

**Navigating “madness” and  
“fatness”: distorted  
spatiotemporalities in experiences  
of antipsychotic-induced weight  
gain**

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# ABSTRACT

Psychiatric interventions of 'the mind' have unexpected effects on 'the body': antipsychotic medications used in the treatment of schizophrenia can produce side effects of rapid weight gain. Ironically, in an attempt to contain a chaotic mind, antipsychotic-induced weight gain distorts the spatiotemporal orientation of bodies and expanding bodily boundaries, rendering them uncontained. This thesis is about the double stigma of having a mental illness and becoming obese; it is about being both 'mad' and 'fat', and how people struggle for mental health and healthy weight. It explores how schizophrenia and the side effects of antipsychotic medication coalesce in a 'unique fatness' that produces distinctive experiences of time and space.

Drawing on qualitative data with people who have been diagnosed with schizophrenia and have experienced antipsychotic-induced weight gain, and the psychiatrists, nurses and pharmacists who are involved in their psychiatric clinical care, I examine everyday and taken-for-granted understandings of bodies and bodily boundaries. Rather than reproduce a reductionist and Cartesian foci of the mind and the body, I utilise the conceptual orientation of embodiment and corporeal transgression theory (Blackman 2010) to argue that medication side effects transgress bodily experiences of space and time. In focusing on the embodied effects of schizophrenia and the side effects of medication, participants describe juxtaposing experiences of accelerated time ('racing thoughts') brought on by psychosis, with the decelerated temporality of antipsychotics that 'slow things down' yet simultaneously create voracious hungers that produce heavy bodies. While the antipsychotics might achieve containment of some of the clinical symptoms of schizophrenia, the side effects of antipsychotic medication result in rapid weight gain and a loss of bodily boundaries.

This thesis thus challenges assumptions about the nature of 'fatness' across critical fat studies (as socially constructed) and clinical/public health scholarship (as an effect of biology, behaviour or obesogenic environments). Participants' understandings of weight gain did not rely on explanations of energy in/energy out imbalances, but was articulated as 'truly due to medication', and thus at odds with popular and medical understandings of large bodies.

The failure to conform to taken-for-granted expectations of bodies, bodily boundaries and their positioning in space and time has practical implications for the provision of psychiatric healthcare. My findings expose the disjuncture between participants' experiences and public health initiatives around obesity (eating less and exercising more) and psychiatric imperatives for compliance (taking medications 'on time'). Importantly, in bridging the experiences of madness and fatness, this thesis exposes the limitations of dualism within modern medicine and calls for interdisciplinary engagement that helps to open, rather than close, interdisciplinary understandings of the experience of mental illness, medication side effects and obesity.

# DECLARATION

I, Tara Bates, certify that this work contains no material which has been accepted for the award of any other degree or diploma in my name, in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission in my name, for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint-award of this degree.

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TARA BATES

12 November 2015



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*For my parents, Louise and Craig Bates.*

*And also for me.*

# INTRODUCTION

## Eli Lilly and antipsychotic-induced weight gain

### Eli Lilly and the 'Zyprexa story'

On the Australian Radio National program, *All in the Mind*, Sandy Jeffs described the side effects of the antipsychotics she was taking as “a horrible trade-off” (All in the Mind 2007). Jeffs is a performer, poet and advocate who quips that her 30-year experience of living with schizophrenia qualifies her for a “PhD in psychosis”. Her experience of weight-gain side effects represents the frequent negotiation of being both ‘fat’ and ‘mad’. The program focussed on pharmaceutical company Eli Lilly’s recent billion-dollar settlement for claims that its antipsychotic medication, Zyprexa (or, the medical name, olanzapine), had resulted in weight gain and complications associated with obesity. In response to the host’s question about the general experience of medication side effects, Jeffs alluded to psychiatry’s narrow focus in treating schizophrenia:

I think that psychiatry hasn't had a very good listening ear about weight gain with drugs, 'cause all it wants to do is medicate a person and make them better ... It also makes you feel quite despairing because the only thing that is going to make you okay in a sort of societal way are things that make you feel really horrible physically, or even emotionally sometimes.

The creation of one condition (fatness) by the management of another condition (mental illness) is known in the clinical literature as iatrogenesis or as an iatrogenic effect. Intrigued by Jeffs' assertion that the way in which psychiatry views and treats mental illness (and its creation of medication side effects) is linked to the iatrogenic effect of weight gain, I researched further into Eli Lilly and olanzapine. With a background in the social sciences and the law, I became engrossed in a 'story' of leaked court documents; allegations of underplaying health risks; claims of conspiracy between lawyers and journalists; accusations of cover-ups; billion-dollar profits and million-dollar settlements; and weight-gain estimates of colossal proportions.

Showing a broad appetite for this story, *The New York Times* have reported extensively on the 30,000 claimants who have undertaken legal proceedings against Eli Lilly for the side-effect profile of Zyprexa (see Berenson 2006; 2007; 2008). Investigative journalist Alex Berenson (2006) released internal Eli Lilly documents showing that the side-effect profile of olanzapine was known to the company who had actively engaged in a concerted effort to downplay these health risks. The documents show that Eli Lilly executives kept important information from doctors about olanzapine's links to obesity. Berenson (2006) claims that an Eli Lilly executive wrote in an internal email that drug-induced obesity is a "top threat" to olanzapine sales; another executive is alleged to have warned that "unless we come clean on this, it might get much more serious" (Berenson 2006). Nonetheless, Eli Lilly continued to manufacture, distribute and market Zyprexa, despite evidence that olanzapine causes more weight gain than its competing antipsychotic medications (Allison *et al* 1999; Lieberman *et al* 2005; Nasrallah 2003; Sussman 2003). Eli Lilly has spent about \$US1.2 billion in settlements (Berenson 2007), though these settlement costs pale in comparison with Eli Lilly's profits, estimated to be \$US30 billion (Berenson 2007), with 23 million people worldwide having taken olanzapine since it was introduced to the global pharmaceutical market in 1996 (Berenson 2008).

I begin this thesis with an excerpt from the *All in the Mind* program to give an account of what it is like to live with antipsychotic-induced weight gain, and I draw on the Eli Lilly court proceedings to highlight the far-reaching nature of the antipsychotic side effects and their devastating impacts. The court proceedings, as well as Jeffs' descriptions of her medications, illustrates how experiences of weight gain among those characterised as mentally unwell and obese are discounted. The research problem that this thesis investigates takes as its starting point that medication-induced weight gain is a problem for those experiencing schizophrenia and for those who provide mental healthcare. Embedded in this research problem is the recognition of fatness as an issue both about social justice and about the increased morbidity and mortality risk. The lived experience of medication-induced weight gain is thus a double burden of stigma in which the stigmatising experiences of madness and fatness are intertwined with the medical risks of schizophrenia and obesity.

My research questions investigate how people live with the simultaneous experiences of madness and fatness? What does it mean to be mad? What does it mean to be fat? What does it mean to be both mad and fat, and how does medication complicate this relationship? How do people reconcile the at-times contradictory lived experiences of the increased medical risks of weight gain and the lived stigma of fatness? Are experiences and treatment of schizophrenia privileged over experiences of weight gain for those with lived experiences of antipsychotic-induced weight gain and for those who provide psychiatric care? How do understandings of schizophrenia and side effects, specifically antipsychotic-induced weight gain, differ for those with experiences of schizophrenia and for the health professionals involved in its treatment? How do perceptions of stigma about madness and fatness interact with or detract from treatment outcomes?

I draw on qualitative data from interviews with people who have a diagnosis of schizophrenia and interviews with the psychiatrists, nurses and pharmacists involved in their clinical care. Carrying out interviews with practitioners and people

experiencing antipsychotic-induced weight gain allows me to draw attention to the relationship between fatness and madness and the particular ways in which these are embodied. This relationship highlights the loss of boundaries inherent within the experience of schizophrenia, and I argue that weight-gain side effects amplify and exacerbate these experiences, to produce further experiences of distorted bodies, space and time.

## **“The worst of the worst”: a snapshot of modern schizophrenia**

Clinical evidence shows that people with diagnoses of schizophrenia experience very poor general health (Lowe & Lubos 2008). Not only are people with schizophrenia likely to have poor quality of life and a reduced sense of wellbeing (Allison *et al* 2003), but mortality rates for people with schizophrenia are two to three times higher than rates in the general population, with life expectancy of men and women with schizophrenia 18.7 and 16.3 years, respectively, less than the general population (Laurson 2011). Heart disease is a predominant factor in these shortened life expectancies (Foley 2014). Internationally respected medical anthropologists Jenkins and Barrett recognise these health concerns when describing schizophrenia as “one of the most severe psychiatric disorders” (2004, 2).

Some recent studies have focussed on antipsychotic medication, exploring the relationship between psychiatric medication and comorbidities (a clinical term to describe additional disorders occurring at the same time or in some causal sequence to a primary disorder). Australian researchers, Foley and Morley (2011), for example, show that cardiovascular risk increases after a person first takes antipsychotic medication, and Foley (2014) draws link between such medication and the risk of type 2 diabetes and heart disease. Antipsychotics also cause significant weight gain (Allison *et al* 1999; Nasrallah 2003; Waterreus *et al* 2012); in their comparison of different antipsychotics’ contributions to weight gain, within a

10-week period Allison and his colleagues (1999) found mean increases of more than 4 kilograms for the two highest weight-inducing antipsychotics, clozapine and olanzapine (4.45 kilograms and 4.15 kilograms, respectively). Of its sample of 1825 people in the most recent population-based survey of Australians with a psychotic disorder, 75.5% were overweight or obese (Galletly *et al* 2012). The mean amount of weight gained in the six months before the survey was 9 kilograms (Galletly *et al* 2012); Galletly and her colleagues agreed that antipsychotic medication is “likely to be a major contributor to the high rates of obesity in survey participants” (2012, 759).

In conceptualising medicated fatness as both a clinical risk and a social stigma, I draw on a broad range of research to seek understandings of the lived experience of antipsychotic-induced weight gain. Cooper (2010) and Gard (2011) alert their readers to some of the implications of abiding by and propagating the either/or paradigm of critical fatness studies and obesity research. My research refuses the perpetuation of these epistemological binaries. Research that operates within narrow parameters can miss those at its centre: fat people, who are “often abstract presences ... a nebulous blob of people sometimes known as ‘the obese’” (Cooper 2010, 1024). Although situated within, and drawing on, social science and critical health literature, this thesis avoids the binaries between these fields by eschewing allegiances with both the obesity and critical fat camps.

Avoiding fidelity to either camps allows me to engage with both to understand the lived experience of fatness. Some researchers draw attention to the morbidity and mortality implications that are attached to weight gain and obesity, including increased risk for diabetes, cardiovascular disease, certain cancers and other chronic diseases, as well as physical and cognitive disability (Friedman *et al* 2005; Houston *et al* 2009; Kawachi 1999). The prevalence of obesity has increased over the past 30 years, particularly in developed countries (Dixon & Broom 2007), and more than 300 million people worldwide can be classified as obese (Kelly *et al* 2008). At a local level, recent Australian Bureau of Statistics data reveals that in

2011–12, 62.8% of adults were overweight or obese – 35.3% overweight and 27.5% obese (Australian Bureau of Statistics 2013).

Government investment in obesity awareness programs throughout the world suggests the heightened recognition of obesity as an important health risk. In the US, the First Lady Michelle Obama leads the *Let's Move* program that, along with a prolific social media campaign, encourages exercise and particular foods and drinks. Similar programs have been initiated in the UK with its *Change4Life* campaign, as well as the *Measure Up?* and *Swap It, Don't Stop It* campaigns in Australia. The establishment of research and advocacy organisations indicate governments' commitment to research into obesity, including the International Association for the Study of Obesity and the former Australian National Preventive Health Agency.

The combined health implications of schizophrenia and obesity are serious. This is why Julia, one of the psychiatric nurses I spoke to during my fieldwork, describes the health status of people with schizophrenia as “the worst of the worst”. In Chapters 2 and 3, I outline some of the methodological principles used to gain insights into those characterised as “the worst of the worst”, recognising the ways in which experiences of schizophrenia render a strangeness towards language and a distrust of communication. In Julia's words, the people accessing the community mental health centre are generally “heavy smokers, heavy users of sugar and high fat ... on a [disability support pension] ... [who] may not be able to afford some of the healthier [food and drink] choices”. These health factors are compounded by the “poor economy” in which these people live. Julia recounts anecdotes of her clients' “appalling” cooking habits who, due to their early onset of schizophrenia, never learnt to prepare food in a safe manner:

For a lot of people, they haven't ever learnt those skills. And then they get to a stage in their adolescence and they start becoming unwell, so we have to start from Square One and actually teach people how to prepare food, how to do it in a clean way, how to store things, how to wash dishes.



The high rates of smoking (Galletly *et al* 2012), low consumption of fruits and vegetables (Hahn *et al* 2014) and low rates of physical exercise (Galletly *et al* 2012) of people with schizophrenia are supported by clinical research findings.

Clinical evidence sheds light on the health of those living with schizophrenia and establishes that antipsychotic side effects requires urgent and critical attention. Despite these morbidity and mortality concerns, little research has explored antipsychotic-induced weight gain, and when weight has received clinical attention, this is usually in relation to how it affects medication compliance and potential relapse (Correll & Malhotra 2004; Perkins 1999; Roe *et al* 2009; Weiden *et al* 2004). This is why prominent clinical and research psychologist Paula Caplan (2012) describes the overlooked health impacts of antipsychotic medication as “the elephant in the room”, and causing some psychiatrists to describe Australian health systems as “failing to provide optimal care for ... co-morbid physical health problems” (Organ *et al* 2010).

## **“The broken brain”: psychiatry and schizophrenic ‘symptoms’**

The failure in responding to antipsychotic side effects can be linked to the ways in which modern psychiatry constructs ‘illness’ and conflates the person with ‘the brain’. The history of psychiatry and schizophrenia that I provide in Chapter 1 offers insights into how the brain has come to be elevated as the lens through which mental illness is defined (Busfield 2000; Luhrmann 2000; Micale 2000). In the adoption of a biomedical and reductionist model, the brain has come to be the locus of all mental illness that has created what Rose terms, a “neurochemical reshaping of personhood” (2003, 59).

This shift renders modern-day conceptualisations of schizophrenia as imagined through the brain. Schizophrenia is viewed as disordered ‘brain chemistry’, the putative imbalance of neurotransmitters or serotonin located exclusively in the

head. Despite these conceptualisations, there is no diagnostic test of the brain for schizophrenia, and Jenkins and Barrett (2004) note that schizophrenia comprises a number of disorders classified under one rubric rather than a single disorder. Such an understanding of schizophrenia as highly fragmented is nonetheless dominated by constructions of the brain.

Within this construction are clinical categories of positive and negative symptoms. Positive symptoms include disordered thinking, disorganised speech, hallucinations and delusions; characterisations of negative symptoms include withdrawal or blunting of emotional expression (Jenkins & Barrett 2004). In describing the simultaneous experience of positive and negative symptoms, medical anthropologist Corin coined the term “positive withdrawal” (2007, 280) to refer to the distinctive retreat and advance behaviours commonly displayed in people with schizophrenia. The experience of “positive withdrawal” creates:

a sense of porosity and fragility of personal barriers and boundaries, and the perceived invasion of one’s mind by insistent voices and messages that can take over the patient’s thoughts and behaviours; and a feeling that becomes uncontrollable and may occupy all of the patient’s attention and block his or her ability to think. Confusion and fear may also blur linguistic boundaries and cloud the patient’s sense of judgment about the world, destabilizing the fundamental benchmarks of existence. (2007, 290)

Voices and visual hallucinations transgress taken-for-granted boundaries of the body and time and space, and the data that I produce and interrogate in Chapters 4 and 5 will have a strong bearing on this argument. Mary, a participant in this study, described how her voices cross both bodily and material borders – she heard voices in electricity wires, radios and televisions, as well as lights, and Mary soon learnt that the removal of the light globes silenced the voices. In my interview with Mary, she told how she heard voices in clothing hangers, but emphasised that the voices only “came through the metal ones”. The metal hangers, like the electricity wires and light globes, are carriers of energy and electricity, and the

voices within them reveal the experience of schizophrenia to cross boundaries and transport thoughts beyond their taken-for-granted borders. Mary's experience of schizophrenia is classic in her articulations of transgressed bodily boundaries, as described by Corin (2007) above. Throughout this thesis, I develop and expand on the argument that experiences of schizophrenia produce violations of personhood and perceptions of spatiotemporalities that fit characterisations of schizophrenia as quintessentially puzzling, enigmatic and mysterious (Sass 1992).

As experiences of schizophrenia traverse culturally constructed boundaries of the self, representations of schizophrenia tend to be presented as uncontained. These representations have a long history. Psychiatric formulations are unified in the "ununderstandable" (Jaspers 1963, 577) nature of the presentation of schizophrenia, beginning with Kraepelin's (1899) and Bleuler's (1915) works around the turn of the century. The inherent "strangeness" (Lucas 1999) and "extraordinary" (Jenkins 2004; Lucas 1999; Lucas 2004) nature of schizophrenia renders experiences as incongruent with Western concepts of personhood as a coherent and bounded whole (Barrett 1996). In transgressing the societal expectations of what it means to be a person, "the broken brain" (Kleinman 2004, xv) of schizophrenia represents an incomplete, disrupted and fragmented person.

As Barrett says:

Insofar as we conceive of the person as a unified, coherent, bounded whole, then the 'schizophrenic' epitomizes the converse of this conception: a divided, fragmented person without boundaries. ... Western concepts of the person draw on a basic metaphor of order, according to which the individual whole encompasses and orders the ensemble of parts. Schizophrenia represents a basic disorder of the person in which the parts disrupt and disorganize the whole. (1996, 216)

## Antipsychotics and the ‘containing’ of thoughts

The thoughts of the person with schizophrenia – like the clinical and cultural representation of schizophrenia – are disrupted, fragmented and ‘uncontained’. Such uncontained thoughts are located exclusively within the head and, in mirroring conceptualisations of schizophrenia, treatment options are similarly targeted within the brain by antipsychotic medication that fixes “the broken brain” (Kleinman 2004, xv). This is manifested (and measured) by the ‘containing’ of the mind and transgressive thoughts.

Along with the history of psychiatry, the history of psychiatric medication, specifically antipsychotics, entrenches the brain as the locus of all mental illness and treatment. As antipsychotic medication is deemed to be the “gold standard of treatment” (Gordon 2010, 51), any side effects of medication that impact on the body are considered to be secondary. In this sense, the brain-centric nature of modern psychiatry and its conceptualisations of antipsychotics understands the body, and any effects on it, as peripheral. This body aligns with what Leder (1990) terms, the “absent” body, the Western phenomenon in which corporeal materiality and processes are commonly ignored.

The effects of medication that sit outside the scope of fixing the brain are sidelined within psychiatry – antipsychotic side effects are indeed side issues. This is despite evidence that antipsychotic side effects are a central concern for those experiencing them (Rapport *et al* 2010; Seeman 2011; Seeman & Seeman 2012; Usher 2001) and the cost–benefit analysis that people apply when weighing up side effects over antipsychotic benefits (Bentley 2010). Incorporating cultural context within the use of pharmaceuticals, Etkin (1992) posits medicine’s privileging of “primary” effects and subordination of other pharmaceutical effects as “side” as having resulted from the biomedical paradigm. Etkin argues that primary and side effects have broad cultural and personal meanings, and the experience of

these effects must be examined with respect to “why a medicine is administered, the intentions of the user and prescriber, and the anticipated outcome” (1992, 102).

The categorisation of weight gain as a side effect of antipsychotic medication supports representations of the broken brain and the absent body within psychiatry. Weight gain, as an effect on the body, is peripheral and secondary. Such an understanding fails to take into account the cultural meanings of antipsychotics (Etkin 1992). Critical attention on weight gain allows for an examination into the complexity of the broader experience of schizophrenia and antipsychotics. In working to contain the uncontainable schizophrenic symptoms and experiences of transgressed bodies, space and time, the weight-gain side effects extend bodily boundaries to make people large. A contradiction arises that in attempting containment of ‘the mind’, antipsychotics actually do the opposite to ‘the body’ – bodies are expanded and bodily boundaries are transgressed. The experience of uncontained bodies rendered by antipsychotics thus amplifies and exacerbates the loss of boundaries and transgressive core experiences of schizophrenia through rapid weight gain, as will be explained further in Chapters 4 and 5.

## **Obesity, fatness and uncontained bodies**

Hunger connects the experiences of medication and fatness; experiences of rapid and unrelenting medicated hunger causes experiences of rapid and unrelenting medicated fatness. Instead of setting up a dichotomy between the framing of the mind in psychiatry and the framing of the body in public health, this thesis uses the example of medication side effects to show the relationship between the two. Psychiatry’s conceptualisation and treatment of schizophrenia revolves around the containment of thoughts that render representations of schizophrenia as fragmented and disordered. Similarly, the focus on obesity in public health is concerned with (physically and morally) uncontained bodies, and deems obese people to be lacking control and discipline of the self.

