
Mary	39	33	6	Office worker	1	I	
Maureen	41	8	33	Office worker	1	I	
Mina	65	59	6	Unknown (retired)	LADA	Q	
Nina	44	44	0	Unknown	1	Q	
Olivia	42	9	33	Lecturer	1	I	
Perry	38	5	33	Unknown	1	Q	
Polly	66	57	9	Unknown	1	Q	

Name	Age	Age at diagnosis	Length of time with diabetes (years)	Occupation	Type 1 (1); Type 2 (2) or LADA	Interviewee (I) or questionnaire respondent (Q)	Notes
Rachel	24	21	3	Unknown	2	Q	Insulin dependent
Regina	22	19	3	Administration based	1	Q	
Richard	69	24	45	Retired/ school teacher	1	I	
Samantha	63	13	50	Retired (clerical worker)	1	I	
Sarah	33	33	0	Unknown	2	Q	
Selena	73	65	8	Retired	2	I	
Sophie	Unknown	15	Unknown	Retired (nurse)	1	I	
Sheila	55	35	20	Social worker	1	I	
Shirley	59	52	7	Unknown	1	Q	
Steven	63	23	40	University teacher	1	I	Married to Allison
Valorie	62	22	40	Retired	1	Q	

**APPENDIX 9
PAPER CODING**

The first picture is a scanned page from the transcript of my interview with Allison. The second picture is a scanned page from my first version of a coding guide (participant initials balcked out). I started my coding guide with few themes to guide my coding adding more themes and ideas as I coding interviews. I updated the guide after every two or three interviews. I ended on the thirteenth iteration of the coding guide which I then used as a basis for coding the questionnaire responses, primarily through Nvivo (see appendix 10).

now that they've given me this I feel so much better I don't really need to jag but my husband explained, you've got two choices, you jag and live or don't and die, [laughs] so guess what one, the jaggging..., but after that its fine, once I got the hang of it and understood it a bit better it wasn't that desperate. *#01010 getting used to it -NP*

M: Did it have a big impact on your life at the time, did it change a lot of what you did?

S: no [laughs]. I think the only difference is settling with the idea you have to jag for the rest of your life. *Realisation -RID*

M: and you said really the only thing you had to come to terms with was you had to jag for the rest of your life.

S: yes I think that was the ultimate was the jaggging issue, that was more something but it didn't last very long, cos obviously as you appreciate its not sore or anything like that unless you hit a nerve. *RID*

So no I tend to do that so I will watch the clock about twelve and I think, right I better think of jaggging and eating. That's the only thing I do for work. *routine*

I think the original idea was they think you don't want to jag, but I don't really care, it keeps you healthy and well. *DICD*