Obesity is a highly medicalised condition of the body, and public health views weight gain and obesity as having serious health implications for the body. The morbidity and mortality risks of obesity propagated in public health have enabled the American Medical Association (followed by the American Heart Association and the American College of Cardiology) to recognise obesity as a 'disease'. Notably, this classification is contentious, and the Australian Medical Association and the federal Department of Health have not yet followed suit, though the Australian government's investment in anti-obesity initiatives signals that obesity is understood to be a significant problem.

Public health accounts of obesity are wide-ranging, spanning explanations from epidemics to genetic factors to obesogenic environments. In their study of the expert opinions of 50 obesity, dietary and physical activity professionals, Banwell and her colleagues find a "smorgasboard" (2005, 568) of competing explanations for the rise in obesity rates in contemporary Australia. Despite the diversity and complexity of opinion about the cause of obesity and how environments impact on rising levels of obesity (Banwell *et al* 2005), the experts frame their understandings around the "Big Two" (Keith *et al* 2006, 1585) of diet and exercise – that is, the causal energy in/energy out equation. This framework understands weight gain as caused by an imbalance in calories consumed and expended, and most anti-obesity public health campaigns encourage individuals to reduce caloric-dense foods and increase exercise.

However, in my study, the weight gain of participants has been caused by pharmaceuticals and not caloric imbalance. The participants' articulations of their 'unique fatness' highlights the futility of traditional public health initiatives and messaging around diet and exercise. Unique fatness is, in the words of one participant, "truly due to medication". Participants reject characterisations of their weight gain as ordinary, conceptualising their weight as so distinct that participants explicitly refute its medical concern by characterising it as "not fat" and "not life-

threatening”. These experiences do not fit public health’s constructions of obesity and the body, and the tensions that arise from differing and, sometimes, conflicting understandings of antipsychotic-induced weight gain forms the basis of Chapter 6. Although obesity experts acknowledge the complexity of the phenomenon of obesity and the ineffectiveness of “simplistic and individualistic solutions” (Banwell *et al* 2005, 567), antipsychotic-induced weight gain offers a different understanding of weight and obesity that has been unexplored in the clinical literature.

In response to the biomedical and alarmist ‘obesity epidemic’, critical fat scholarship seeks alternative positions to the “fat panic” (LeBesco 2010, 72). Contrary to the construction of obesity as located exclusively within the body, critical fat studies identifies ‘fatness’ as a social construction. These researchers, writing in the social sciences and humanities, apply a critical and analytical perspective to identify fat as a “cultural artefact” (Lupton 2012, 3), “a three-letter word larded with meaning” (Kulick & Meneley 2005, 1). Critical fat scholars reject fatness as equated with illness, and argue against the moralising (rather than medicalising) discourses of fatness in the Western world that produce pathologised fat bodies. The modern and Western “crusade against fat” (Stearns 1997, 3) is said to arise from a person’s greed, laziness and lack of control, reflecting the “moral injunctions against sloth and gluttony in Judeo-Christian culture” (LeBesco 2010, 75; see also Stearns 1997).

The conceptualisation of fatness as a social construction allows for an understanding of obesity as a concern about loss of containment. Drawing on Kristeva’s (1982) work on abjection, Bordo’s (1990) slender female body as a metaphor for contained desire and Shildrick’s (1997) ‘leaky bodies’, Lupton (2012) draws attention to the representation of the grotesque fat body as excessive, lacking control, and the result of someone who has literally and symbolically “let themselves go” (see also Braziel & LeBesco 2001). The transgressed bodily borders of fatness signify disorder and chaos, and fat bodies:

deviate from the norm, mainly by exceeding it. They defy clear definitions and borders and occupy the liminal middle ground between life and death. They are permeable and uncontained, transgressive of their own limits ... Grotesque bodies are, above all, carnal: that is, they are overtly fleshly and expressive of desire rather than the simply neutral containers for the disembodied consciousness which is such a valued ideal of the body in western culture. (Lupton 2012, 55)

The bodily excess of fatness connotes the self's inferiority (Lupton 2012) in containing and controlling the body.

## **Experience, embodiment and the transgression of bodily boundaries**

These theorisations of containment revolve around prevailing notions of the body as a container (Lakoff & Johnson 1980). This body is conceptualised as a universal one, with firmly fixed boundaries and within one specific temporal and spatial location (Mann & Jaye 2007; Robinson *et al* 2006). However, in this thesis I argue that the container metaphor is limited in that it has been drawn from *representations* of schizophrenia and obesity. Beginning in Chapter 4, I extend these representations to the *experience* of antipsychotics and weight gain, building on Csordas' (1994) classic work on embodiment and experience and Blackman's (2010) critique of the contained body. Expanding on feminist criticisms of representation and drawing on phenomenological traditions, Csordas offers a term for thinking beyond representation, "being-in-the-world" (1994, 10). Embodied explorations privilege the "existential immediacy" (Csordas 1994, 10), or being-in-the-world, of antipsychotic-induced weight gain, and challenge prevailing ideas about the containment of bodies, time and space.

A key commitment of embodiment scholarship is avoiding all binaries when thinking about the body (Blackman 2010; Grosz 1994). The legacy of dualist thinking is the privileging and hierarchising of one term over the suppression of



another (Grosz 1994), such as the dichotomies of mind/body, inside/outside and self/Other. As Grosz explains, within the mind/body dualism, the “body is thus what is not mind ... It is what the mind must expel in order to retain its ‘integrity’” (1994, 3); the mind and the body are deemed to be separate, autonomous and entirely confined within its own borders. Relics of such Cartesian thinking have proliferated in modern medicine, which has allowed schizophrenia to be conceptualised and treated as exclusively within terms of the brain.

In refuting these hierarchies, however, embodiment challenges notions of the mind and body as discrete entities and containers. In her introduction to the *Body & Society's* special edition on bodily boundaries and transgression, Blackman (2010) critiques the notion of bodily integrity. Blackman disputes the body as bounded and autonomous, arguing that:

the materiality of bodies ... are extended and multiplied ... [and] challenge the idea of bodies as discrete entities, clearly bounded and differentiated such that we know what is inside and what is outside, what is self and what is other, what is natural and what is cultural, and what is ‘pure experience’ and what is mediated. (2010, 1)

Embodiment thus provides theoretical scaffolding for understanding bodies as “rich in the possibility of intercorporeality” (Shildrick 2010, 12); bodies are not bounded, autonomous and fixed in time and space.

Instead, bodies are perennially transgressive (Blackman 2010; Williams 1998). In Chapters 4 and 5, I draw on corporeal transgression theory to present data on how antipsychotic-induced weight gain further reveals this transgressive nature of the body. Corporeal transgression is defined as the “breaking or crossing of corporeal boundaries within the prevailing ‘order’; boundaries which seek to de/confine the human body in certain sociocultural and historically specific ways” (Williams 1998, 60). The crossing of bodily borders represents the failure to conform to “body laws” (Blackman 2010) – that is, taken-for-granted assumptions about bodies and their relationships to time and space.

Contesting bodies as fixed and bounded offers opportunities for alternative understandings of embodied experiences. Embodiment theory, and its conceptualisation of bodies as transgressive, draws together constructions of madness and fatness that allow a focus on temporal and spatial experience. This thesis thus explores experiences of the containment of minds and bodies beyond representations of antipsychotic-induced weight gain.

## **Outline of the dissertation**

Concepts of bodily transgression extend theorisations of bodies, time and space, and reveal how the transgressive and disrupted experience of time and space are amplified through the rapid weight gain caused by antipsychotic side effects. This thesis gives a nod to phenomenology, particularly to the phenomenology of the body and pain (Csordas 1994; Leder 1990; Toombs 2001a & 2001b) and the phenomenology of time (Flaherty 1993; 1999), and recognises the history of psychiatry's relationship with phenomenology (see Barrett 1996). However, this thesis is not a phenomenology of antipsychotic-induced weight gain; instead, I use embodiment theory to conceptualise bodies as transgressed and contained, and incorporate notions of representation along with the lived experiences of those who experience the weight gain and those who offer clinical healthcare. This thesis is also not a critique of the clinical systems of classification for obesity and schizophrenia. There is an extensive body of commentary available on the Body Mass Index (BMI) (Evans 2010; Monaghan 2008), and on the *Diagnostic and Statistical Manual of Mental Disorders 5* (DSM-5) (indeed, Cosgrove and Krimsky (2012) and Jones (2012) offered critiques even before its release, and Frances, who was instrumental in the creation of the DSM-4, has written a book titled *Saving Normal* (2013)). This thesis instead takes as its starting point the lived experience of medicated fatness.

Chapter 1 contextualises the experience of medication side effects by outlining the key sociological and medical debates around fatness and madness. An historical overview of psychiatry, schizophrenia and antipsychotic medications highlights how ‘the brain’ has come to be the pivot by which all mental illness is theorised; obesity, on the other hand, is understood almost exclusively in bodily terms. Instead of setting up a dichotomy between psychiatry (and the mind) and public health (and the body), however, embodiment concepts of containment and bodily transgression (Blackman 2010) bridge these conceptualisations, and Csordas’ (1994) work on experience and embodiment provides the foundation for drawing attention to the lived experience of time and space.

Chapters 2 and 3 set out the methodological foundations and research principles that underpin this thesis. I explain how constructionism and postmodernism help in deconstructing dualisms and seeking social meanings. This methodology allows for an understanding of fatness and madness that is grounded in the lives of those experiencing antipsychotic-induced weight gain; this is important when seeking to understand lived experiences that have historically been framed within a biomedical and psychiatric paradigm. In this sense, qualitative methodologies allow the seeking of meaning beyond measurement, and I outline how the qualitative methods of interviews and observation provided insight into the meaning of being mad and fat. My ‘arrival scene’ of entering the “red doors” of the mental health centre is extended in Chapter 3 to highlight the communication difficulties inherent in speaking with people whose lives are characterised by a lack of communicable understanding, and a lack of bodily and social boundaries.

Chapters 4 and 5 elaborate on the experiences of these transgressions and loss of boundaries through the lens of space and time. I draw on a spatiotemporal framework to illustrate the effect of antipsychotic medication in exacerbating bodily boundaries within experiences of schizophrenia. Chapter 4 focuses on the ways in which the antipsychotic medications amplify these transgressions of space through rapid weight gain. Blackman’s (2010) concept of bodily integrity provides grounding

for the metaphor of 'heaviness'. The three heavies – extended bodily boundaries, flattened and numbed emotions, and the openness of extreme tiredness – highlight the experiences and implications of bodily transgressions, in which the disrupting characterisations of schizophrenia are amplified by the disrupting experiences of antipsychotic medication. These transgressions embody the cataclysm of the Western, whole and ordered person (Barrett 1996; Williams 1998).

In Chapter 5, the focus shifts to the temporal dynamic to highlight how antipsychotic-induced weight gain disrupts the relationship between clock time and lived time. After the “meds kick in”, perceptions of time are severely altered: the *accelerated* time that is embodied in experiences of schizophrenia is juxtaposed with the *decelerated* temporality of the antipsychotics and the *distorted* temporal experience of medication side effects. Unlike constructions of structured, institutional clock time, I draw on analyses of time (Elias 1992; Flaherty 1993 & 1999; Wyllie 2005) to show that antipsychotic-induced weight gain expands taken-for-granted understandings of time and distorts temporalities experienced in the body. The inability to share (social) constructions of time make participants feel “odd” and estranged from broader society. To counteract these disrupted temporalities, participants use idiosyncratic management strategies of temporal-benchmarking to mark moments throughout their day, highlighting the disjuncture between different modalities of time.

The focus of Chapter 6 is on the repercussions of these disrupted senses of space and time. Webster-paks – medication systems used for people characterised as living 'chaotic' lives – provide a useful example for bridging understandings of clock time and lived time. Chapter 6 extends the relationship between fatness and madness, and the related links between bodies, time and space, that are outlined in Chapters 4 and 5; this is used to demonstrate the practical repercussions of failed bodily containment. For example, the public health approach taken by community mental health nurses advocates the importance of diet and exercise in alleviating antipsychotic-induced weight gain; however, lifestyle factors do not align

with the experience of distorted spatiotemporalities of antipsychotics and weight gain. Privileging the participants' experiences of their weight gain acknowledges that there is always a "spectrum of knowledge(s)" (McClellan & Shaw 2005, 729) and a multiplicity of ways for understanding antipsychotic-induced weight gain. This approach contradicts Foucault's (1967; 1977) earlier articulations of power (McLaren 2002; McNay 1992; Warin 2010), recognising that individuals do have the agency to resist dominant discourses and create their own paradigms for understanding their experiences.

The conclusory Chapter 7 draws together the different understandings of antipsychotic-induced weight gain to offer a new way for conceptualising and treating this weight. This new understanding offers important contributions to scholarship and clinical practice. Embodied experiences of the weight gain, with its distinct spatiotemporal sensibilities, exposes the limitations of dualisms within modern medicine. This new paradigm for thinking about antipsychotic-induced weight gain has implications for public health initiatives around obesity as well as psychiatric imperatives for medication compliance.

# CHAPTER ONE

## **Bodies in time and space: contextualising madness and fatness**

In this chapter, I illustrate the theoretical and conceptual orientations that underpin this thesis. I map the various fields of academic literature that span the phenomenon of antipsychotic-induced weight gain, including works within psychiatry, critical and cultural psychiatry, medical anthropology, obesity and critical fat studies, embodiment theory, and contemporary spatiotemporal philosophy. I have chosen to draw together and examine the relationships between these complex and contested fields because experiences of madness and fatness contravene and violate (social and bodily) boundaries. Doing so allows me to elaborate and bring to light the lived experiences of schizophrenia and obesity, experiences that are both transgressive, located in bodies, and stigmatised.

These writings help to illuminate the experiences arising from medicated fatness by highlighting the social construction of bodily boundedness, containment, and transgressions of bodily and social boundaries. I first map the history of psychiatry and its transition away from understandings of madness to clinical classifications of mental illness; such conceptualisations have given rise to framing schizophrenia as a transgressive experience that needs to be contained. Following these understandings, antipsychotics provide for the containment of 'uncontainable' schizophrenic symptoms, but ironically amplify the core disrupting experiences of

schizophrenia through rapid weight gain. Drawing together the broad fields of obesity and critical fat studies exposes some of the gaps in knowledge in psychiatric, public health and critical health research, particularly with regard to antipsychotic-induced weight gain. I draw on social theories of space and time to highlight the centrality of embodiment theory to my thesis, highlighting the usefulness of spatiotemporalities for understanding the transgressive experiences of madness and fatness. My thesis is thus aligned with contemporary medical sociology, medical anthropology and gender studies writings that position the body as central to theoretical analysis.

## **Psychiatry and the brain**

Despite positioning itself as an objective branch of biomedical science in which ‘the brain’ lies at its centre, a history of modern psychiatry illustrates how Western constructions of madness continue to proliferate. The mythology of ‘the madman’ invokes connotations of “a wildman and a beast ... a child and a simpleton ... a waking dreamer ... [and] a prophet in the grip of demonic forces” (Sass 1992, 1). A number of important works offer critiques of madness to demonstrate the prevalence of Western understandings of madness within contemporary psychiatry, and to illustrate how madness has come to be represented as the separation from what is considered to be features of personhood: rationality and reason (Barrett 1996; Foucault 1967; Goffman 1962; Sass 1992; Ussher 1991).<sup>1</sup>

During the Christian Middle Ages, the barbaric treatments inflicted on those thought to be experiencing what later came to be known as mental illness reflected the madman’s status as “lower than human” (Fabrega 1990, 104; see also

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<sup>1</sup> It is important to note that feminists have long been interested in the relationship between women and psychiatry, especially pharmaceuticals (Blum & Stracuzzi 2004; Metzl 2003; Prather & Minkow 1991; Ussher 1991 & 2010). The “feminine typed” (Blum & Stracuzzi 2004, 271) conditions of depression and hysteria has received much criticism, particularly the high rates of antidepressant medication prescriptions for women (Blum & Stracuzzi 2004; Prather & Minkow 1991; Ussher 1991). In her exploration of “women’s madness”, Ussher (1991) critiques the emotive and meaning-laden nature of madness, and argues that madness serves the dual purpose of social control and scapegoating individuals (1991, 139).

Harrison 2008). By the nineteenth century, though, medical understandings of illness began to gain popularity and credibility, transforming moral understandings of madness. This era reflects the transition away from the moral treatment era (Scull 1994) to the beginnings of a medical framework for understanding mental illness. This coincided with the rise of modern medical science, and the crystallisation of medicine as a profession and psychiatry as a medical specialisation. Those under the care of psychiatry were accordingly categorised as psychiatric patients and segregated into special medical institutions: asylums (Foucault 1967).

Prior to the nineteenth century, treatment of the mentally ill focussed on the restriction of bodily movement, through techniques of isolation and physical restraint (Healy 2009). However, the era of modern medicine inspired an “orgy of experimentation” (Scull 1994, 8) on the mentally ill. Treatments varied from the administration of cocaine, manganese, castor oil, sulfur oil (Ban 2004) and animal blood (Lehmann & Ban 1997); to sleep treatment and insulin coma therapy (Ban 2004); bleeding and purging of the body (Micale 2000); as well as chemically-induced shock therapy and frontal lobe brain surgery (Moncrieff 1999). Practitioners and the broader community became disappointed with the limited success of these treatments, creating a crisis for psychiatric knowledge and practice (Micale 2000). What followed was a century of oscillation between psychiatric attention on the body and the mind: “psychiatric ‘brainlessness’ ... [fluctuated with] psychiatric ‘mindlessness’ in a continual cycle of onesideness” (Micale 2000, 344).

The turn of the twentieth century characterised the profession’s optimism in theories of psychoanalysis. Sigmund Freud’s psychoanalysis posits the mind as the locus of mental illness and mental treatment, and from the late-nineteenth century to the middle of the twentieth century, psychoanalysis dominated every avenue of clinical and academic psychiatric knowledge and practice. In contrast to psychiatric asylums and the treatments that took place in them, the “Freudian



revolution” (Micale 2000, 329) is thought to be the “birth of modern psychiatry” (Micale 2000, 329).

Such “brainlessness” was soon met with ferocious criticism, giving way to a renewed interest in the brain and biomedical understandings of mental illness. Critics of psychoanalysis argued that it was too expensive and time-consuming (Gordon 2010); others argued that psychiatry had drifted away from medicine and called for the remedicalisation of the profession (Rogler 1997). In his social history of psychiatry, Shorter describes psychoanalysis as “an interruption, a hiatus ... a pause” (1997, 145) in the broader biological approach to psychiatry, although Metzler (2003) and Luhmann (2000) argue that psychoanalysis laid the foundation for contemporary psychiatric approaches.

Since the 1960s, psychiatry has been embedded within a biomedical and neurological paradigm: “The broken brain has become the dominant professional (and popular) image” (Kleinman 2004, xv) of psychiatry. A renewed interest in the brain draws on the disease model of biomedicine, and mental illnesses are understood as illnesses of the body (or, the brain). In her ethnography on the training of modern psychiatrists, Luhmann observes that mental illnesses are treated “as if the illnesses really ... [are] like heart attacks in the brain” (2000, 133).

This renewed biomedical attention interacts with the commercial and professional interests of the psychiatric profession. Unlike the hitherto “second class” status of psychiatry (Moncrieff 1999, 477), the promotion of psychiatry as a branch of medicine and the adoption of a reductionist model of mental illness has promised professional respectability to a specialty denied legitimacy in the medical hierarchy (Micale 2000; Porter 2002; Shorter 1997). Micale characterises this adoption as an “aggressive attempt by psychiatry to embrace the medical mainstream” (2000 336), highlighting the privileging of the medical model within the contemporary “culture of science” (2000, 336). Put simply, the biomedical and pharmaceutical approaches to mental illness seem “more like the rest of medicine” (Luhmann 2000, 203).

Rose conceptualises the emergence and proliferation of the brain as “somatic individuality” (2003, 54): all discontents are mapped onto the body itself (or one particular organ of the body – the brain). Rose (2003) blames the rise and acceptance of neurochemistry for this shift, and uses the example of mental illness to highlight the way in which all explanations for mental pathology must now pass through the brain and its neurochemistry – previously, this would have been an “extraordinary bold” (Rose 2003, 57) endeavour. Micale similarly recognises the influence of neuroscience on modern biological psychiatry in creating a manifold of psychiatric subfields, including “neuroanatomy, neurophysiology, neuropathology, neuropharmacology, neurochemistry, neuropsychology, and neuroendocrinology” (2000, 337). The influence of these sciences has created Rose’s “neurochemical reshaping of personhood” (2003, 59): “a way of thinking” (2003, 57) that not only renders the understanding of illness through conceptions of the brain, but also entangles the brain with notions of “what humans are or should be – that is to say, specific norms, values, judgments” (2003, 59).

### ***‘Uncontainable’ schizophrenic symptoms***

The “specific norms, values, judgments” (Rose 2003, 59) of biomedicine are reflected in psychiatric understandings and treatments of schizophrenia. In this sense, conceptualisations of schizophrenia reflect the prevailing scientific and medical context of the time. Pervading the way in which contemporary schizophrenia is perceived, biomedicine posits schizophrenia as a fundamental disturbance in neural chemistry, a ‘brain imbalance’ of ‘uncontainable’ symptoms.

This mirrors the original constructions of schizophrenia at the turn of the twentieth century, in which Kraepelin (1899) and Bleuler (1915) espoused the organic causes of dementia praecox (later relabelled as schizophrenia). Although my history of modern psychiatry establishes the reclamation of the mind in the middle of the twentieth century, these conceptualisations of schizophrenia have

nonetheless survived into the modern era. The work of these early psychiatrists “continues to operate with force in contemporary psychiatric taxonomies” (Martin 2007, 18).

The oscillation between “brainlessness” and “mindlessness” provides a useful metaphor for describing the history of modern psychiatry, but it would be crude to characterise modern psychiatry as entirely focussed on the brain to the exclusion of all other considerations. Instead, modern psychiatry encompasses and incorporates both psychodynamic and biomedical approaches. Psychodynamic understandings conceive mental illness as a “continuum of reactions” (Rogler 1997, 10) to social problems and personal stresses, and is closely associated with Freudian psychoanalysis; the biomedical approach, on the other hand, “envisages life at the molecular level” (Rose 2007, 5). Luhrmann (2000) explores the tensions between these two models of psychiatry in her book, *Of Two Minds*, arguing that Cartesian dualism continues to be deeply embedded within modern psychiatry. This is owed, Luhrmann argues, to the “fundamental division between mind and body that our society, for all its sophisticated caveats, still endorses” (2000, 8). Instead of a homogenous discipline, Blackman describes contemporary psychiatry as a “loosely assembled set of practices” (2001, 2).

Despite the adoption of Kraepelin’s and Bleuler’s early works by ‘brain-enthusiasts’, the construction of schizophrenia remains controversial. Schizophrenia is characterised as the most philosophically and scientifically contentious (Bentall 1992) and the most enigmatic (Sass 1992) of all modern medical conditions. A major controversy is the difficulty in defining the condition:

‘hard facts’ or discoveries about schizophrenia are difficult to identify. The multiplicity of theories proposed to account for schizophrenic behaviour itself suggests a substantial degree of uncertainty about the nature of the hypothesized disorder. (Bentall 1992, xiv)

As highlighted by medical anthropologists, the biomedical construction of schizophrenia also fails to recognise the European and North American intellectual

and cultural milieu in which it has arisen (Barrett 1996): indeed, culture is integral to the experience of schizophrenia in the timing and type of onset; symptom formation; clinical diagnosis; gender and ethnic differences; the personal experience of schizophrenic illness; and social response, support, and stigma (Jenkins & Barrett 2004, 6-7). With his clinical and anthropological experience, Barrett incorporates understandings of culture into definitions of schizophrenia to posit it as an “historically constructed category that captures, constitutes, and shapes reality” (1996, 179).

These considerations have led to cross-disciplinary philosophical approaches to schizophrenia. The establishment of the journals, *Culture, Medicine and Psychiatry* (in 1977) and *Philosophy, Psychiatry & Psychology* (in 1994), and the book series, *International Perspectives in Philosophy and Psychiatry* (in 2003) highlight the interest in thinking about psychiatry (particularly schizophrenia) within a broader framework. This reflects psychiatry’s long history of engagement with phenomenology (Barrett 1996), and early cultural psychiatrists were particularly interested in being simultaneously trained in psychiatry and phenomenology.

### ***Madness and personhood***

Despite the putative framing of schizophrenia within the tradition of objective medicine, constructions of schizophrenia align with broader Western constructions of madness. Sass alludes to the way in which schizophrenia is “the quintessential form of madness in our time” (1992, 13). The positive and negative symptoms of psychiatric definitions of schizophrenia reference modern concepts of madness as fragmented and transgressive. Positive symptoms are often associated with hallucinations, delusions, and what is termed as ‘disorganised’ behaviour and speech (Shen 1999), and so named because these symptoms comprise of active behaviours and actions. Negative symptoms, on the other hand, commonly include the passive symptoms of severe social withdrawal, inactivity and apathy (Shen 1999). Visual and auditory hallucinations are perceived as crossing bodily borders.

In her ethnographic work with people with schizophrenia, Corin recounts experiences of schizophrenia as “an excess of signifiers, sensations, and meanings that escape order and coherence, and to a blurring of boundaries that creates a deep sense of confusion and uncertainty” (2007, 302).

The excessiveness associated with schizophrenia contravenes assumptions about bodies and boundaries. The experience of gravity for one participant, George, is profoundly distorted during psychosis: gravity disrupts and violates experiences of time and space. Gravity, for George, can become “accentuated”, becoming a “really quite violent ... powerful force”. The borders of George’s body is intruded upon when showering, for example, and water drops penetrate George’s body with the spatiotemporal force that contradicts common-sense understandings and unsettles bodily boundaries.

Drawing on Western concepts of personhood and metaphors of order, ‘the schizophrenic’ is conceptualised as failing to achieve Western ideals of progress, productivity and coherence, and is deemed to be inherently flawed (Barrett 1996; Jenkins & Barrett 2004). For Barrett, schizophrenia is:

more than a biological disease or a sick role. It is culturally defined as a basic flaw in the core attributes of personhood. The patient with schizophrenia becomes a fundamentally diminished person ... In the popular imagination, as in psychiatric thought, schizophrenia still implies an incurable disintegration of the person. (1996, 216)

These representations of schizophrenia as disordered and fragmented perpetuate Western notions of failed containment and personhood. Lovell’s ethnography of homeless people living with schizophrenia similarly observes the “lack of distinction” (Lovell 1997, 362) – or, loss of containment – in the experience of schizophrenia. People with schizophrenia experience a “far more radical loss” (Lovell 1997, 356) of identity than people with bodily illnesses because of the way in which schizophrenia blurs one’s sense of self (Lovell 1997).

This fragmentation of bodily experiences is mirrored in the loss of containment of time, space and social/personal identity. As well as crossing notions of bodies, the experience of schizophrenia flouts ordinary understandings of time and space. Experiences of positive and negative symptoms simultaneously expand, constrict and disintegrate spatiotemporalities, contributing to the “alienation, estrangement, and incomprehensibility that often characterize schizophrenia” (Lovell 1997, 355).

Estroff alludes to the ways in which schizophrenia “may overtake and redefine the identity of the person” (1989, 189), and indeed experiences of schizophrenia come to represent and stand for the person with schizophrenia. In her classic ethnography of the lives of people diagnosed with schizophrenia, Estroff explores the relationship between self, subjectivity and schizophrenia to argue that schizophrenia is an “*I am illness*” (1989, 189, *original emphasis*), demonstrating how the blurring and disrupting nature of acute stages of schizophrenia unsettle one’s sense of self, of ‘who I am’.

In effect, the experience of schizophrenia as fragmented and disjointed render people with schizophrenia as fragmented and disjointed:

Becoming a schizophrenic is essentially a social and interpersonal process, not an inevitable consequence of primary symptoms and neurochemical abnormality ... The point is that there are simultaneous, equally influential neurophysical, social, and personal processes at work. Within this conceptual framework, chronicity is a transformation of a prior, enduring, known, and valued self into a less known and knowable, relatively recent, devalued, and dysfunctional self. (Estroff 1989, 194, *original emphasis*)

## **Antipsychotic medication and the containment of schizophrenia**

Despite the breadth and variety of understandings of schizophrenia, the discovery of antipsychotic medications in the second half of the twentieth century has

strengthened psychiatry as a branch of biomedical science, and schizophrenia as a brain disorder. Along with the repudiation of psychoanalysis, Shorter's history of psychiatry shows that "the other wind that carried psychiatry into the biological era was drug therapy" (1997, 246). In their "anthropology of pharmaceuticals", Van der Geest and colleagues draw attention to the entanglement of biomedicine and pharmaceuticals: "Medicines are tangible, usable in a concrete way ... Medicines thus fit logically into biomedicine and most other medical traditions. Practicing medicine, after all, is the art of making dis-ease concrete" (Van der Geest *et al* 1996, 154). This is a two-way process: not only did developments in drug treatments bolster the biological orientation of psychiatry, but a biomedical approach provided fruitful ground for the development of new medications to treat "the broken brain" (Kleinman 2004, xv).

In his overview of the pharmaceutical industry, Goodman describes how, at the turn of the twentieth century, pharmaceutical companies were very different to what they are today: "most pharmaceutical companies were very small, did little or no research and development, prepared bulk therapeutics based largely on botanicals and were marginal to society's health concerns" (2000, 141). Now, these same pharmaceutical companies are cumulatively known as Big Pharma: "giant corporations and the darlings of Wall Street" (Healy 2004, 2). Indeed, the pharmaceutical industry is "big business" (Rose 2003, 57) and Moynihan and Cassels in their book, *Selling Sickness*, estimate it to be a \$500 billion dollar industry (2005, ix).

Money imparts influence, and pharmaceutical companies influence the perceptions and understandings of physicians, the experiences of those seeking treatment, and the broader medical and psychiatric modes of thought. In his self-described "auto-ethnography" about his career in the pharmaceutical sector, Matheson (2008) worries about the conflation of commerce, medicine and science in modern times, and calls for an "International Standard of Integrity in Science". The respective motivations of commerce (profit), medicine (health) and science (truth) are

inherently contradictory (Matheson 2008). Moynihan and Cassels agree, arguing that the proliferation and expansion of the pharmaceutical industry is “literally changing what it means to be human” (2005, x). Conrad (2005) reconceptualises his important work on medicalisation to coin the term, “biomedicalisation”, recognising the role that biotechnology and the pharmaceutical industry has had on what is deemed ‘normal’.

Although the contribution of antipsychotics to the pharmaceutical sector cannot be overestimated, the history is not a straightforward account. As a psychiatrist involved in the development of antipsychotic medications, Hippus characterises the discoveries as a “combination of paradoxes, luck and unfortunate incidents” (1989, S3). Similarly, the history of these developments are described as “a long and torturous course, often based on chance findings” (Shen 1999, 407) and based on a “mixture of ideas, hypotheses – which often even proved to be erroneous – luck [and] serendipity” (Jacobsen 1986, 142).

Despite antipsychotic medications serving “as important, albeit indirect, evidence of schizophrenia’s *physical substrate*” (Lehmann & Ban 1997, 152, *my emphasis*), the terminology and discovery of the medications has generated significant controversy. Described as “close to a penicillin of the mind” (Healy 2004, 343), the original antipsychotic, chlorpromazine, was discovered in the 1950s with the propensity for decreasing psychosis. Although effective in the treatment of psychosis, chlorpromazine failed to alleviate the negative symptoms associated with schizophrenia (notably, withdrawal and apathy), and produced what is clinically known as extrapyramidal symptoms (a cluster of symptoms that describe Parkinsonian-like movement disorders). Historian Crilly describes how this second problem contributed to the “widely accepted conclusion that, in order for a drug to be a ‘true’ antipsychotic, it had to cause these side effects” (2007, 41).

The discovery followed a “flurry of scientific activities” (Crilly 2007, 40) within the pharmaceutical industry, and the newer antipsychotic, clozapine, was soon



discovered in 1958. However, clozapine did not cause extrapyramidal symptoms, and was therefore not considered to be an effective antipsychotic. It would not be for another 30 years that clozapine would be recognised for its treatment capabilities; the release of clozapine into the pharmaceutical market in 1990 is described as a “stellar success” (Crilly 2007, 50) and as having “changed the face of psychiatry” (Crilly 2007, 39).

Chlorpromazine is commonly referred to as a first generation antipsychotic, and clozapine as a second generation antipsychotic. Medications like clozapine are described as ‘atypical antipsychotics’; the association of atypicality with the second generation antipsychotics was intended to differentiate it from its earlier incarnation, emphasising its supposedly greater efficacy and lower propensity for extrapyramidal side effects. However, the term has received criticism within and outside the medical establishment: psychiatrist Healy considers the “buzz term” (2009, 16) to be “clinically and scientifically meaningless” (2009, 16).

Antipsychotics are also broadly referred to as ‘neuroleptics’, ‘tranquillizers’, ‘major tranquilizers’, ‘deturmoilizers’ and ‘anti-schizophrenics’ (Shepherd 1994, 94). The use and proliferation of these terms were constructed so as to signal to the broader medical community that the medications were fundamentally different to the previously-used sedatives. Neuroleptic literally means “nerve seizing” (Healy 2009, 9) or “to grasp the neurone” (Shepherd 1994, 93), further demonstrating the psychiatry profession’s allegiance to the biomedical framing of the brain. The diversity of the language also highlights “how little the fundamental action of these drugs was understood at that time” (Jacobsen 1986, 139). Despite the accidental nature of these developments and the controversy surrounding their terminology, the discovery of the first and second generation antipsychotics is considered to be the “engine that drove change” (Healy 2004, 33) with respect to the modernisation and professionalisation of contemporary psychiatry.

Mirroring the construction of schizophrenia as uncontained and disordered, antipsychotics are conceptualised as having capacity to contain the ‘uncontainable’

brain. Antipsychotics sedate the hallucinations and speeding thoughts common in experiences of psychosis; as Desjarlais explains, antipsychotics “worked to integrate, reconnect, rebalance, clarify, steady, and calm a person's innards or faculties” (1997, 119). Constructions of containment are embedded in Western metaphors of healing and transformation (Etkin 1992; Kirmayer 2004; Lévi-Strauss 1963). Lévi-Strauss (1963) identifies the metaphoric space that is mapped onto the bodily experience through the ritual of healing. Antipsychotics, as a form of healing, change the body from ill to well, and from afflicted to healed (Kirmayer 2004).

In this sense, antipsychotics transform the bodily experience of schizophrenia from a loss of containment to the bodily experience of bounded and contained thoughts. The use and acceptance of antipsychotics highlight how antipsychotic medication represents a “healing practice [that] is part of a larger system of values or a way of life” (Kirmayer 2004, 44) that is taken-for-granted within broader society. The “larger system of values” (Kirmayer 2004, 44) is the representation of schizophrenia as disordered and of antipsychotics as containing, demonstrating the preoccupation of containment within Western thought.

Etkin (1992) and Kirmayer (2004) attend to the cultural construction of pharmaceuticals, and draw attention to the complex experience of medication-taking. As Kirmayer explains:

The understanding of illness and healing within biomedicine tends to be narrowly conceived in terms of physiological processes and does not always attend to powerful psychological, social, moral and political dimensions of medical interventions. These wider dimensions have demonstrable physiological effects as well as involving psychological and social processes, which are important in their own right for individual well-being and recovery from illness. (2004, 46)

Incorporating psychological and social processes into extended understandings of antipsychotics challenges conventional psychiatry. The concept of “personal medicine”, first coined by psychologist and qualitative researcher Deegan (2005),

privileges the activities that people with mental illnesses do – rather than something people take – to obtain wellness and achieve resilience. For Deegan, resilience is defined by the “capacity of people who are faced with adversity, to adapt, cope, rebound, withstand, grow, survive, and define a new sense of self through situations of adversity, including psychiatric disability” (2005, 29). Resilience is achieved through strategies of self-initiated, non-pharmaceutical, personal medicine: self-care activities that give “life meaning and purpose, and that ... raise self-esteem, decrease symptoms, and avoid unwanted outcomes such as hospitalization” (Deegan 2005, 29). Work, or activities that resemble work, serve an important role for people with schizophrenia in providing a sense of identity and alleviating the stigma attached to mental illness and unemployment: “‘work’ becomes that of restitution or compensation for a stigmatized identity” (Lovell 1997, 358). The dominance of pharmaceutical approaches thus overlooks the cultural and social dimensions of taking psychiatric medications: that is, “the over-fetishization of pharmaceuticals aimed at repairing the body can miss the social principle of healing altogether” (Petryna & Kleinman 2006, 9).

### ***The marking nature of ‘side’ effects***

The visible side effects of antipsychotics expose the “deficiencies and differentness” (Estroff 1981, 109) of those who take them. In contrast to the extrapyramidal symptoms commonly experienced in first generation antipsychotics, Bentley (2010) catalogues a broad suite of side effects associated with second generation antipsychotic medication, ranging from spitting, dry mouth and drooling, to twitching, restlessness and rapid heartbeat. In their study on the subjective experience of schizophrenia, Jenkins and her colleagues (2005) state that 90.8% of those who report an improvement in their experience of schizophrenia as a result of second generation antipsychotics also describe at least one distressing side effect. Weight gain, drooling and tiredness, respectively, were the three most commonly reported side effects perceived to be the worst amongst the participants (Jenkins *et al* 2005, 219). Indeed, participants in Jenkins and Carpenter-Song’s

work describe the common “catch 22” (2008, 400) dilemma: the choice between ‘becoming fat’ on antipsychotics or cease taking the medications whilst remaining ‘crazy’.

The impact on external appearance is a major consideration in the acceptance of antipsychotics (Seeman & Seeman 2012). However, the uniquely rapid nature of the weight-gain side effect represents more than a concern about appearance: the weight poses as a physical marker to others about difference and identifies people with schizophrenia. Along with considerations of medications’ efficacy, medications are often accepted on how well they induce the feeling and look of ‘normality’ (Carrick *et al* 2004; Seeman & Seeman 2012). For many people, the distinguishing nature of weight gain fails to achieve the “liveable-with” threshold (Carrick *et al* 2004, 28): the test that takes into account the whole experience of antipsychotics; “a trade-off between the benefits the drug confers and the risks it entails” (Healy 2009, 2). This reveals a complicated picture of why people choose to take, and not take, medications.

For people taking antipsychotic medication, side effects and symptoms are not experienced and conceptualised as separate issues (Carrick *et al* 2004). Despite side effects being understood as ‘side’ issues within psychiatry, when we think about medications as “symbolic interventions” (Kirmayer 2004, 37), we begin to understand the experience of taking medications as a holistic experience (see also Etkin 1992; Metzl & Riba 2003). The construction of side effects aligns with the biomedical paradigm, requiring all medications to have a singular “primary effect” (Etkin 1992, 100) which is privileged above all other effects, despite the multiplicity of effects found in all medications. The categorisation of “primary” and “side” effects is apportioned to the “effects of drugs ... [that] we wanted and the side effects [that] were all unwanted” (Weatherall 1990, 275).

Despite the “reassuring” (Weatherall 1990, 275) biomedical framing of ‘side effects’, weight gain is not experienced as a ‘side’ experience. It is a complex

phenomenon that interacts with notions of health, social stigma and lived experiences, and some research demonstrates the connection between antipsychotic-induced weight gain and the decision to stop taking antipsychotics (Seeman 2011). The weight-gain side effect establishes the paradox of psychiatric medications: antipsychotics treat psychosis to contain experiences that transgress bodily boundaries so that people can pass as 'normal', but antipsychotic side effects mark people as different so as to reveal their identity as 'crazy' (Estroff 1981). The weight-gain side effects of the newer atypical antipsychotics further extends this paradox: the unique nature of the antipsychotic-induced weight as rapid exposes difference.

## **Differing approaches to obesity and fatness**

The distinctive rapidity of this type of weight gain contradicts medical and popularist accounts of weight gain as something that "creeps on" (Crossley 2004, 242). Antipsychotic-induced weight gain is distinguishable because of its rapid nature, and is differentiated from what one might consider as ordinary weight gain. The time-period over which antipsychotic-induced weight gain occurs contravenes taken-for-granted assumptions about gradual weight increases: one participant gained 70 kilograms over an eight-month period after first taking antipsychotic medication. The weight gain not only amplifies the distorted experiences of time that are commonly experienced in schizophrenia, but also intensifies the loss of bodily boundaries and distorted experience of space. One of the participants in my study describes how people who take atypical antipsychotics are easily sighted because of how the weight gain changes body shapes and compositions:

I'm just seeing it over and over and over again. People go onto a particular drug or they change from one drug to another, and you know, a few weeks and a few months down the track, you can just see this really observable weight gain, where people are sort of ... puffing out, you know. They've got pudgy cheeks and sort of bulging arms. I think there's a particular look to weight that's been gained quite quickly.

Unlike the involuntary bodily movements experienced in early incarnations of antipsychotic medication, the specific nature of weight gain created by atypical antipsychotics has become the new (visible) signifier of schizophrenia. As “fat cannot hide” (Stearns 1997, vii), the “pudgy” and “bulging” descriptions of antipsychotic-induced weight gain not only mark people with schizophrenia, but also demonstrate how the weight gain contravenes ordinary understandings of time and space.