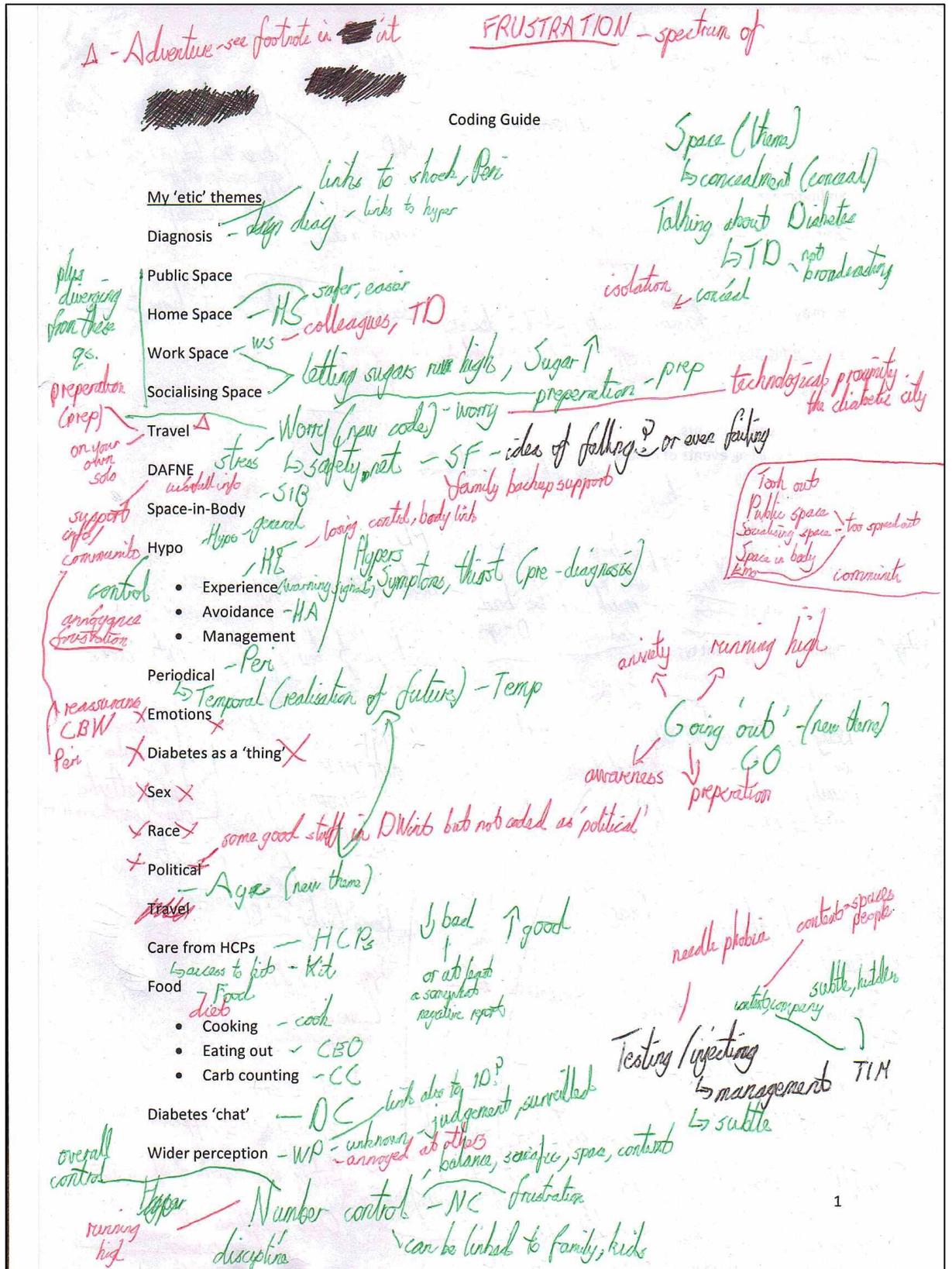
Compares No it would depend on the company to be fair, or what I was wearing if I was wearing a dress there is no way I'm going to hike my dress up in front of people! If I was wearing trousers and a top then no it wouldn't worry me. *I don't deliberately jag in front of people because some people don't like needles. So I'm conscious of if its like our friend who's diabetic, in front of him and his family we wouldn't bother about jaggging but if people in the house, if we have visitors then I would tend to go to the hallway to jag rather than jag at the table. If it just Euan and I then we don't bother out noddle. I'm not a secret injector, how's that? (SE)* *Context, company, dress* *Phobia* *company* *captain's places* *strangers friends*

UJT discreet dress toilet timing?
S: if you were able to do it discreetly at the table then I wouldn't make a big deal about getting up and causing chaos. If I was wearing a dress I would head to the toilet just before the meal is due to come.

Injects across her tummy. Some talk about injection sites.

company discreet dress
S: no never, but to be fair I'm not a public injector if you know what I mean. I'm not worried about it but I wouldn't consciously inject in front of my work colleagues or you know if they came into my office when I was injecting its very discreet cos I've got the pen so I'm having to..., and most of the time I wear trousers and a top in there so

1



**APPENDIX 10
NVIVO SCREENSHOTS**

The first screenshot show some of my coding categories (or nodes). The column ‘sources’ indicates how many sources, both interviewees and questionnaire respondents, that the code appears in. The ‘references’ column indicates the total number of times I applied this code. The second screenshot shows a list of questionnaire respondents. The ‘nodes’ column indicates the number of nodes identified in their questionnaire answers. The ‘references’ column indicates the total number of coded instances in the response.

The screenshot displays the NVivo interface for a project titled "The Everyday Geographies of Living With Diabetes2.nvp". The main window shows a list of nodes (coding categories) with the following data:

Name	Sources	References	Created On	Created By	Modified On	Modified By
Bad feedback	1	1	13/02/2014 21:31	ML	13/02/2014 21:31	ML
Balance	7	13	28/12/2013 15:11	ML	11/02/2014 17:48	ML
bibbit	2	3	26/02/2014 22:50	ML	26/02/2014 23:13	ML
Blood	1	1	22/01/2014 15:18	ML	22/01/2014 15:18	ML
Body control	17	30	11/12/2013 12:49	ML	26/02/2014 22:34	ML
Body general	16	23	17/12/2013 10:27	ML	21/05/2014 10:40	ML
Body Knowledge	7	13	19/01/2014 16:01	ML	13/02/2014 17:32	ML
Boring people	4	5	26/02/2014 22:14	ML	27/02/2014 16:50	ML
Brekhus	7	20	29/12/2013 10:58	ML	29/01/2014 16:13	ML
brightsidng	1	1	29/01/2014 16:16	ML	29/01/2014 16:16	ML
Carspace	7	8	18/01/2014 12:18	ML	13/03/2014 15:38	ML
Changing lifestyle for the better	3	5	11/12/2013 15:53	ML	29/12/2013 11:12	ML
Citizenship	1	2	08/01/2014 11:42	ML	08/01/2014 11:43	ML
Coming out	7	23	22/12/2013 11:35	ML	11/07/2014 18:01	ML
Community	29	44	11/12/2013 15:37	ML	27/02/2014 17:05	ML
Company	14	26	17/12/2013 10:00	ML	26/02/2014 21:39	ML
Confidence	10	14	17/12/2013 09:58	ML	26/02/2014 23:21	ML
Contested	8	9	14/12/2013 10:23	ML	13/02/2014 15:24	ML
Contradiction	1	1	08/12/2014 13:17	ML	08/12/2014 13:17	ML
COS	8	19	17/12/2013 10:31	ML	20/01/2014 17:38	ML
Could be worse	5	8	19/01/2014 12:25	ML	11/02/2014 19:47	ML
Cyborg	3	5	08/01/2014 11:24	ML	19/01/2014 12:19	ML
DAFNE	18	72	11/12/2013 16:07	ML	26/02/2014 20:50	ML
DAFNE broadening horizons	1	1	14/03/2014 18:01	ML	14/03/2014 18:01	ML
Denial	1	2	21/12/2013 15:45	ML	21/12/2013 15:49	ML
Dependency	16	32	17/12/2013 10:41	ML	04/03/2014 21:01	ML
Depression	11	11	17/12/2013 11:09	ML	26/02/2014 21:02	ML
Diabetes as 'easy'	11	16	11/12/2013 12:40	ML	26/02/2014 20:40	ML
Diabetes Chat	3	4	22/01/2014 11:05	ML	29/01/2014 16:01	ML
Diabetes UK	1	1	22/01/2014 14:49	ML	22/01/2014 14:49	ML

The Everyday Geographies of Living With Diabetes2.nvp - NVivo

File Home Create External Data Analyze Query Explore Layout View

Look for: Search In Questionnaire Re Find Now Clear Advanced Find X

Sources

- Internals
 - Interviews
 - Questionnaire Responses
- Externals
- Memos
- Framework Matrices

Sources

Nodes

Classifications

Collections

Queries

Reports

Models

Folders

Questionnaire Responses

Name	Nodes	References	Created On	Created By	Modified On	Modified By
Clare	37	56	06/08/2013 17:47	ML	06/08/2013 18:02	ML
Clark	17	21	06/08/2013 17:58	ML	06/08/2013 18:02	ML
Colleen	36	51	06/08/2013 11:05	ML	06/08/2013 11:05	ML
Craig	20	26	17/04/2013 15:05	ML	17/04/2013 15:05	ML
Damien	8	8	06/08/2013 14:51	ML	06/08/2013 14:52	ML
Dean	4	4	17/04/2013 14:10	ML	17/04/2013 14:22	ML
Debbie	37	50	17/04/2013 14:44	ML	17/04/2013 14:44	ML
Declan	12	14	06/08/2013 17:59	ML	06/08/2013 18:02	ML
Dora	2	2	06/08/2013 15:00	ML	06/08/2013 15:07	ML
Edna	18	22	06/08/2013 11:02	ML	06/08/2013 11:02	ML
Elliot	2	2	06/08/2013 15:06	ML	06/08/2013 15:07	ML
Emma	51	83	17/04/2013 14:15	ML	17/04/2013 14:40	ML
Frederica	39	57	06/08/2013 11:09	ML	06/08/2013 11:10	ML
Gail	37	58	06/08/2013 11:00	ML	06/08/2013 11:01	ML
Gary	53	84	06/08/2013 14:48	ML	06/08/2013 14:52	ML
Gavin	27	41	06/08/2013 11:12	ML	06/08/2013 11:12	ML
Georgia	11	14	06/08/2013 15:00	ML	06/08/2013 15:07	ML
Geraldine	16	18	06/08/2013 10:51	ML	06/08/2013 10:52	ML
Gil	32	40	06/08/2013 14:58	ML	06/08/2013 15:07	ML
Gillian	47	60	17/04/2013 14:25	ML	17/04/2013 14:41	ML
Gilly	14	14	06/08/2013 18:01	ML	06/08/2013 18:02	ML
Gina	20	28	06/08/2013 14:36	ML	06/08/2013 14:52	ML
Gladis	2	2	06/08/2013 17:26	ML	06/08/2013 18:02	ML
Glenda	4	4	17/04/2013 14:52	ML	17/04/2013 14:56	ML
Graham	25	30	17/04/2013 14:58	ML	17/04/2013 15:06	ML
Grant	4	4	17/04/2013 14:54	ML	07/08/2013 14:49	ML
Gregory	9	11	06/08/2013 10:53	ML	06/08/2013 10:54	ML
Greta	4	4	17/04/2013 14:51	ML	17/04/2013 14:56	ML
Harriet	22	26	17/04/2013 14:20	ML	17/04/2013 14:22	ML
Harvey	4	4	17/04/2013 13:52	ML	17/04/2013 14:04	ML

ML 127 Items

11:05 30/12/2014

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