These articulations of weight gain contradict how weight and obesity are broadly conceptualised within medical and public health discourse. Since the last decade of the twentieth century, concern for what is referred to as the ‘obesity epidemic’ or the ‘obesity crisis’ has intensified in the popular media and in medical accounts (Lupton 2012). Obesity researchers, writing from as diverse life science fields as epidemiology, biology, nutrition, life course and health promotion, draw attention to the reputed health crisis and devastating health consequences of obesity. Writing within the dominant biomedical framework, these researchers rely on a number of assumptions to position obesity as an urgent and serious global problem. Obesity is understood as being on the rise; as having negative health implications at an individual and societal level; and as being preventable through the individualistic strategies of diet and exercise and reversible through weight loss strategies (which are endorsed as always being beneficial) (Aphramor 2005).

Body fat is pathologised, and obesity is conceptualised as an “*actual disease*” as well as a “*risk factor for disease*” (Paradis *et al* 2013, 152, *original emphasis*). Obesity is both temporalised and spatialised. Notions of risk and riskiness highlight the temporal connotations of obesity (Evans 2010), and the classification of obesity as a disease (when a Body Mass Index (BMI) is calculated to exceed 30) reflects the spatialisation of the classification system. This score represents population-level correlations with potential future illnesses (Gard & Wright 2005), including coronary heart disease, diabetes and some cancers. As well as these adverse disease outcomes, obesity is associated with impaired physical functioning,

reduced quality of life and poor mental health (Kawachi 1999). Treatment options pivot around the individual, and individuals are implored to lose weight by behaviour modifications: the “Big Two” (2006, 1585) is a term used by Keith and colleagues to problematise the “hegemony” (2006, 1585) of dietary and activity considerations in obesity medicine.

As precluded in the Introduction to this thesis, not all researchers share the same assumptions about obesity, and critiques about obesity and its causes can be found both within and outside the biomedical paradigm. A number of burgeoning fields in nutrition, dietetics and health promotion challenge the pathologised focus of obesity research and initiatives, including those representing critical weight science (Bacon & Aphramor 2011), critical dietetics (Aphramor *et al* 2013) and the Health At Every Size (HAES) approach (Robison 2005). These writers draw on scientific evidence to refute the weight-centred framework of Western medicine, and advocate for weight-neutral and non-dieting approaches to health.

Supporting a health-focussed approach, writers in these fields use their insider status as members of the medical community to challenge assumptions about weight. Puhl and Heuer (2010) dispute the role of weight stigma in reducing obesity rates and improving health, and point out the significant physical and psychological negative impacts that weight stigma has on obese individuals. Weight stigma, not obesity, is “a priority for public health” (Puhl & Heuer 2010, 1019). Some researchers expose the futility of weight loss through dieting (Aphramor 2005; Bombak 2014; Mann *et al* 2007; Tomiyama *et al* 2012): indeed, drawing on the low success rate of weight loss attempts, Aphramor labels medicine’s continued focus on weight loss as “simply unethical” (2005, 317). Even when it is achieved through dietary strategies, this weight loss – and the quest for weight loss – causes significant harm (Harrington *et al* 2009). Research shows that dieting and weight cycling pose serious adverse health effects, causing some authors to question the ethical beneficence and nonmaleficence of dieting recommendations (Bacon & Aphramor 2011).

A “wellbeing oriented paradigm” (Provincial Health Services Authority 2013) is offered as a safe and feasible weight-loss alternative, incorporating both scientific and “experiential knowledge” (Aphramor *et al* 2013, 94). Instead of advocating for a dietary weight-loss approach, a report produced by the Provincial Health Services Authority (PHSA) of British Columbia understands there to be “no simple fixes” (PSA 2013, 41) to shifting the current health paradigm “from weight to wellbeing” (PHSA 2013). Such a paradigm incorporates features of the HAES movement to re-frame health away from pathology. HAES is a “weight-neutral, nutrition- and physical activity-based” (Bombak 2014, e60) program. The tenets of this approach are size acceptance and self-acceptance; fun and physical activity; and ‘intuitive’ or ‘mindful’ eating (Robison *et al* 2007).

The HAES movement highlights the usefulness of Banwell and her colleagues’ description of the varied explanations for obesity as a “smorgasboard” (2005, 568). The metaphor of a “smorgasboard” highlights the tensions and contradictions between medical experts about the cause and best treatment options for obesity. Expert opinion diverges from the causal energy in/energy out equation of most public health initiatives, to the “fatuous myths” (Aphramor 2005, 332) of critical dietetics.

### ***Critical fat studies***

Critical fat studies extends these understandings of fatness and obesity, further enriching and elaborating on the “smorgasboard” of obesity explanations. Contesting the assumption that fatness is synonymous with sickness and ill-health, critical fat scholars not only challenge the clinical domain of obesity, but also conceptualise it as a social and cultural construct. In this sense, some see fat studies as having roots in identity politics, in that it “questions and problematises traditional understandings of obesity and draws upon the language, culture and theory of civil rights, social justice and social change” (Cooper 2010, 1020).



Critical fat scholarship employs genealogies of fatness to highlight its ahistoricity, arguing that fatness can almost exclusively be explained by moral injunctions (as opposed to health concerns). Stearns' (1997) "fat history" demonstrates the modern concern for weight: it is "not timeless; its origins are modern and can be quite precisely traced" (Stearns 1997, ix). An historical and genealogical analysis sheds some light on the factors that have helped to establish and perpetuate the problem of fat bodies, which is useful in tracing contemporary understandings of fat (Stearns 1997; Braziel & LeBesco 2001; LeBesco 2010). Associations can be found between the "new modern code" (Stearns 1997, viii) of fatness and the older "preachments of moderation and the Christian attack on gluttony as sin" (Stearns 1997, viii). In their book entitled *Bodies out of Bounds*, Braziel and LeBesco understand the modern concern for fatness to have arisen from the "pious Christian ideal of beauty ... [and] the humiliation of the flesh" (2001, 27).

These fat theorists draw attention to the social construction of fatness, highlighting the relationship between the individual and society. Some writers draw attention to the broader historical and cultural context in which these anxieties about fatness have arisen: the beginnings of contemporary consumerism (Rayner 2005; Stearns 1997). In a society burgeoning with "desirable commodities" (Bordo 1990, 96), new ideas about restraint have been created as a response to these changes, privileging dominance over the body through self-control and constraints on eating and body shape.

This history illustrates the connection between fatness and boundary infringements; "out of bound" (Braziel & LeBesco 2001) fat bodies transgress moral and social conditions. Representations of fatness as uncontained, uncontrolled and disordered continue to exist in contemporary Western society. In her anthology on fat, Lupton (2012) associates fat bodies with connotations of grotesque, culturally repellent bodies, drawing on earlier influential feminist works (Bordo 1990; Kristeva 1982). Grotesque bodies are the physical manifestation of internal leakiness and

permeability, and fat flesh is culturally marked as “contaminating, soiling and revolting in its lack of containment, its oiliness and propensity to spread over boundaries” (Lupton 2012, 57).

### ***Collapsing the hierarchies in obesity research***

The perspective from which one writes determines whether the body is characterised as fat or obese. Although the locus of such research concerns the same body, it is written about in very different terms with different methodologies. In mapping out these different discourses, Cooper (2010) outlines two distinct camps: those who biomedically frame obesity (the obesity ‘alarmists’) and those who take a more social approach to fatness (the obesity ‘sceptics’). Cooper surmises that what has arisen is “a distressing polarisation between those who wish to preserve dominant obesity discourses and those who wish to dismantle them” (2010, 1028).

Gard (2011) similarly sets up a dichotomy between the fatness/obesity camps, arguing that the failure of social constructionists to engage with biological explanations creates limitations. Gard places the responsibility of bridging the fatness/obesity divide with those working in the fat studies sphere to “be more scientifically literate in order for the excesses of sciences to be managed and tamed” (2011, 399); fat scholars must “be able to speak more than one language” (Gard 2011, 399). Crossley (2004) points out the inherent contradiction of what some writers call the “body-conscious society” in which we live; as he challenges: “How could there be an obesity crisis in a society as conscious of the body and as concerned with thinness as ours is alleged to be?” (2004, 223). This question exemplifies the dangers of fatness scholars and obesity researchers “agree[ing] to stay off each other’s turf” (Gard 2011, 400): the two camps lack the mutual language to speak between and with one another. This may lead to the flouting of fruitful areas of investigation, like Crossley’s (2004) example of body-

consciousness and health consequences, and my example of antipsychotic-induced weight gain.

Writing in the *Boston Globe* (and, later, in the first edition of the *Fat Studies* journal), clinical psychologist Caplan (2010; 2012) exposes what she terms ‘the elephant in the living room’. The metaphorical elephant, despite it being “right in front of one’s eyes” (2012, 92), is the overlooked “cause-effect relationship between [psychiatric] drugs and poundage” (Caplan 2012, 93). Caplan draws attention to the rise of weight-inducing psychiatric prescriptions to explain increased rates of obesity in the general population, and is puzzled by the “near blackout” (Caplan 2012, 92) of public health, academic and popular discussion about this phenomenon. Although much has been written from the fatness and obesity research camps, the side effect profile of psychiatric medication has been absent from both groups of writings: it is the proverbial elephant. Embodiment theories of containment and transgression help to reconcile these camps, offering an embodied analysis of antipsychotic-induced weight gain.

## **Embodiment and the transgression of bodily boundaries**

Embodiment scholarship extends understandings of schizophrenia and fatness, and provides the theoretical foundation for conceptualising these experiences as transgressing bodily boundaries. ‘The body’ in embodiment theory deconstructs taken-for-granted understandings of bodies as fixed and concrete. This thesis conceptualises the body as “transgressive” (Williams 1998); the body is fluid, changing, partial, penetrable and relational. Like contemporary theories of time and space (Brazier 2006; Dodgshon 2008; Rodemeyer 2006; Toombs 2001a & 2001b), the body similarly transgresses and crosses boundaries.

## ***Theories of embodiment***

Australian feminist philosopher Grosz identifies the body as being “a conceptual blind spot” (1994, 3) in Western traditional philosophical thought. Since the beginnings of the “sociology of the body” that emerged in the 1980s, there has been a surge of theoretical interest in the body. A number of factors have influenced this growing academic interest, including the rise of second wave feminism; critical attention given to the successes and failures of Western medical science; an increasingly ageing population throughout the Western world; and a shift in the structure of advanced capitalist social systems (Shilling 2012). Those writing about the embodied body hail from the diverse academic backgrounds of feminism, anthropology, sociology, psychology, cultural studies and queer studies, though commonly share the theoretical lens of postmodernism. The critical uniting principles amongst these theorists and researchers is their commitment to challenging the binary of Cartesian duality that has rendered understandings of the body in simplistic and fixed terms.

In the trajectory of body studies, some scholars point to the “absent presence” (Shilling 2003, 10; see also Leder 1990) of the body in historical and contemporary Western thought. Such a “blind spot”, argues Grosz (1994), has come about as a result of the long history of the body as being understood only within the dichotomous terms of mind and body. This ‘mind/body split’, as it is termed, is attributed to the legacy of Descartes’ 1637 philosophical proposition, “I think, therefore I am”. Privileging the “I think” process, the mind is elevated to the definition of the person, and the body is relegated as merely an instrument in which the mind is located. The body is oppositional and secondary to the valorised mind.

Feminists and philosophers have resisted the Cartesian duality within Western knowledge. The “bifurcation of being” (Grosz 1994, 3) affords the mind as capable of observing and making judgements not only about the body, but also the surrounding world (nature). Grosz’ (1994) important work on dichotomies reveals

how all dualisms create hierarchies, polarise ideas and privilege terms over one another. The unprivileged term then becomes the “suppressed, subordinated, negative counterpart” (Grosz 1994, 3) and is characterised as the “absence or privation of the primary term” (Grosz 1994, 3). Within the mind/body dichotomy, the mind has come to occupy the privileged space and the body has been given a lesser status as irrelevant and suppressed. Other dichotomies fall in line, including the association of ‘man’ with reason and the mind, and the correlating subordination of ‘woman’, nature and body (Brook 1999; Grosz 1994).

The legacy of Cartesianism and the mind/body split endures throughout contemporary medical and psychiatric theory and practice. The material corpse, long used as “a methodological tool and a regulative ideal” (Leder 1990, 146), has resulted in “objectivist, depersonalized” (Leder 1990, 147) medicine. Cartesianism compartmentalises the body into discernible and discrete body parts, which is mirrored in the specialisations of modern medicine – for example, cardiology is the branch of medicine that deals exclusively with the anatomy, physiology and diseases of the heart; dermatology is the speciality of skin; and ophthalmology is the speciality of the eye.

In simple terms, constructions of schizophrenia draw on notions of the damaged brain (the deficient body). Although the brain is constructed as a body part, the brain affects the rationality and reason implicit with the mind; “the broken brain” (Kleinman 2004, xv) distorts perceptions of reality. Therefore, despite representations of psychosis infringing Western notions of personhood, schizophrenia continues to be constructed as contravening “the supposedly atheoretical classificatory systems of ... [modern] psychiatry [and] denies the subjectivity of persons experiencing schizophrenia” (Lovell 1997, 356).

Embodiment, instead, conflates the space between the mind and the body, and challenges binary modes of Western thought (Blackman 2010; Shilling 2012). The body is grounded in the experience of embodiment, and Csordas’ (1994)

philosophical insights reveal how the Cartesian legacy has privileged the representation of mind and body. Csordas (1994) offers critiques of representation to show the limitations and failures of representation in understanding the body. Csordas offers “something non-representational” (1994, 10) to capture the “existential immediacy” (1994, 10) of the experience of the body. Shilling (2012) draws on phenomenological tradition to demonstrate how Csordas’ “being-in-the-world” (1994, 10) provides robust insight into the conditional body.

This “experiential understanding of being-in-the-world” (Csordas 1994, 269) moves understandings of schizophrenia and fatness away from objectivist medical approaches that has relegated the symptoms as exclusively within the domain of the brain or the body. The experience of embodiment goes beyond representations to interrogate how bodies are lived and experienced; this thesis, likewise, goes beyond representations to seek understandings of the lived embodied experience of madness and fatness. Such an exploration embraces the body as fluid and permeable, and aligns with Braidotti’s classic proposition that “the body has turned into many, multiple bodies” (1994, 19). Bacchi and Beasley draw attention to the interrelationship between citizenship and bodies, and offer the concept of “social flesh” to capture the complex “vision of interacting, material, embodied subjects” (2002, 330). Such a “fleshly, social intersubjectivity” (Bacchi & Beasley 2002, 327) avoids the binary of bodies being subject to biology (“controlled by body”) and bodies being controlled by citizens (“control over body”) (Bacchi & Beasley 2002, 327).

Embodiment scholarship thus seeks out “the fleshy situatedness of ... modes of living” (Mol & Law 2004, 43); the embodied body is “highly plastic and rich in the possibility of intercorporeality” (Shildrick 2010, 12). The body that this thesis is interested in is encapsulated by Grosz’s important contributions to corporeal feminism:

the body ... [is] a discontinuous, non-totalisable series of processes, flows, energies, speeds and durations, [and] may be of great value to feminism’s

attempt to re-conceive bodies outside the binary oppositions imposed on the body by the mind/body, nature/culture, subject/object and interior/exterior oppositions. (1994, 164)

### ***Metaphors of bodily containment and transgression***

As experiences of madness and fatness contravene and violate (social and bodily) boundaries, embodiment theory is useful in theorising the inside/outside dichotomy and in critiquing the notion of containment. The mind/body split has broad-reaching implications for other dualisms fundamental to Western thought and to the experiences of schizophrenia and fatness, including the self/Other dichotomy. The notion of a contained, bounded body is intimately connected to the understanding of selfhood in Western thought.

The concept of the “self-boundary” has arisen from one of the essential components of all dualisms: separation. All dichotomies rely on the assumption of separation and clearly bounded entities (Blackman 2008). The body achieves its status as a separate and unitary entity by the process of “Othering” (Blackman 2008, 48). As the body is the self, anything outside of the body is the Other; within this dichotomy, the body represents what it is to be whole (Mol & Law 2004). To be whole means to be separate, autonomous and have clear boundaries between the self and Other. As Shildrick describes in her essay on disability and corporeal fluidity, “To be a self is above all to be distinguished from the [O]ther, to be ordered and secrete, secure within the well-defined boundaries of the body rather than actually being the body” (1999, 79). Containment, in this sense, means discrete boundaries between interiority and exteriority, between self and Other.

Metaphors of containment are pervasive throughout Western society, and Lakoff and Johnson’s (1980) classic text on metaphorical framing posits the body as responsible for the prevalence of these metaphors: “metaphor”, argues Lakoff and Johnson, “is as much a part of our functioning as our sense of touch, and as

precious” (1980, 239). Metaphors are not only a linguistic figure, but also a “fundamental part of people’s ordinary thought, reason, and imagination” (Gibbs *et al* 2004, 1191). Bodies possess “embodied knowledge” (Johnson 1991), meaning that we come to understand and experience the world through the interactions and activities of our bodies. Contemporary writings of cognitive science have been instrumental in inserting bodies into metaphorical analyses of thought and language (Gibbs 1994; Lakoff & Johnson 1980; Lakoff & Johnson 1999; Kövecses 2000; Gibbs *et al* 2004), demonstrating the intrinsic relationship between bodies and metaphors.

Along with a number of concepts used to think about the body, such as machine, tool, instrument, intruder, military, vessel, property, and self-moving automaton (Blackman 2008; Grosz 1994), the body-as-container metaphor is particularly relevant to the notions of separation and individualism implicit in the mind/body split. As bodies and the self are conceptualised as containers, we impose boundaries and borders on everything else to make them “just as we are: entities bounded by a surface” (Lakoff & Johnson 1980, 25). The container metaphor has a number of important components: all containers are “gestalt structure[s]” (Lakoff & Johnson 1999, 32) that always comprise an inside, a boundary and an outside (Lakoff & Johnson 1999).

Ingold’s (2015) work on “blobs and lines” expands cultural constructions of containers and containment. For Ingold, the “very essence of sociality” lies in the connection with, and the “clinging” to others (2015, 3), something inherently impossible for “blobs”:

It is more usual to think of persons or organisms as blobs of one sort or another. Blobs have insides and outsides, divided at their surfaces. They can expand and contract, encroach and retrench. They take up space ... What blobs cannot do, however, is cling to one another, not at least without losing their particularity in the intimacy of their embrace ... [I]n a world of blobs, there could be no social life: indeed, since there is no life that is not



social – that does not entail an entwining of lines – in a world of blobs there could be no life of any kind. (Ingold 2015, 3–4)

Participants' descriptions of madness and fatness as heavied, and as I describe in Chapter 4, 'blob-like', shows the implications of these experiences: antipsychotic-induced weight gain reduces movement and sociality, rendering experiences to "no life of any kind".

Embodiment theory reveals the fallacy of the notion of wholeness; the bounded, separate and autonomous body is contrary to understandings of the embodied self. Contradicting Cartesian understandings of the body as bounded and whole, the body is understood to be inherently transgressive in nature. Characterised by their "transgressive potentialities" (Williams 1998, 63), bodies, body parts and bodily boundaries are "expanded and constricted" (Mann & Jaye 2007, 184). Bodies thus occupy the space "in transition ... in the marginal zones ... [and] a position of categorical ambiguity" (Hockey & Draper 2005, 47).

Those who fail to maintain an autonomous body governed by a rational mind present serious challenges to what is constituted as 'personhood' in traditional Western thought. People with schizophrenia epitomise the failure of achieving wholeness; experiences of schizophrenia render representations of self as divided and fragmented (Barrett 1996). Schizophrenia being an "*I am* illness" (Estroff 1989, 189, *original emphasis*) transposes the connotations of schizophrenia onto the identity of the person with schizophrenia. 'The schizophrenic', then, represents a disorder of the person "in which the parts disrupt and disorganize the whole" (Barrett 1996, 216). Goffman's classic work shows how stigma is manifested when someone is "not quite human" (1963, 5). People with schizophrenia carry with them the stigma of the failure to achieve 'wholeness' (and personhood). Scambler's (2006; 2009) extension of Goffman's work reveals the ways in which "stigma ... mark[s] and patrol[s] the boundaries of the social or symbolic order ... ultimately comprising a form of 'symbolic violence'" (2006, 279).

Similar connotations of disruption and fragmentation are found in notions of fatness. The fat body inscribes on the person the failure of the rational mind to achieve Western constructions of personhood. The mind fails to achieve control of the body: the fat body is thus the embodiment of the “inability to discipline one’s desires” (Lupton 2012, 52). In its representation of disorder and chaos, the fat body symbolises the failure of personal responsibility (Lupton 2012). As Lupton describes, “[f]at bodies are Other to the privileged contained and disciplined Self” (2012, 57). The thin body signals the achievement of health and attainment of rational control (Crawford 2006). In her work on the “meaningful social practice” of health, Crawford argues that the designation of being ‘healthy’ defines the self:

In a health-valuing culture, people come to define themselves in part by how well they succeed or fail in adopting healthy practices and by the qualities of character or personality believed to support healthy behaviors. They assess others by the same criteria. (2006, 402)

These conceptualisations align with embodied theories of corporeal transgression, which defy assumptions about bodily wholeness and inviolability (Slatman & Widdershoven 2010), especially Blackman’s (2010) work on bodily integrity that exposes the fluidity of the body. A significant body of work has used medical and bodily phenomena to explore experiences of transgression, including examples as diverse as reincarnated children (Gupta 2002), phantom limbs (Crawford 2013; Sobchack 2010), pregnancy and breastfeeding (Hockey & Draper 2005; Schmied & Lupton 2001; Young 1990), twins (Mann & Jaye 2007), hand transplants (Slatman & Widdershoven 2010), and disability (Lupton & Seymour 2000; Shildrick 1999; Shildrick & Price 1996; Toombs 2001b). These explorations of malleable bodily borders reveal the impossibility of such borders. Thinking through the body in such a way highlights the “fictional” and “fantas[tical]” (Johnston 2001, 5) nature of the body, and the way in which understandings of bodily integrity and boundedness are “immaterial” and “fanciful” (Crawford 2013, 3).

The bodily experience of breastfeeding offers insights into theories of liminality (Mahon-Daly & Andrews 2002; Schmied & Lupton 2001). Liminality provides the analytic language with which to speak about experiences that are at the edges and transitioning. In their qualitative study on breastfeeding, for example, Schmied and Lupton (2001) shows the destabilisation of bodies that are on the borders of multiplicity and singularity. Like my participants' experiences of weight gain, oftentimes breastfeeding involves a dramatic change in the appearance and feeling of the body, particularly with respect to one's breasts. Participants of Schmied and Lupton's study describe their newly-transformed breasts as "'strange', 'heavy' and sometimes painful, even excruciating" (2001, 242). Encapsulating the changed form and nature of the breastfeeding breast, Schmied and Lupton argue that "breastfeeding blurs or challenges the boundaries between mother and child, between self and Other" (2001, 243). Parallels can be drawn between the pregnant body in Young's (1990) pivotal work on pregnancy and the leaking breasts and breast milk in Schmied and Lupton's (2001) study: both symbolise the ambiguity between self and Other. As Young writes, "pregnancy challenges the integration of my body experience by rendering fluid the boundary between what is within, myself, and what is outside, separate. I experience my insides as the space of another, yet my own body" (1990, 163). In pregnancy, the Other is in the self.

Transgressive bodies and body parts "seep and flow" (Williams 1998, 68), stressing the impossibility of their containment. In his work on embodied transgression, Williams describes the way in which bodies "befuddle cultural categories based on purity, order and the solidarity of things" (1998, 68). People and things that are liminal are often positioned as dangerous and out of place. Ingold's (2015) "lines" offer an alternative to thinking about bodies as contained "blobs"; lines offer possibilities for movement, motion and bodies in flux. Unlike blobs, lines have "torsion, flexion and vivacity ... life" (Ingold 2015, 4), and their innate movement reflects their innate capacity for transgression. Such transgressive bodies and body parts transform and contradict "body laws" (Blackman 2010), especially taken-for-granted assumptions about time and space.

## Bodies and time and space

The interrelationship between time and space and bodies has only recently received critical attention. Traditionally, time and space have been positioned as a dichotomy within Western philosophy. In her text on the feminist and queer theorisations of time, space and bodies, Braziel (2006) demonstrates how time has remained the realm through which 'man' and the mind were conceptualised. This prioritises time over space as masculine and active (Rodemeyer 2006). Space, in this dualism, is associated with passivity, corporeality and the feminine, rendering space "erased ... subsumed [and] radically de-ontologized" (Braziel 2006, 113). Dodgshon's (2008) pivotal essay on the importance of space and time in human geography explains how this split came about. Drawing on Whitehead's early work on time, Dodgshon differentiates the "presentational immediacy" (1927, 21) of space compared to the way in which constructions of time needs to be developed through memory and observation (Dodgshon 2008).

In turning to the body, feminist scholars attempted to unsettle the time/space dichotomy by bringing critical attention to space. However, some theorists have challenged this move, arguing that it has disproportionately unbalanced the scales towards space, creating a body of work that is couched in a "timeless space" (Dodgshon 2008, 1). This has led to calls for the reintroduction of temporality into analyses of bodies (Rodemeyer 2006). In doing so, Rodemeyer (2006) argues that the simultaneously active and passive components of time will be revealed, dismantling binary conceptions of active/passive, mind/body, and time/space.

In line with the call to incorporate temporalities into all philosophical analyses is the increasing recognition that time and space are intimately connected – indeed, the two are so connected that Dodgshon describes them as "sticky concepts" (2008, 11). Anthropologist Munn's (1992) seminal treatise on the importance of time in anthropological research recognises the relationship between time and space, as well as the way in which the two impact on all aspects of the social experience.

Bringing together and granting equal status to the dimensions of time and space reveals the immediate relationship between time and space and issues of embodiment. Leder's (1990) classic theorisations of the "absent body" helps to strengthen the importance of integrating bodies, particularly transgressive bodies, into analyses of spatiotemporalities. To explain his concept of bodily absence, Leder posits that:

Insofar as the body tends to disappear when functioning unproblematically, it often seizes our attention most strongly at times of dysfunction; we then experience the body as the very *absence* of a desired or ordinary state, and as a force that stands opposed to the self. (1990, 4, *original emphasis*)

The body, argues Leder, is "forgotten in its seamless functioning" (1990, 127), but "comes to thematic attention" (1990, 127) during times of breakdown. Experiences of dysfunction render the body as *dys*-appeared: the body is directed away from its ordinary state of absence and instead *appears* during moments of *dys*function (Leder 1990). The body, contradicting assumptions about it as concrete and stable, comes to the fore when undergoing dysfunction.

Time and space, in contrast to assumptions about them as static and fixed, are likewise transformed by what is happening to the body. Extending Leder's (1990) theory, the dysfunctional body not only renders present the body, but also renders present perceptions of time and space. As Williams argues, "the very notion of transgression implies a form of bodily *dys*-appearance" (1998, 77). The spatiotemporal transgressions implicit in the experiences of madness and fatness therefore bring to the fore the body, as well as perceptions of time and space that are ordinarily experienced as 'absent'. Institutional time, or "clock time" (Elias 1992, 6), for example, is usually experienced as taken-for-granted. However, when a conflict arises between institutional and embodied perceptions of time, such as when experiences of rapid weight gain contravene ordinary conceptualisations of "creepy" (Crossley 2004, 242) weight gain, time is exposed and its inherent concealment (absence) is thwarted.

A growing body of experiential research shows how pain, illness and disability complicate experiences of time and space (Bendelow & Williams 1995a & 1995b; Honkasalo 1998; Paterson & Hughes 2012; Toombs 2001a & 2001b). In her essay on her lived experience of multiple sclerosis, Toombs establishes the body as the “spatial and temporal center around which the rest of the world is grouped” (Toombs 2001a, 6). Ascertaining the relationship between bodies and spatiotemporalities, Toombs (2001b) illustrates how the experience of her disability disrupts her perception and experience of time and space. Honkasalo’s (1998) exploration of pain offers examples into how the interrupted bodily experience of pain obstructs taken-for-granted understandings of time and space: “space and time are the main constituents of sufferers’ stories” (Honkasalo 1998, 37). Like participants’ experiences of schizophrenia and side effects, experiences of pain render experiences of time and space as “multiple and moving ... shifting and fluctuating ... but also expanding ... immense, without boundaries” (Honkasalo 1998, 36).

## Summary

This chapter exposes the long history of contested meanings around the definition of schizophrenia. Contemporary understandings of schizophrenia align with the dominant intellectual and medical milieu of the time, and I have shown that these conceptualisations influence how schizophrenia is treated. My analysis demonstrates how the construction of schizophrenia as fragmenting lays the foundation for the construction of antipsychotic medication as bringing the body back together: antipsychotics attempt to contain the uncontainability of schizophrenia. This literature review reveals the ways in which prevailing Western, Cartesian and biomedical frameworks render side effects of antipsychotic medication as peripheral. Within these paradigms, antipsychotic-induced weight gain and obesity are constructed as marginal inconveniences. However, experiential bodily accounts expose the distorting and transgressive nature of

schizophrenia, and I argue that weight-gain side effects exponentially amplify these experiences of bodies and time and space.

Recognising the intertwining interrelationship between issues of embodiment and spatiotemporalities highlights the ways in which the interaction of schizophrenia and medications explicitly flout understandings of time and space. This is an important contribution to critical health, as these medical fields are viewed as promoting health. Bringing philosophies of time and space into analyses of the ill body theoretically extends embodiment theory to provide complex alternatives to medical understandings of the body. I now explain how I undertook the research that forms the basis of this thesis, drawing on relevant literature to explain the methodological foundations of this study.

# CHAPTER TWO

## “Is she a dragon?”: research foundations for entering the “red doors”

Um, when [my psychiatrist] says he wanted you to interview me, I said ‘She’s not a dragon is she?’. And he says ‘No, she’s not a dragon’.

*Okay.*

And I think to myself ‘If she’s green and has serrated teeth, then I’m not doing the interview’.

*Okay.*

But I know that’s just bullshit, you know.

*Right. What does a dragon mean? Like literally?*

I don’t know. It’s just, you know, it’s just a private sort of joke, you know.

Like, it’s this, but to somebody like me it’s not this. You know what I mean?

George pauses, and looks into my eyes pointedly; although he ostensibly wears a grin, I can read from George’s eye contact that he is testing whether I appreciate the seriousness of this disclosure. For George, and for others I speak to with experiences of schizophrenia, antipsychotic medication and side effects, everyday experiences do not always match up to taken-for-granted understandings of reality. As demonstrated in the last chapter, experiences of schizophrenia are fundamentally unsettling because ‘symptoms’ transgress bodily boundaries and alter experiences of time and space. These experiences are amplified by the transgressive nature of antipsychotic-induced weight gain, exacerbating



perceptions of language and reality that are already profoundly fractured and fragmented (Barrett 1996; Lucas 1999).

I begin this chapter with George's anecdote of a dragon-filled world because it provides a lived account of living with and attempting to reconcile experiences of transgressed bodily and social boundaries. This chapter will set out the methodological orientations of this thesis' research process. I will begin by explaining the importance of Crotty's (1998) four research elements in gaining insights into experiences of madness and fatness. I first explain the definitions of constructionism and postmodernism, then move to show how these are applied as the epistemological and theoretical orientations of this research, and finally demonstrate how these orientations support a grounded theory methodology and a qualitative research approach.

I show how the research methods of qualitative interviewing and observation satisfy Popay and her colleagues' principles for rigour in qualitative research (Popay *et al* 1998). Beginning with my 'arrival scene' at the mental health centre from where my research was conducted, I thread the metaphor of the "red doors" throughout this chapter to demonstrate how entry through the doors and into the private world of mental health services gave me access into experiences of antipsychotic-induced weight gain and antipsychotic-prescription. I set out the preliminary and ethical considerations needed when working with people with experiences of schizophrenia and obesity, and then elaborate on how these considerations (and the grounded theory approach to simultaneous data collection and analysis) became imperative throughout the recruitment process. I conclude with a brief description of the strategies I put in place to preserve the anonymity of the participants, before demonstrating how inductive analysis and qualitative coding helped to generate theory and develop a narrative about the experience of antipsychotic-induced weight gain.

## Research foundations

The spatiotemporalities that are unsettled by experiences of madness and fatness fuel and exacerbate cultural constructions of schizophrenia (and obesity) as chaotic, fragmented and disrupted (Barrett 1996; see also Braziel & LeBesco 2001; Lupton 2012). Such experiences exemplify the “mess” (Crotty 1998, 185) that is fundamental to human inquiry. Crotty (1998) outlines the four elements of all ‘messy’ research: epistemology, theoretical perspective, methodology and methods. The importance of establishing these four elements is twofold: they simultaneously help to ensure the “soundness” (Crotty 1998, 6) of the research, and they help to make research outcomes and findings “convincing” (Crotty 1998, 6). The four research elements that comprise this project are constructionism, postmodernism, grounded theory and interviews/observation, and I discuss each in turn here.

As epistemology is the theory of knowledge, a constructionist epistemology identifies knowledge as being entirely contingent on human practices, beliefs and interactions (Crotty 1998). Unlike the global and universalised accounts that are intrinsic to an objectivist epistemology, constructionism instead focuses on the particular and the dissimilar (Beasley 1999). The constructionist epistemology of this research has implications for the kind of knowledge that this project will render: knowledge that rejects objectivist and positivist notions of a singular ‘truth’ and instead deems knowledge to be multiple, ambiguous and relational. This is why it was important to carry out interviews with two cohorts of people: those with experiences of antipsychotic-induced weight gain; and the health professionals who offer services and support within the public mental health service. Exploring a diversity of understandings of this weight gain ensures that my research renders multiple and, likely, contradictory meanings of the same phenomenon. As Creswell (2014) explains, research based within the constructionist paradigm is obligated to always investigate a complexity of views.

The theoretical perspective of postmodernism characterises the “reality” (Crotty 1998, 2) and “assumptions” (Crotty 1998, 7) that researchers bring to their research, and has profound implications for the choice and use of methodology and methods. My research assumptions embrace the plurality and the “fuzzy logic” (Crotty 1998, 15) of postmodernism; like constructionism, postmodernism jettisons “totalising and essentialist orientations ... [and] generalised, indubitable truths” (Crotty 1998, 185). Although some writers stress the difference between the two terms<sup>2</sup>, postmodernism and poststructuralism, Crotty (1998) argues that the two have generally been used interchangeably in some literature (see also Blaxter *et al* 2010). Crotty nonetheless argues postmodernism to be the overarching theoretical approach where “poststructuralism is subsumed under postmodernism as a more specific form of thought under the more general” (1998, 195).

Consistent with the epistemology of constructionism, postmodernism draws critical attention to the ways in which knowledge can be produced, reproduced and mediated through social processes. The influence of social power within postmodernist works provides opportunities for research to gain insights into the transgressive nature of the human experience. This is why postmodernist thought is characterised by its “ambiguity, relativity, fragmentations, particularity and discontinuity ... [and its] delight in play, irony, pastiche, excess – even ‘mess’” (Crotty 1998, 185).

A grounded theory methodology resonates with research that embraces ‘messiness’. Responding to what they observe as sociology’s overemphasis on objectivism and theory verification, in 1967 Glaser and Strauss developed grounded theory and its guiding principles of theory generation. In putting this

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<sup>2</sup> Postmodernism and poststructuralism, to borrow Crotty’s phrasing, are “slippery” (1998, 183) terms to define. The ‘slipperiness’ is related to its emphasis on pluralism and rejection of fixed singular meanings, stressing “plurality rather than unity” (Beasley 1999, 81). However, postmodernism/poststructuralism is particularly concerned with meaning, subjectivity and language (Weedon 1996). For poststructuralists, “the common factor in the analysis of social organization, social meanings, power and individual consciousness is *language*” (Weedon 1996, 21). In this sense, language is the place in which our sense of ourselves is constructed (Weedon 1996) and, through an analysis of participants’ language and enunciation of their experience, postmodernists understand knowledge to be created.

principle into practice, grounded theory recognises the importance of change, conceding that “phenomena are not conceived of as static but as continually changing in response to evolving conditions” (Corbin & Strauss 1990, 5) and, like constructionism and postmodernism more generally, rejects “strict determinism” (Corbin & Strauss 1990, 5).

Although research should begin with a defined purpose, grounded theory recognises that this purpose may become modified throughout the research process. The data collection/analysis phase allows for “theoretical positions and understandings ... [to] emerge” (Gray 2009, 502). The interconnectedness of data gathering and data analysis is paramount: Corbin and Strauss decree the first principle of grounded theory to be that “data collection and analysis are interrelated processes” (1990, 6). In simultaneously conducting data collection and analysis, I was able to remain dynamic and flexible throughout all aspects of the development, implementation, analysis and documentation of my research.

This allowed for a highly flexible approach to research, which is important when conducting qualitative research. Qualitative research principles, as argued by Holloway and Biley, are characterised by the pursuit for “meaning over measurement” (2011, 969). Meaning, here, can be drawn back to the constructionist mode of understanding the world, where “meanings are constructed by human beings as they engage with the world they are interpreting” (Crotty 1998, 43). Qualitative health researchers, Liamputtong and Ezzy, encapsulate my project’s purpose when they define qualitative research as research that “draws on an interpretative orientation that focuses on the complex and nuanced process of the creation and maintenance of meaning” (2005, 2). Intrinsically, qualitative methodology is the “most humanistic and person-centered way of discovering and uncovering thoughts and actions of human beings” (Holloway & Biley 2011, 974). In this sense, qualitative research helps to illuminate and gain insights into social structures and individual experiences – two things that are crucial in learning about the lived experiences of antipsychotic-induced weight gain.

In their treatise on the “standards” required in all qualitative health research, Popay and colleagues set out the three interrelated criteria for good qualitative research: “interpretation of subjective meaning, description of social context, and attention to lay knowledge” (Popay *et al* 1998, 341). Qualitative research, they argue, privileges subjective meaning and lay knowledge, especially where expert knowledge has failed to address “key policy issues that have eluded the efforts of many policy makers” (Popay *et al* 1998, 345). George’s description of the dragons in his world, and other participants’ descriptions of weight and side effects, highlight the discrepancies in world-views and knowledges of antipsychotic-induced weight gain, and demonstrate the importance of privileging the lived experience of the weight gain when writing about the phenomenon.

To privilege the perspectives of research participants, Popay and her co-authors outline a number of questions that should be attended to when assessing the quality and credibility of qualitative research:

1. Is there evidence of the adaption and responsiveness of the research design to the circumstances and issues of real-life social settings met during the course of the study?
2. Does the sample produce the type of knowledge necessary to understand the structures and processes within which the individuals or situations are located?
3. Is the description provided detailed enough to allow the researcher or reader to interpret the meaning and context of what is being researched?
4. How are the different sources of knowledge about the same issue compared and contrasted?
5. How does the research move from a description of the data, through quotation or examples, to an analysis and interpretation of the meaning and significance of it?

6. What claims are being made for the generalizability of the findings to either other bodies of knowledge or other populations or groups? (Popay *et al* 1998, pp. 346-348)

These questions help to assess how well a piece of qualitative research responds to social context, draws on principles of purposeful sampling, demonstrates adequate description and data quality, illuminates theoretical adequacy, and can be assessed for typicality (Popay *et al* 1998, pp. 346-348). Following Popay *et al*'s (1998) principles ensures rigour by establishing integrity, authenticity, honesty and fairness throughout the research process (Liamputtong & Ezzy 2006).

## **The mental health centre: entering the “red doors”**

Qualitative research principles not only ensured that participants' experiences remained pivotal throughout data collection/analysis phases, but the qualitative principle of reflexivity also guaranteed that I was firmly embedded within the research data (discussed in more detail in next chapter). This is illustrated by my field note of the quintessential 'arrival scene', describing my experience of entering the “red doors” of the mental health centre:

*Despite explicit directions from the centre's Clinical Director as “the building with the red doors”, I had difficulty finding the mental health centre that would be my ‘research base’ for the entirety of my research project. A single-storey cream building with red trimmings and green vines growing along the red poles out the front, the centre is distinguished by two large red doors, above which has a plaque that displays the building's street address. Other than the red doors, the building is indistinguishable and has no signage as to what is in the building. In my later interview with the centre's nurse, Gary spontaneously describes the centre as not having “a big neon sign saying ‘Mental Health’ and everything else”. Asked to elaborate, Gary explains that it is so “people can just walk in” for their business, and not attract, in his words, the “stigma [attached] to mentally ill clients”. In this*

*sense, the characteristic red doors serve dual purposes: they act as a beacon for those familiar with them whilst also hiding from the public what is behind them.*

*The centre's entrance opens up to a large waiting room with dark slate (and slippery) flooring; I lose my footing when walking from the bitumen outside and, cursing my customary clumsiness, I quickly jerk my head around to see if anyone noticed my stumble. Empty, the white room is flanked by locked doors on either side of the room, and a long reception desk is covered by security glass and accessed through open glass panels. A small television hangs from one corner of the room, and a small box of unused plastic toys and board games sits in another corner. On the walls hang pin-up boards and posters, advertising the centre's day programs and the work of non-government organisations like Beyond Blue and Narcotics Anonymous; providing information about exercise, flu prevention and hygiene; and 'welcoming' the centre's visitors in a number of languages. The television is switched to a commercial television station and is loud, drawing the waiting people's attention, despite the plethora of written and visual posters along the walls, and the tattered blue 'Suggestion Box' that sits on the reception desk. A clock is displayed behind the reception desk that cannot be viewed when sitting.*

*I walk to the reception desk and a receptionist looks up from her computer screen. Behind the glass sit the other administrative staff and to the left of the desk is one of the two internal doors which can only be opened from the inside or by a button pressed by the receptionist. After reporting my name and purpose for my visit, the receptionist flicks her eyes to the waiting room chairs and telephones William, the centre's Clinical Director. I take a seat in one of the stained chairs lining the waiting room walls and focus my eyes on the well-dressed man and woman discussing the benefits of health insurance on the morning television program. Like me, upon arrival clients*

*walk to the reception desk, report their name and with which health professional they have an appointment and take a seat on one of the chairs; in this way, clients look directly at one another whilst waiting or focus their attention on the television. Without viewing access to the centre's clock, I guess that 10 minutes have passed before the buzzer clicks and I am greeted and welcomed by William.*

Crucial to research that builds on the narratives of those with experiences of antipsychotic-induced weight gain was locating a pathway into an appropriate research setting, and William provided such a pathway. After meeting with a number of individuals who had insights into the South Australian mental health sector, including academics, mental health providers, and people working within non-government organisations and government agencies, I was put in contact with William, a psychiatrist and the Clinical Director of a mental health centre of a region in South Australia. William proved to be a highly invaluable 'gatekeeper'; for the purposes of my research, gatekeepers are individuals who assisted in finding a research setting, or who assisted with recruitment. Prior to obtaining ethics approval, I telephoned William and was struck by his enthusiasm and support for my research project because, in his words, the region in which the mental health centre is located has been markedly "under-researched". After gaining the appropriate university and hospital ethics approvals, I excitedly scheduled with William an opportunity to meet with him and the excerpt above describes my first experience of going beyond the centre's "red doors".

My account illustrates the way in which visitors are marked as different to healthcare providers. The location of the mental health centre highlights how it is embedded in the community. Despite there being no beds in the facility, demarcating the space between waiting-rooms and consulting-rooms highlights how people are socially controlled through the use of space within medical encounters, like the users of women's and community health centres in Warin and her colleagues' (2000) study. Locked doors and 'private' and 'staff only' signage



represent the “boundaries of movement” (Warin *et al* 2000, 1864) for different people within the mental health centre, and this thesis explores how these demarcations of roles create particular experiences of madness and fatness.

After meeting with William, I was invited to present at the Monday morning Ward Round, a weekly meeting where the centre’s psychiatrists, nurses, social workers and allied health professionals meet to discuss matters pertinent to the centre. As well as briefing the staff generally on my project, I explained how they could assist in the recruitment process. Some of these health professionals agreed to participate in my research both as interviewees and as gatekeepers by being intermediaries between potential participants and myself.

From the Ward Round, I learned that this public mental health centre provides mental health support and assistance to approximately 500 clients, the majority of whom have been diagnosed with schizophrenia and prescribed antipsychotic medication. These clients are aged between 18 and 65 years of age, with the mean age group being 30-40 year olds. The area in which the centre is located has a broader population of approximately 200,000 and is “quite naturally multi-cultural”, in the words of psychiatrist Gopal. As already explained, the people accessing this centre are characterised by the centre’s nurse as “the worst of the worst”, in that they are usually belonging to a low socioeconomic background, on a disability support pension, minimally educated, and with past and current experiences of violence, alcoholism and drug addiction. Gopal adds to Julia’s characterisations by recognising that those the centre provides services for are “the most serially-unwell patients in the [broader] population”.

## **Preliminary considerations**

When taking into account the lives of some of the people involved in my research, and their experiences of mental and physical illness, traumatic life histories and low socioeconomic status, particular considerations must be given to ethical concerns.

This is explicitly outlined in the *National Statement on Ethical Conduct in Human Research*, which characterise individuals diagnosed with mental illness as having “distinctive vulnerabilities” (National Health and Medical Research Council [NHMRC] 2007, 65). However, the characterisation of vulnerability is highly prejudicial and disempowering; William was especially disappointed with the assumption that people with mental illness are characterised as lacking decision-making capacities.

I was very aware of the potential power imbalances between those being researched and myself, and I attempted to deflect some of the presumptions carried over from the NHMRC definition – and the assumptions implicit in the researcher-researched relationship. I began all interviews with a statement setting up participants with the “expert” subject matter, reasserting their power within the interviews. I explicitly distanced myself from the expert medical team that works with the participants, saying “I am not a doctor and I am not part of the team that works with you”. I then briefly summed up my project’s focus, reiterating to the participants that they were the experts of such subject matter, before asking the participants to tell their own story:

Okay, so as you know, my research is exploring the experience of gaining weight from taking antipsychotic drugs. For my research, I’m interested in hearing about your story, your experiences and your opinions, and I’m very interested in hearing what you have to say. I’m not the expert here, but you are the expert because it is your experiences that I would like to hear about. Throughout the interview, I will guide you with some questions but please feel free to raise any issue that’s important to you as we go along ... So can you start by telling me your story? Tell me about how you came to be accessing this service. (see Appendix 1)

Nonetheless, as required in all research that works with people, I had to satisfy the concerns of the ethics committees who subscribe to the *National Statement on Ethical Conduct in Human Research* and, although the considerations outlined

here may suggest that special attention was given to the participants' ability to consent, it is important to note that many of these protocols are common practice in all types of qualitative research.

Recognising that the nature of the interviews may cause participants some discomfort (particularly with respect to questions about participants' weight gain, body weight and body size), I worked to provide the most appropriate and sensitive responses to the participants (such as pausing the interviews, offering tissues, fetching glasses of water and suggesting postponement). As well as having information about free counselling services, the location of the interviews at the mental health centre also provided the advantage of having access to support staff should participants become distressed by the issues raised at the interviews. Although I had carefully drafted the Interview Schedules to ensure that the questions were framed so as to avoid emotional distress, some participants did nonetheless become upset throughout the interviews (see Appendix 1). A question about the participants' history of mental illness did not seem to upset the first 15 participants I asked but, for Mary, the question provoked some sensitivity and distress: welling up, Mary explained that "we don't know which genes [cause schizophrenia] ... because we didn't know anything about it". Surprising me, I responded by offering Mary a tissue and time to pause or stop the interview.

To seek feedback on my Interview Schedules, not only did I carry out a joint pilot interview with Marilyn and Jessica, but I also met with a number of professionals, including two psychiatrists working in the public and private sectors and three people involved in mental health non-government organisations (NGOs). I also attended two forums run by NGOs that explored the physical health of those with mental health issues.

## Data collection: interviews

In actively engaging with interview participants, the semi-structured nature of the interviews allowed me to follow up on answers, re-phrase questions, seek clarification and ask open-ended questions. The qualitative interview “attempts to understand the world from the subjects' points of view, to unfold the meaning of their experiences, to uncover their lived world prior to scientific explanations” (Kvale & Brinkmann 2009, 1), and seeking understanding from the participants' points of view aligns with this project's broader constructionist epistemology and postmodern theoretical orientation.

Through the centre's gatekeepers, I recruited 18 participants (nine women and nine men). All 18 participants had a diagnosis of schizophrenia, were prescribed and taking atypical antipsychotic medication, and had experienced antipsychotic-induced weight gain. Although weight gain is also a common side effect of antidepressant medication (see Paige *et al* 2015 for current Australian context), I chose to narrow my research to antipsychotic-induced weight gain because of the complexities it raises of the interrelationship between madness and fatness. As the participants were recruited through the psychiatrists at the mental health centre, all had diagnoses of schizophrenia that fit the criteria of the DSM-5 (for an overview of the definition of schizophrenia in the DSM-5 and how the definition has evolved throughout the six iterations of the DSM, see Tandon *et al* 2013). The average age amongst the participants was 43 years of age and ranged from 25 to 61 years. All except four were of Anglo-Saxon background: Krishna describes his parents as being Indian-Malaysian, Dren identifies as Croatian-Australian, Rasmey's parents are Cambodian, and Josephine was born in Germany before migrating to Australia as a child.

Most of the participants' living circumstances are characterised by isolation: nine of the 18 participants live alone. A further six participants live with their parents; despite living in the family home, living with ageing parents is depicted as lonely

experiences. Two female participants, Stacey and Kylee, live with their fiancé and husband, respectively; Sam, who has lived in boarding houses for most of his life, has recently moved into a share-house arrangement with two older men he met in his previous boarding home. Attending appointments at the mental health centre is often described as providing the opportunity to talk with and engage with someone, especially to talk about their own experiences.

All participants reported the weight-gain side effect of their antipsychotics as a concern. The participants' weight and their level of concern was self-reported; as this study explores the lived experience of antipsychotic-induced weight gain, the weight status of the participants was not important for their eligibility in this project. I drew on a range of techniques for deducing the participants' experiences of weight, including the use of timelining (see next chapter). Many participants were reticent or were unable to recall how much weight they had gained since first taking their antipsychotics, and some estimated they had gained "maybe 10 kilos". The average weight gain among the 18 participants was 43 kilograms, ranging from 10 to 130 kilograms. Some of the more dramatic weight increases occurred in a short period of time: Dren gained 20 kilograms in the two-month period following his diagnosis of schizophrenia and prescription of clozapine, and Krishna gained 70 kilograms in eight months.

I also recruited eight health professionals for my second cohort of interviewees and, of these, three were psychiatrists, two were pharmacists, and three were nurses (two of whom were the only female health professionals involved in this study). All participants were connected to the mental health centre, whether as staff members of the centre, recipients of regular treatment at the centre, or as recipients of William's private psychiatric treatment. Popay and colleagues explicitly illustrate the importance of qualitative research that "recognizes and deals with the juxtaposition of professional and lay knowledge – different ways of knowing – among professionals" (Popay *et al* 1998, 345). As "qualitative research treats all data as the product of interaction" (Popay *et al* 1998, 348), sampling two

cohorts of research participants allowed me to compare and contrast the differing understandings and experiences of antipsychotic-induced weight gain. This helps to ensure the research project is grounded in purposeful sampling and evidence of data quality (Popay *et al* 1998).

As the first cohort is a classic 'hard to reach' population, I engaged a number of different recruitment strategies. Accessing "information-rich" (Patton 2002, 169) narratives were reliant on purposeful sampling, one of Patton's (2002) seven commonly employed recruitment strategies. I had originally planned that, if potential participants were interested in participation, then those participants would directly contact me; the identity of prospective participants would not be known until I was contacted. However, as with all qualitative research, anticipating, reacting and adapting to practical recruitment challenges was a fundamental component of this research. This was important for flexibility of research design: "the hallmark of good qualitative methodology is its variability" (Popay *et al* 1998, 346). I had initially received enthusiastic feedback from William, as well as from the centre's two other psychiatrists, Gopal and Ming. However, a month after speaking at the centre's Ward Round and leaving my Information Sheets (printed on bright yellow paper so as not to get lost amongst the doctors' piles of paperwork), I had yet to receive any phone calls or emails from potential participants. William and I soon realised that, despite initial interest from potential participants when talking about the project to their psychiatrists, this enthusiasm did not follow through to the realities of their lives – that is, the potential participants did not feel confident (or indeed, did not have access to resources) to call a researcher (and stranger) to schedule an interview.

Similar challenges also arose in McLoughlin's research into youth homelessness and 'couch surfing', and McLoughlin advocates for qualitative research that is embedded within practices of "adaptation" (2011, 67): "fundamental aspects of *enacting* the fieldwork called for an adaptable, troubleshooting approach" (2011, 68, *original emphasis*). I adapted the plan for recruitment: the contact details of

participants would be given to me only after the gatekeepers had determined that the potential participants understood the nature of the research and after the participants had fully agreed to have their details passed on for me to contact them. By having the gatekeepers in place and funnelling the contact details of potential participants to me, I was able to continue ensuring that participants were not coerced into recruitment.

The principles of grounded theory and the contemporaneous carrying out of data collection and analysis (Corbin & Strauss 1990) ensured that such a revision of participant recruitment was possible. Patton's (2002) opportunistic sampling also fits within this methodology. Recognising that "fieldwork often involves on-the-spot decisions about sampling to take advantage of new opportunities during actual data collection" (Patton 2002, 179), at times I had to be dynamic and flexible in my approach to recruitment. Flexibility and adaption of research design allowed for greater insight into the lay knowledge of the research participants:

In contrast to most quantitative studies, the phases of the research process – sampling, data collection, data analysis, and interpretation – are not separate. Sampling for example, is interdependent with data collection, data collection overlaps with data analysis, and the movement from analysis to interpretation is not clear-cut. ... qualitative methods need to be able to be responsive to circumstances as they exist, rather than attempt to create a situation in which the variables of interest can be controlled and their relationships examined and compared across all other similarly controlled situations. (Popay *et al* 1998, 346)

Bradshaw and Stratford draw on Patton's work on opportunistic sampling to illustrate the onus on researchers to be flexible and "follow new leads during fieldwork, taking advantage of the unexpected" (2010, 75). An appreciation of the need for flexibility and potential change allowed me to seek alternative modes of recruitment. After contact details were given, I telephoned potential participants almost immediately so as to maximise them remembering their agreement to be

involved in the research. Upon calling, I introduced myself and indicated that their details had been given by the relevant gatekeeper and briefly explained my project. All participants expressed an immediate recognition of my research and their willingness to be involved.

Drawing on principles of snowball or chain sampling, I relied on “well-situated people” (Patton 2002, 176) to recruit the health professionals needed for my second cohort of interviewees. The gatekeepers provided support in finding appropriate participants until, drawing on Patton’s metaphor of a snowball, “the snowball gets bigger and bigger as you accumulate new information-rich cases” (2002, 176). Along with the three doctors, I also met the two nurses, Gary and Barbara, at the Round Ward, who both agreed to be interviewed. As there are no pharmacists practising from the centre, William suggested I invite Vien to participate, the pharmacist whom he commonly sends private clients; and Barbara telephoned Tu, the pharmacist at the local pharmacy from where the centre’s clients fill their medications to advise that I would be visiting the pharmacy with an invitation to participate in this research. Julia is the centre’s Nurse Practitioner, and she was a suggestion of Barbara’s.

In sum, 26 participants were recruited and interviewed and, in total, 35 interviews were conducted. Of the first cohort, multiple interviews were conducted for people who were interested in meeting for another interview and, as such, 26 interviews were conducted with this group of people (some people were interviewed only once, whereas six were interviewed twice, and one person, Kylee, was interviewed three times). Barbara was the only health professional interviewed twice and the other seven participants were interviewed only once. The opportunity to conduct multiple interviews was helpful in checking themes and patterns that were identified from the transcripts of the first interviews that required further elaboration (see McKeever *et al* 2002). I conducted all interviews, and the average time of each interview was an hour (for both sample groups), with a range of 15 minutes to 90 minutes. My second interview with Kylee fits within the lower end of this spectrum



of interview time, as our interview was cut short (and rescheduled) due to her unrelenting coughing fit; the two particularly robust and enthusiastic interviews with George, in contrast, were over 80 minutes each in length. Mirroring my distance from the medical team was my distance from the standard psychiatric interview (the maximum time the psychiatrists in this mental health centre had with their clients was 30 minutes) and I allowed participants to choose the length of our meetings.

Determining sample size in qualitative research is difficult, but the simultaneous carrying out of data collection and analysis allowed me to tie together the number of participants I interviewed with the quality and richness of my data (Kvale & Brinkmann 2009; Popay *et al* 1998). This was achieved when my data reached saturation, defined by the point of the data-gathering process when no new information or insights are being generated” (Hay 2010, 387) or, pithily, as the “law of diminishing returns” (Kvale & Brinkmann 2009, 113). Throughout some of my later interviews, I found myself anticipating responses based on earlier interviews. Although I was enthralled with some of the details of Mary’s experiences of psychosis, as she was the 16<sup>th</sup> participant to be interviewed, no new themes arose. My findings were vindicated when, after interviewing two more women, no new concepts or themes were revealed throughout the interviews, and thus saturation had occurred.

## **Data collection: observation**

As well as in-depth and semi-structured qualitative interviews, practices of observation further helped to understand the meanings attributed to the places and spaces of interaction between health professionals and their clients. ‘Tracing the steps’ of the centre’s clients provided insight into how the clients engaged with the centre and staff. After each visit, I wrote extensive field notes about my observations and experiences, and took photographs and sketched diagrams.

These research tools of systematic note-taking assisted in collecting data beyond “the facts” (Gray 2009, 398).

As well as generally tracing the steps of the centre’s clients, Barbara also invited me to observe a clinical consultation between herself and one of her clients, Jan. Barbara is the Director of the Clozapine Clinic; the Clinic oversees all of the centre’s clients who are prescribed the atypical antipsychotic, clozapine, and monitors the side effects associated with this antipsychotic, including low white cell count, weight gain and diabetes. My field notes about Jan’s consultation illustrates the pivotal role that antipsychotic-induced weight gain plays in the interactions of some health professionals and their clients:

*After being telephoned by the centre’s receptionist that her client, Jan, has arrived (a protocol I observed on my first visit to the centre), Barbara leaves her office, walks down the corridor, opens the door to the waiting room and welcomes Jan. Usually, Barbara tries to engage in small talk as she accompanies clients to her office, and she uses this opportunity to assess her clients’ responsiveness and general well-being. In the corridor leading up to Barbara’s office, displayed on the wall are a number of “healthy eating” and “healthy living” posters.*

*Barbara’s office door opens immediately to a small wooden desk from where the consultation will be conducted. Tucked into this desk is a chair similar to the ones in the waiting room, as is the chair next to the desk (presumably where clients sit). The desk is laden with piles of patient files (the ones for the clients Barbara will see that day), an electronic thermometer and an electronic blood pressure-reader, a hand sanitiser pump bottle and a display stand filled with pamphlets about “healthy living”. Above the desk is a whiteboard and pinned to it are more “healthy living” posters, a calendar and a poster about “storing old medicines”.*

*From the sitting chair, clients get a full view of Barbara's office, seeing much more than when first entering. Upon first glance, the office appears very full: the room is cluttered and imposes a sense of disorder and disarray. The office is carpeted with grey carpet, and painted a cream colour with mismatched furniture. On one side of the room sit digital scales; the scales are modern and electronic with a glass base and the numbers of the weight appear in digital lettering and underneath the scales sit a thick piece of cardboard, presumably to give a more precise reading.*

After looking over Jan's file, Barbara noted that Jan had refused to have her waist measured during her previous four consultations. This is common amongst Barbara's clients, especially the refusal of waist measurement. Barbara admits to "bending the rules a little" by only measuring and weighing her clients when they feel comfortable. For some, this process of 'getting comfortable' can take several gradual steps – for example, after gaining the trust of her clients, Barbara first suggests measuring just one body part with her tape measurer, and then measuring more body parts each time they meet, until she finally suggests weighing them.

*Sitting in Barbara's desk chair, I overhear Barbara tell Jan how good she looks as she collects Jan from the waiting room and they walk along the corridor together to her office. In a high pitch, Jan hurriedly and enthusiastically replies that she has lost some weight in the prior month due to her regular Weight Watchers meetings. After we shake hands, Jan immediately hops onto the glass scales positioned in front of the office door. Weighing herself before she sits down not only indicates her excitement in having her weight recorded, but also suggests that this is usual procedure during these consultations. There is palpable tension in the room as Jan settles on the scales and the digital numbers pause to give a reading; in reaction to Barbara's reading of 101.2 kilograms, Jan appears deflated, rebutting that she weighed 98 kilograms at her last Weight Watchers*

*meeting. Barbara seems to discount this disappointment, reiterating the positive recording and commenting that all scales are different. In a bright bubbly voice, Barbara encourages that, by next month, Jan could be under the “100 kilo mark” (many participants speak of this “mark” as having special significance). Throughout the interview, Barbara remains very upbeat and continually reiterates that Jan is “looking good”.*

*Asked if she had changed her mind about having her waist measurement taken, Jan refuses, saying she would allow the measurement once she had lost another 10 kilograms. After the weigh-in, Jan and Barbara both sit down in their respective chairs (again indicating that this is usual protocol), and Barbara writes the weight recording in Jan’s file.*

## **Pseudonyms and protection of data**

All of the participants were allocated pseudonyms to maintain anonymity and protect confidentiality. I invited participants to nominate a pseudonym. “I always wanted to be a Stacey”, explains one participant, and six participants from the first cohort excitedly suggested an alternative name when asked for one. All of the other participants instead preferred for me to allocate pseudonyms, and I did so by matching a name appropriate for the gender, ethnicity and age of the participant.

The pilot interviewees, Marilyn and Jessica remarked, unprompted, that the strategy of asking participants to provide pseudonyms was a good one, and indicated that it would mark my interviews as being different to the consultations the participants usually had in the centre – namely, clinical consultations with psychiatrists and nurses. In this sense, the opportunity to choose pseudonyms helped to subvert and collapse the power dynamics within the researcher–interviewee relationship. The recognition and interrogation of power is very important within all postmodernist research. Holloway and Biley explicitly advocate for “voice-centric” (2011, 972) strategies in qualitative research, explaining that

“qualitative research should empower and enhance the decision making of the participants” (2011, 972).

All but two of the participants agreed to have the interviews audio-recorded and, for the two that did not, I was permitted to take hand-written notes. Regardless of whether the interviews were recorded, I made contemporaneous field notes immediately following the interviews, which often included reflections on the participants' demeanour, bodily comportment, facial expressions and interpersonal interactions, along with insights into impressions of the data generally. As “one of the mainstays of qualitative data collection methods” (Gray 2009, 185), these field notes were integral in providing detailed information and insights into the interviews, and constituted the early processes of data analysis (see next section). Heeding Gray's (2009) imperative for field notes to be recorded as soon after the interviews as possible, I also transcribed the interviews usually on the day of the interview; I transcribed these audio-recordings into Microsoft Word verbatim using a foot pedal and Express Scribe. To protect anonymity and confidentiality, interviews were transcribed by me and all field notes and transcriptions were kept in a locked cabinet or on a password-protected computer.

## **Analysis**

As a child who loved to read and write my own detective stories, the metaphor of research analysis as “detective work” (Cope 2010, 281) particularly resonated with me in describing the nature of qualitative data analysis as seeking answers to complex social problems. Rigorous qualitative research is grounded in rich, “thick” description, which is used to interpret the meaning and context that is being researched (Popay *et al* 1998, 347), and the movement from adequate description to theoretical adequacy mirrors the movement from “quotation or examples” to “analysis and interpretation of the meaning and significance of it” (Popay *et al* 1998, 348). The analysis phase of research thus involves the generation of

'meaning' (or theory) to formulate a narrative about the phenomenon that is being researched.

The principles of grounded theory, along with the work of Ezzy (2002), and Gray's (2009) six steps of qualitative research, were useful when thinking through the interview and observation data that I had collected. Although I used the software program, NVivo, for the organisation and analysis of literature, I manually organised my research data so as to ensure that interviewing and analysis were conducted as instantaneously (and simultaneously) as possible.

I drew on an inductive mode of analysis so that participants' narratives influenced the direction of my research and theory generation. Inductive discovery – unlike deduction – describes the research process whereby data is used to explore patterns and relationships between variables and, from these observations, theories may be generated (Gray 2009).

The first stage of data analysis, open coding, begins during and immediately after the interviews: the writing of field notes of important insights, ideas and silences (Ezzy 2002; Gray 2009). For example, what struck me most about Ashley was his slow and deliberate movements (I described him as "big-person slow" in my field notes), and this helped to formulate later theory about the everyday experiences of antipsychotic-induced weight gain as being heavying and immobilising (see Chapter 4). Interview transcription provides another component of this coding, as transcribing always "encourages detailed reflection" (2002, 70), serving as a "preliminary form of data analysis" (2002, 70). Transcribing, highlighting, labelling and writing notes not only helped me to become familiar with the data, but also allowed me to bring together a story around my project's broader themes and concepts.

Axial and selective coding helped to further develop my coding scheme. Axial coding is the recognition of relationships (Corbin & Strauss 1990; Ezzy 2002), and

the 'playing with' labels (or codes) developed as ideas began to be formed or lose significance. A much more sophisticated process, selective coding is the "identification of the core category or story around which the analysis focuses" (Ezzy 2002, 92). In this final stage of coding, categories are integrated to produce theory, where theory is generated by developing hypotheses about the connections realised through axial coding, and then returning to the literature to see if such hypotheses can be confirmed (Gray 2009). Following on from my field note about Ashley's slowness, this idea was developed into the analytic and theoretic concepts of containment and spatial boundaries, and, from here, selective coding allowed me to engage with literature on transgression and the impossibility of bodily integrity (Blackman 2010). My early observation about the reduced mobility of one participant demonstrates the significance of the intuition and record-keeping inherent in "detective work" (Cope 2010, 281), and is an invaluable and exciting component of data analysis and research.

## Summary

In this chapter, I have explained the methodological approaches that I used for the design and implementation of this project, and how these approaches elicited data that I report on throughout Chapters 4 to 6. I have explained how the overarching epistemological framework of this project has direct implications for the methods chosen for data collection and analysis. The principles of rigour, multiplicity, reflexivity and flexibility have been useful in producing comprehensive data on the experience of antipsychotic-induced weight gain. To complement this chapter's methodological basis, the next chapter will examine some of the more practical aspects of the research, particularly for research into the lives of those who often evince a distrust of the spoken word. The next chapter will explore these difficulties in communication, and outline some of the strategies I used to gain insight into the "private" (and dragon-filled) world of my participants, including the use of reflexivity, attention to language and terminology, and sensory awareness.

# CHAPTER THREE

## A strangeness of language and other communication barriers

As I highlighted in the last chapter, classical clinical and popular formulations of schizophrenia presume the strangeness, incomprehensibility and uncontainability of schizophrenia (Barrett 1996; Corin 2007). Having demonstrated the usefulness of constructionist and postmodern methodological approaches when seeking insights into the experiences of antipsychotic-induced weight gain, this chapter will build on my argument that the lives of people with experiences of schizophrenia are inherently difficult to grasp. Lucas (1999; 2004) uses the concept of “extraordinariness” to illustrate the experience of schizophrenia: people with schizophrenia take up the “anomalous positioning” (1999, 3) of experiencing both the “ordinary and the exceptional” (1999, 2). I will draw on examples from my qualitative interview data to argue that these distinctive experiences of schizophrenia render language as strange, creating a “lack of communicable understanding” (Lucas 2004, 150) and distance between those being researched and myself, the researcher.

This chapter will highlight the importance of reflexivity principles in gaining access to the lives of those affected by medication-induced fatness. All rigorous qualitative research requires “interpretive validity” – that is, “reflexive accounting on the part of the researcher” (Popay *et al* 1998, 348) – that demonstrates the development of conceptual and theoretical adequacy from the collected data. I will begin by examining how the terms, ‘schizophrenia’ and ‘obesity’, create distrust and impede rapport with participants, and outline strategies I used to overcome these



difficulties. I will then draw attention to the nature of the interviews, outlining the spaces used for the interviews, and how these spaces, as well as the bodies of the participants, provided distractions that sometimes enriched data collection. Bodies were used to convey meanings that language failed to, and I explore some of the repercussions of communication barriers and the approaches used to gain rapport and insight. I then focus on my own writing and argue that writing can be a research method to extend beyond the official (clinical) documentation of illness. I finish by setting out the limitations of this study, and show how a practice of reflexivity helps to rebut one's insider/outsider status (Hesse-Biber 2007).

## **A strangeness and distrust of language**

People with schizophrenia express a marked sense of strangeness towards language (Lucas 1999). Language fails to communicate meaning, and poses as a barrier between expression of experience and connection with others. An “absence of a language that [can] ... ‘translate’ ... experiences” (Lucas 2004, 150) is exemplified by the participants’ frequent lamentations about the difficulties in finding appropriate words to express their thoughts and experiences: Stacey, for example, moans “Oh, it’s very hard to say ... I just wish I could explain myself better!”; and after ending our interview and farewelling one another, Sam continued to mutter from the corridor “I hope I haven’t said the wrong thing!”. Although these experiences may punctuate social life for people without diagnoses of schizophrenia, I highlight them here to illustrate the everyday, “extraordinary” experience of schizophrenia (Lucas 1999; 2004) and its implications for participation in qualitative research.

At the conclusion of our interview, I invited Ashley to give feedback on his experience on the interview and on my interviewing style. Ashley reveals the complications in speaking to someone who has not experienced psychosis:

*How has it been talking to me these last two interviews?*

Ah, bit worrying.

*Why is that?*

Just in case I say something wrong.

*What would be wrong?*

Ah, trying to explain things, sometimes it comes out wrong to what I think it's supposed to come out as ... It's hard to put it in words what you experience. Because you can say 'I hear voices' [but] it's hard to explain that side of the schizophrenia. It's hard to tell people in words!

The use of words in explaining experiences is especially problematic for my participants. Many participants expressed difficulty in providing information about the specific details of their diagnoses, weight changes and medications. Speech represents "the failure ... as a taken-for-granted instrument of meaning" (Lucas 1999, 298). Instead of providing the name and dosage of medications they take, participants used descriptive language to talk about their medications: Stacey invariably described her medication by colour ("the pink tablets" were laxatives), by how many she takes ("probably about six or eight"), as well as by when she takes them ("the morning medication").

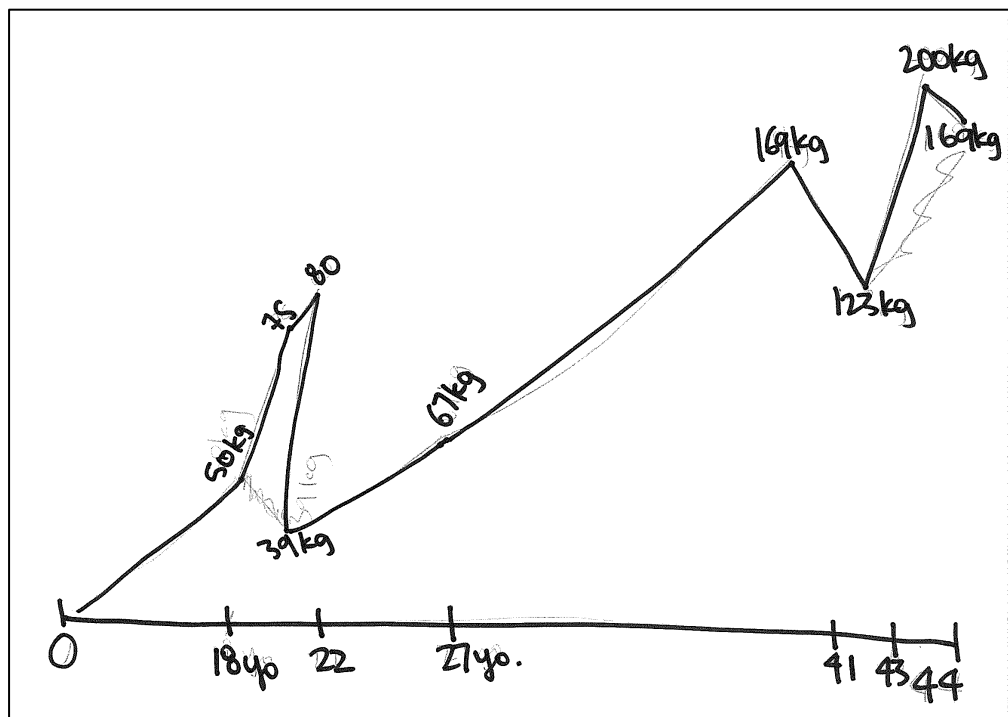
In framing schizophrenia as an "extraordinary" experience, Lucas argues that schizophrenia impedes communication with words, and that the "most striking and ubiquitous feature [of schizophrenia] ... was its inability to be represented by words" (Lucas 1999, 300). The monosyllabic and mumbled answers of another participant, Dado, seemed to be a response to living in a world that fails to understand him and his experiences. After introducing myself at the centre's waiting room and bringing him into the interview room, Dado sat hunched-over in the chair, staring at the carpeted floor and giving only minimal eye contact. Throughout the interview, Dado was very confused, asking me to re-ask questions and several times stating that his "brain's not working too well". Speech, for Dado, has betrayed him to such an extent that he now refuses to rely on it for everyday communication, and instead spends his life mostly mute.

These feelings of betrayal are grounded in experiences of language that have been interpreted as a ‘symptom’ of mental illness (Barrett 1996; Lucas 1999). Talking and the expression of inner thoughts is the diagnostic means through which schizophrenia and most forms of mental illness are determined, and for this reason language has a “heightened significance” (Lucas 1999, 270) for people with schizophrenia. Speech comes with a “pre-established aura of expectation and suspicion” (Lucas 1999, 270) for people with diagnoses of schizophrenia, and is often read as a manifestation of illness rather than as an expression of the truth of experiences.

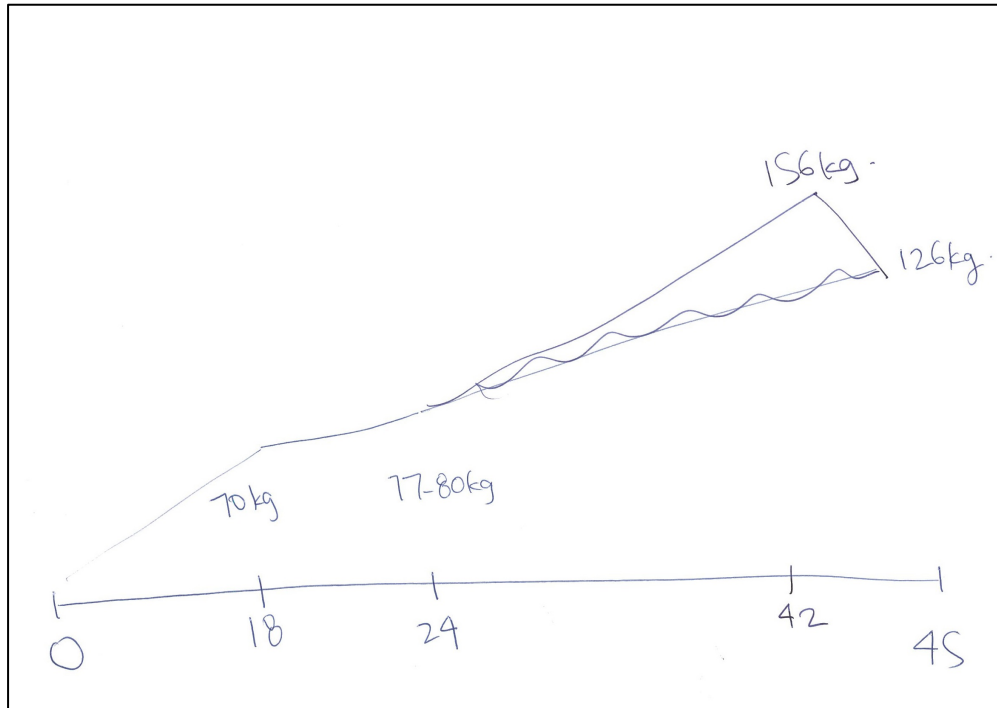
Despite these inherent language difficulties embedded within the schizophrenia experience, “dialogic negotiation” (Lucas 1999, 13) is the primary means of engaging with participants in qualitative research. As well as it being a source of potential conflict, language also provided a means for sharedness and commonality between participants and myself. By reiterating the participants’ status as experts and inviting them to narrate what was significant for them within their experiences of antipsychotic-induced weight gain, participants were given the agency to re-define their diagnoses and broader experiences – though this agency was only ever confined within the interview setting. Lucas argues that speech has a “validatory aspect” (1999, 14) for people with schizophrenia, in that it allows people to confirm or distinguish “the ‘reality’ of their accounts, the validity of their interpretations, and their value as persons” (1999, 14). The postmodern and grounded theory principles of my research methodology allowed this reassertion of expertise, which helped to develop relationships between the (separated) worlds of the researched and the researcher.

In bringing together these different worlds and recognising the participants’ distrust of language, the interviews also required communication of information outside of verbal language. Weight graphs, drawings, body language and embodied responses were integral to gaining insights into participants’ lives (Sheridan *et al* 2011). As grounded theory is “responsive to circumstances” (Popay *et al* 1998,

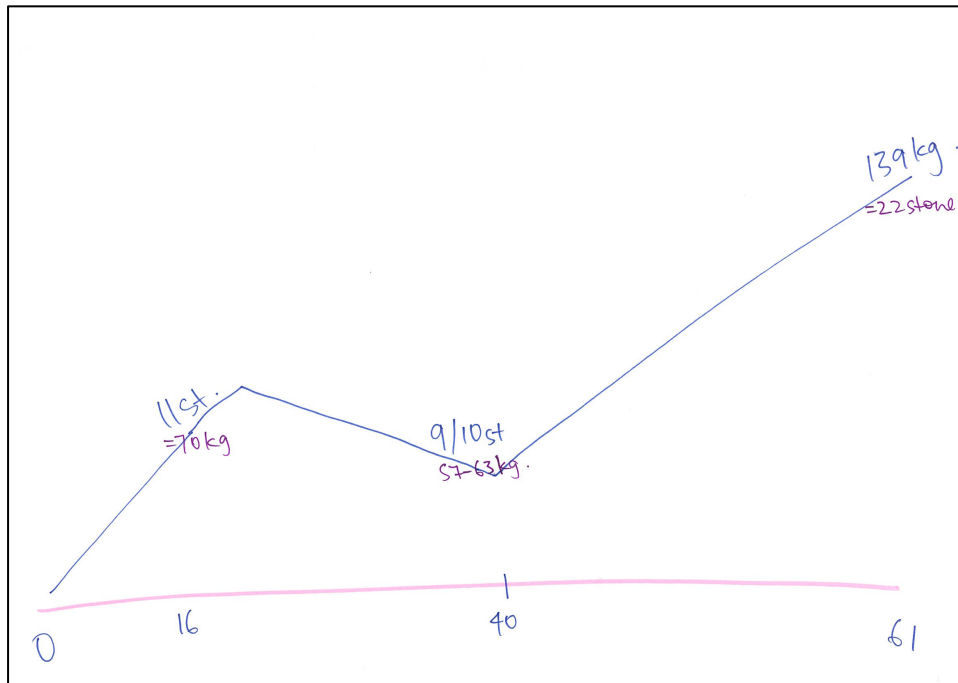
346), I devised a number of strategies to help draw out details from the participants. Weight graphs provided rich data about participants' weight gain. Instead of the participants verbally describing their lifetime of weight fluctuations, I asked participants to draw these weight changes on a graph that mapped their age against their weight. I allowed the participants to draw the graph how they wished, but for those who were apprehensive to do so (such as Stacey's initial response of "Oh gee, oh gee! Oh no!"), I asked pointed questions and sketched the participants' weights at various points in their lives, including weight during adolescence, at time of diagnosis, after initial weight gain, during other weight fluctuations, and current weight (see Figures 1–3 for examples of these weight graphs).



**Figure 1:** Kylee's weight graph. Kylee illustrates her weight fluctuations throughout her 44 years of life. At 18 years, Kylee was 50 kilograms (kgs), and gained weight during her two pregnancies as a 20 year old and 21 year old. After the birth of her children, she lost a considerable amount of weight, but since her diagnosis of schizophrenia and since taking antipsychotics at 27 years of age, she has experienced a gradual weight increase. At 41 years old, Kylee weighed 169 kgs and dropped down to 123 kgs through the drastic reduction of food intake; this weight loss caused her to be hospitalised to gain weight, peaking at 200 kgs. Kylee now weighs 169 kgs.



**Figure 2:** Keith's weight graph. Keith demonstrates the weight gain he has experienced since being diagnosed with schizophrenia at 24 years of age. As at 45 year old, Keith has gained nearly 80 kgs since first taking antipsychotics. Recently, Keith has attempted to lose weight, resulting in a weight loss of 30 kgs.



**Figure 3:** Mary’s weight graph. Throughout the drawing of her weight graph, Mary described her weight fluctuations in the European unit of weight, stone, and I later converted these measurements to kilograms (see my purple annotations). Mary was first diagnosed with schizophrenia at 45 years of age, and since taking antipsychotics at this time, she has gained approximately 80 kgs.

Drawing the graphs together not only allowed for physical closeness, but also assisted in the development of rapport and acted as a “bridge between two strangers” (Sheridan *et al* 2011, 557). The weight graphs became a focal point for the interviews, and the weight graphs were added to and amended when a deeper narrative was reached. For example, John was characteristically difficult to attain answers from, and was reticent to give details about his experiences of antipsychotic-induced weight gain. However, the physical presence of the graph prompted John to guess that he had gained “maybe 10 kilos” after taking the antipsychotic medication.

The weight graphs have similar benefits to the “timelining” or the “innovative method of graphic elicitation” (2011, 552) in Sheridan and her colleagues’ narrative-based research project on weight gain and weight loss. Although the use

of visual props have a long history within qualitative research methods, timelining extends these methods by incorporating together “time, events, photographic images and storytelling” (Sheridan *et al* 2011, 560). Demonstrating its “subtle, malleable and reflexive” (Sheridan *et al* 2011, 555) features, the weight graphs were particularly useful in understanding the many weight fluctuations that Kylee has experienced since adolescence and throughout her two pregnancies, mental illness diagnosis and subsequent weight loss attempts (see Figure 1), particularly as she remembered more details about her weight during later interviews.

Artistic works were also used to help illustrate the participants’ experiences of transgression and disruption (see Chapter 4). Asked to elaborate on his earlier discussion of bodily borders, George stammers, pauses and sighs, before asking “Can I just show you something?”. I nod, and George pulls from his backpack a large book that he opens to reveal a compilation of Willem de Kooning’s abstract artwork. For the participants in Lucas’ study, artwork is used “not as sources of madness, but as a verification of the reality of ... experiences” (2004, 157). De Kooning’s paintings and sculptures (see Figure 4) help George to illustrate the “reality” and the ways in which schizophrenia has changed his relationship to his own body. As language cannot be trusted to convey the truth of experiences, the value of visuals speaks for the participants’ lived experiences of disordered bodies, space and time.



**Figure 4:** An example of Willem de Kooning’s works. George points to a photograph of the sculpture, ‘Cross Legged Figure’, constructed in 1972.

## The importance of terminology

The psychiatric terminology of schizophrenia and the medical labelling of obesity digress from the participants’ own understandings and lived experiences of madness and fatness. Participants describe experiences of psychosis and schizophrenia in as broad terms as “breakdowns”, “ups and downs”, “episodes”, “the edge” and as “a little bit of mental illness”. The importance of having a “common language” with clients – in psychiatrist William’s words – was explicitly recognised by some health practitioners, who mirrored their clients’ terminology and used phrases like “stressed out” and “emotionally upset”. Likewise, the participants’ construction of ‘unique fatness’ explicitly avoids the public health concerns and societal stigma of obesity.



For George, the contrast of the experiences of “hard” and “soft” offers an apt metaphor for his experiences of schizophrenia and antipsychotics, respectively. Describing his antipsychotic medication as “soft” and “quiet”, George explains that his medications present a “window to the soft side of things”. Such a “softly presence” is violated by the “hard acid” experience of schizophrenia:

I think we all experience [psychosis] ... but that people with schizophrenia get a little bit more. We all get close to the edge from time to time, and some people go over the edge.

*So “the edge” represents – ?*

The breakdown, the point where things actually start to fall apart in a big way, and you lose control of your mind.

George uses his new piece of artwork, titled “Hard Acid and Soft Acid”, to explain his lived experiences of schizophrenia. Although he acknowledges that some experiences of (acid-induced) hallucinations can be enjoyable, the “unpleasant hard acid” experiences of schizophrenia are instead terrifying and upsetting. For George, schizophrenia is simultaneously “good and bad, chaos and control, hard and soft”.

Articulations of schizophrenia in terms of “hard acid” experiences are absent in psychiatric discourses and categorisations, and I was careful to avoid terminology that would result in missing out on these descriptions within my own interviews. My pre-interview meetings provided the opportunity to receive feedback on the Interview Schedules, something that is crucial to all qualitative research embedded in the grounded theory principles of flexibility and change (Glaser & Strauss 1967; Popay *et al* 1998). Initially, I invited participants to talk about their “diagnoses of schizophrenia”. However, the professionals indicated that this label may damage rapport and impede the flow of the interview, and I instead substituted this opening with an open-ended question asking how the participants “came to access the centre”. This was essential in building rapport and privileging the participants’ experiences and narratives.

In light of this, throughout this thesis I refer to the participants as “people diagnosed/living with the diagnosis of schizophrenia” instead of labelling them as “schizophrenics”. This is an extension of Martin’s (2007) work on terminology used for people with mental illness, and recognises that participants comprise of more identities than only their clinical diagnoses; Martin argues that mental health diagnoses are “only one description of a person among many” (2007, 10). The two terms, clients and consumers, are the preferred terms amongst the health professionals in this study, and I use it accordingly where appropriate. Warin (2002) distinguishes between the historical use of the terms, patients and clients, in psychiatric settings, in which both terms serve different political agendas. Client, in particular, was introduced to “overcome some of the inequalities ingrained in the language of the ‘doctor-patient relationship’” (Warin 2002, 70). Although the use of the terms, client and consumer, attempt to subvert the power imbalances within clinical encounters, it also perpetuates the neoliberal and behaviour-focused paradigm of modern medicine (see Chapter 6 for a critique of contemporary neoliberalism and “lifestyle” interventions).

As well as the negative connotations of madness, I also anticipated that the negative connotations of fatness would impact on my participants. Throughout my interviews, I chose to avoid the term, obesity, and the word did not appear in any of the questions asked or in my Information Sheets. Psychiatrist Gopal cautions against “labelling people as fat”, recognising that “people don’t want to be labelled obese or fat”. Ashley, for example, emphatically describes how he “hasn’t been diagnosed for any fatness or anything!”. The construction of unique fatness to describe understandings of antipsychotic-induced weight gain demonstrates the misapplication of the clinical categorisations of obesity to the lives of the participants.

Warin and Gunson (2013) explore the “silences in obesity research”, drawing on the theoretical works of Foucault (1977, 1988), Bourdieu (1975, 1984, 1993) and

feminist theory. Even though I chose not to use the word obesity in my interactions with participants, I agree with Warin and Gunson that my “silencing language” (2013, 1686) does not erase the stigma of the word from my research; “the tacit judgments that accompany discursive categorization” (Warin & Gunson 2013, 1686) nevertheless continue to exist. Eschewing the word does not refute the power of the “collective knowingness about fat bodies” (Warin & Gunson 2013, 1686) and the shame that is associated with fatness. I explore this theme later in this chapter, and draw on the social research principle of reflexivity to bring awareness to my own ‘situated fleshiness’ as a slim researcher to reveal how my body impacted on the participants’ interview experiences.

## **Place distractions and bodily disruptions**

As well as the words used to describe experiences of madness and fatness, the places and spaces used for the interviews are also important in eliciting insights into participants’ experiences, as highlighted by my field note of the interview room used for most of my interviews:

*William leads me to the room from where I will conduct most of my interviews. The door is marked ‘Interview Room 3’ and, before entering, William peeks through the peep-hole to check that the room is empty. Before knocking and unlocking a door to speak with its occupant, I observed the centre’s custom of first looking through the peep-hole to see if the person inside has a client with them. This peep-hole is accessed by moving aside a piece of metal, and a fish-eye lens magnifies the entire room and interior. Realising that the room is empty, William unlocks the door and extends his hand, offering me to enter.*

*The room is quintessentially ‘office-like’: it is carpeted and has white walls, a corner desk, desk chair, three armchairs, coffee table and waste-paper bin. Upon entering, I am struck by the room’s small size and lack of*

*distinguishing features. Although a whiteboard is attached to one wall, the board is bare and the only thing that sits on the desk is a computer, some pens neatly stacked in a cup and a tissue box. The room looks unoccupied, and William explains that it is a “spare room” used for visiting practitioners and will be available for my interviews.*

After agreeing to participate in the research, I scheduled with the participants a convenient time and place to meet. Most of the participants of the first cohort were interviewed in ‘Interview Room 3’ or another office almost identical to it. I was cognisant of the burdens associated with travel for some of these participants, and I offered to meet when the participant had another meeting scheduled at the centre, although some were excited to meet as soon as possible and were not concerned about making a second trip to the centre.

For the health professionals, interviews were usually conducted at their place of work and during lunch breaks or gaps in their working day. Six of the participants worked at the mental health centre and the interviews were conducted in their offices; interviews with the two pharmacists took place in their respective pharmacy staff rooms. Interviewing these participants at their place of work enriched the data in a multitude of ways, such as providing the health professionals with the opportunity to draw on materials at their desks or in their bookshelves.

At times, however, these benefits were overridden by the distractions and interruptions of work places. All of the interviews were interrupted with knocks on the door, telephone calls and corridor noises. William answered three phone calls during our 50 minute interview, stopping the interview recording and interrupting the flow of our conversation. To my surprise, Ming had three medical students in his room when we met for our interview; it is usual custom within the public sector for medical students to ‘follow’ and observe the daily practices of doctors. Ming’s responses to answers provided an opportunity to teach the students and, at times,

our interview resembled a small-group seminar, where the students were invited to offer their own answers to my questions.

The nature of all qualitative interviews is characterised by distractions and interruptions (Byrne 2004); narratives and information were thus grasped in fragments. These fragmented narratives highlight the “messiness of the lived world” (Rossman & Rallis 1998, 8) for all participants, and the ways in which research can only ever give a partial reflection and account of people’s experiences. Yet for participants living with schizophrenia, the everyday intrusions were even more prevalent. Illustrating the difficulties in having conversations, Ashley demonstrates the everyday experiences of interjecting and interrupting voices:

In the day-time, when I see my doctor, they’re saying ‘Don’t dob me in’. My voices are saying ‘You’re dobbing me in, don’t dob me in’. They swear at me and they say ‘Don’t dob me in, you’re dobbing me in, you shouldn’t be dobbing me in’. And I’m trying to listen to what my doctor’s saying but I’m hearing my voices, and they’re saying ‘Don’t dob me in, you’re dobbing me in, you shouldn’t dob me in’.

*Are they talking to you now?*

Ah, yeah.

*Oh, okay.*

Saying that I shouldn’t say anything.

Similarly, midway through our interview, Keith stops mid-answer, tilts his head and bewilderingly exclaims “They’re not even saying anything while I’m in here, the voices!”. For Keith, the silence of the voices can be as equally distracting as their presence: “That’s why I forget what I’m talking about, because I’m used to someone always saying something, and then when they stop, you go ‘What was I talking about?’”.

Bodies, too, cause distractions. Coinciding with Dren’s descriptions of hunger, my stomach rumbles, to which we both laugh and Dren jokes “Are you hungry?”.

Unlike this joviality, Kylee's rumbling stomach causes her some agitation. Kylee spontaneously questions: "I wonder why my tummy is making that noise?". In response to my suggestion of digestion, Kylee wonders if her stomach is "eating [her] fish" (which she had for lunch) and perhaps even that her "digestive fluids are trying to chase down the fish to dissolve it when it goes in the stomach". Such an embodied way of thinking about metabolic and digestive processes is a pertinent example of data that would not have become available had such interruptions (and followed-up comments and questions) not occurred.

Providing a catalyst for conversation about medicated tiredness, Dren invariably interrupts the interview to yawn and rest his head on his hands. Other examples of these bodily interruptions include tears (Sam cries when he spontaneously begins to discuss the death of his long-term girlfriend, as does Ruth when disclosing her history of sexual abuse), moments of dizziness, and thirstiness (and subsequent drink breaks).

The interviews were not always restricted within the confines of the places in which the interviews were conducted. During our first interview together, Sam excitedly boasts of his new scooter and, after the conclusion of our interview, Sam invited me to look at it. Parked outside the front door of the centre, Sam continued our time together by pointing out the functions and features of the scooter, disclosing how the scooter creates for him feelings of freedom from societal judgment. Not only did the interview with Kylee cross the boundaries of the interview room, but it also crossed days. Arriving for our third interview, Kylee asked at reception if she could use the centre's scales. The receptionist put the scales outside of the interview room and the receptionist and I stood next to Kylee as she weighed herself: Kylee later explained that the scales help her "work out whether [she has] actually lost weight or whether [she's] just fooling [her]self".

## **Reflexivity, sensory awareness and other strategies for rapport-building**

The dragon metaphor used at the beginning of the last chapter highlights the ways in which my status as ‘the researcher’ impacted on my interactions with participants, and highlights the inherent complexities and repercussions of the gulf (or “betweenness” (England 1994)) between the researched and the researcher. At the beginning of all interviews, I always asserted that I was interested in hearing the participants’ “stories, experiences and opinions”.

Despite this, not only did my position as a researcher impact on the dynamics within the researcher–researched relationship, but so did my identity as a white, middle-class researcher from a research university entering the centre in a temporary and exclusively research-based capacity. Reflexivity provides the methodological foundation for “critical self reflection” (Johnson 1997, 283) or “taking a critical look inward” (Hesse-Biber 2007, 129). Drawing on Harding’s (1987) work, Hesse-Biber characterises reflexivity as “the process through which a researcher recognizes, examines, and understands how his or her own social background and assumptions can intervene in the research process” (2007, 129; see also Popay *et al* 1998).

The process of reflexivity requires that I name and draw critical attention to my own social background and positioning within the research, compelling me to recognise when my body, socioeconomic status and education influences the research. Incorporating Gray’s (2009) definition, I always recognised the relationship between researcher and object of research, conceding the fallacy of the researcher ever being a neutral observer. I carried this practice of reflexivity through to all stages of the research, including research design, implementation, analysis and writing-up, and doing so ensures that my research is rigorous (Popay *et al* 1998). My examples below show the ways in which my slim body and my (privileged) classed status impacted on the interviews.

But it is not enough to only name my privilege; I must also explain the strategies I used to dismantle the effects of my privilege. Reflexivity is the recognition that the “self is always present in fieldwork” (Holloway & Biley 2011, 971), and all qualitative practices of reflexivity require researchers to work towards employing strategies to subvert power imbalances (see Popay *et al* 1998). A “movement ... to commonality” (Lucas 1999, 75) was a critical strategy of Lucas’ in collapsing the researcher–researched divide. This involved seeking to understand the intricacies and complexities of the participants’ lived worlds, and legitimising the participants’ concerns and meanings of unique fatness and medication-induced fatness.

Commonality is:

bringing the ‘individual worlds’ of both researcher and participants closer together, developing relationships as a way of constructing an often tentative and experimental social reality, and finding mechanism which allowed a joint exploration of that reality. (Lucas 1999, 75)

My tall and slim physique was particularly disruptive and troubling for some participants, especially when posing questions about body size and weight gain. Reflexivity assists in bringing attention to “the unspoken vulnerabilities of the imbalance of power that accompanies bodies” (Warin & Gunson 2013, 1692), exemplified by Kylee’s responses to some of my questions. Attempting to build rapport, I laugh along with Kylee’s anecdote of pumping up her exercise ball, to which she abruptly interrupts, incredulously declaring “You wouldn’t need to do exercise!”. In the same interview, Kylee compares her own weight gain with her husband’s comparatively-small gain:

*So what does he say about your weight gain?*

He doesn’t care ... He takes me for who I am, and not what I look like.

*Yeah. So do you accept yourself for how you look then?*

*[shakes head]*

*Why not?*

I don’t like looking like this.



*[softly] Why not?*

Ah, would you if you were fat?

*[shakes shoulders] Don't know*

I was startled to be asked how I would feel about being fat. Emphasising the expert status that the participants had in the experience of antipsychotic-induced weight gain did not dissolve my own privileged position as a slim and educated researcher, conducting research into fatness, without the signs of being a fat person. Despite my attempts to thwart this privilege, “bodies of a slim or ‘normal’ size tread lightly yet weigh heavily in spaces and conversations” (Warin & Gunson 2013, 1692), and Kylee calls out the heavy space that my slim body occupies within our relationship.

Not only were the participants aware of my difference from them, but I also became aware of being different and occupying different social status and class to them. Keith’s animated anecdote of his loose teeth “flying out” particularly conflicted with what I term as my own middle-class sensibilities:

I don’t clean them or anything.

*You don't clean your teeth?*

Nah.

*Okay. Why not?*

Ah, I don’t know. I used to, but these two are loose *[wobbles two front teeth]*.

*Oh.*

*[wobbles teeth so much that they look like they're coming out]*

*Ooh! Okay.*

*[laughs]* And I owed the dentist 30 bucks. I was going to pay him, but I’ll just wait until they fall out, I don’t really care. Because I haven’t been to the dentist in years and the thing is, teeth usually get loose and they get looser and looser, and then, if you give them long enough, they just fall out. And that’s just what I’ve been doing. I’ve lost about three teeth along the top here *[points to top teeth]*. The last one I pushed out, but it only hurt for about a month or two.

*Oh!*

This one here was about a year. I was just coughing really hard one night, because I had a bit of a flu, and the tooth comes flying out.

*[whispers] Far out.*

As a middle-class woman with private health insurance, I was dismayed to learn of Keith's descriptions of inadequate dental care. My gasps and exclamations throughout this interchange reinforce Holloway and Biley's (2011) assertion that researchers are always present in their research. Sam also surprised me by baring his empty gums and proclaiming "I've got no teeth!"; he explains that they were removed because he did not brush his teeth when first diagnosed with schizophrenia. Rousseau and her colleagues (2014) shed some light on the meanings of tooth loss and replacement, critiquing the conflation of the "neglected mouth" with connotations of moral failures in maintaining dentition (Rousseau *et al* 2014). These interchanges highlight the impossibility for me to maintain objectivity when exploring the lives of those who are described as "the worst of the worst".

To bridge the researched–researcher divide, I learned to attune my own "sensory awareness" (Harris & Guillemin 2011) towards the participants, and I was often able to recognise the participants' needs and act quickly so as to avoid further distress and discomfort. Becoming aware of Kylee's developing flu, I set aside a box of tissues and a glass of water at the beginning of our third interview; upon entering the room, Kylee remarked "Oh, thanks for that glass, that's really nice!". Although we had built rapport in our previous two interviews, throughout this interview Kylee disclosed many details about her own life that she had not revealed before, including her relationship with her abusive and drug-addicted ex-husband, experiences of being adopted, financial pressures and details of her sister's mental illness and suicide. Rapport, argues Travers, comprises of trust and ease between researcher and interviewee, interview qualities that are "more important than perfecting technique in achieving good results from interviews" (2010, 305); in developing sensory awareness towards Kylee, I was able to develop rapport, which positively affected the interview quality.

As well as building rapport, the sensory awareness of sounds of coughing and thirstiness, and looks of discomfort, help enrich data and analysis and “offers us potential insight into dimensions that would otherwise remain unexplored” (Harris & Guillemin 2011, 690). In bringing sensory awareness into the interviews, I was privy to dimensions of the experience of antipsychotic-induced weight gain that may not be accessed through spoken word; in this way, my senses were a “powerful portal” (Harris & Guillemin 2011, 697) to the participants’ lived experiences of madness and fatness.

In his work on “sensuous scholarship”, Stoller (1997) recognises the importance of the senses in providing full and rich data. He calls for the reawakening of the “scholar’s body” (Stoller 1997, xvi) to escape researchers remaining “blissfully asleep in analytic nirvana” (Stoller 1997, xvi). For my participants, the “notion of text ... is not important” (Stoller 1997, xv) or is difficult to convey. As verbal communication is inherently untrustworthy for people with experiences of schizophrenia, sensuous inclusions were especially important in overcoming communication barriers and difficulties.

One strategy for overcoming these barriers was offering the participant some of my time in listening to their stories. Although my Information Sheets explain that they will not directly benefit from the research, I nonetheless tried to give back to the participants. As most of the participants live deeply isolated lives, dedicating some time to talk with the participants was one way I could reciprocate their donations of time and story-telling. As well as talking about his scooter at our first interview, Sam spoke about his travels during our subsequent interview the week after; his appreciation for my listening was confirmed when he thanked me for “listening and stuff”: “I love talking to you, you’re a very nice lady ... and you’ve listened to my story”. Echoing similar sentiments, amongst his family and pets, Krishna lists “having something to do related to mental health ... like an interview like this” as things that provide him with joy and purpose. In contrast to the ending of my

interview with Dren, Peter's seemingly genuine well wishes before parting justify spending extra time talking about his family's holiday-house: "With your studies and everything, Tara, yeah, I hope you go through and make it, I hope you make it".

This participatory benefit is exemplified with Rasmey's eventual realisation that she is "not the only one with schizophrenia!". Rasmey is a private client of William's, in her second year of a university teaching degree, and was diagnosed with schizoaffective disorder three years earlier. Rasmey emphasises the importance of keeping her mental illness "confidential" and "private" and notes that only members of her immediate family knows that she sees a psychiatrist and takes psychiatric medication. After we had concluded our interview, Rasmey seems to have a light-bulb moment in realising that I had done other interviews for my research and tentatively asks "How many people have [you] studied?". She was curious to hear that, at that midway point in my research, I had interviewed 14 other people with experiences of antipsychotic-induced weight gain:

So there are many people with schizophrenia out there?

*Yeah!*

Really? ... Because I haven't met one so far, I want to know if there's any, because I feel like I was the only one or something.

*Yeah, I can imagine.*

Yeah ... So you've interviewed 14 people, which means there are a lot ...

Oh! [*eyes light up!*]

*Yeah.*

So I'm not surprising. I'm not the only one!

*No.*

Oh ... That makes me feel better.

Rasmey was very curious to hear how others with a diagnosis of schizophrenia like her were doing and explains that she had always thought that her diagnosis was unique.

## Writing up

As well as alluding to the life-threatening nature of her weight, Kylee's concerns about being "worked-up" (Barrett 1988; 1996) into an impersonal and abstract written form highlights the inadequacies of clinical writing in understanding the broader lived experience of health:

It's hard enough having a mental illness ... [but to also] have somebody write down on a piece of paper when they do a case-plan. They say 'This person is such and such age, dresses such and such, and is morbidly obese'. But what does the word 'morbidly' mean? Does that mean you're so overweight that you make people grossed out?

*So who writes down those things?*

You know, when you go to the doctor at the hospital ... every single person that writes anything about me says that I'm morbidly obese. I know it shouldn't worry me but the word 'morbidly', to me, means 'so fat and ugly that I make people sick'. Not very nice when you're called that.

Heeding Kylee's caution against reducing participants to psychiatric case-notes, this project will instead provide "thick" (Geertz 1973) descriptions of the embodied experience of antipsychotic-induced weight gain. Doing so provides opportunities for "understand[ing] these conditions in a broader cultural and historical context" (Martin 2007, xviii).

Written records, argues psychiatrist and social anthropologist Barrett, has the "power to damage" (1988, 267). Within medical and psychiatric settings, case-records, case-plans and work-ups describe the history and extent of a person's illness. As I have already mentioned, mental illness is often diagnosed with reference to a person's language and physical appearance, and psychiatric case-plans contain observations about a person's thoughts and personal hygiene as evidence of manifestations of mental illness. Kylee's rejection of the clinical term, morbid obesity, demonstrates how these case-records are "an account that characterizes the illness as an active agent in control of an ultimately passive

patient” (Barrett 1996, xiv). Kylee is concerned with the way in which case-records discount her perspective and diagnose her as morbidly obese without her consent or knowledge, rendering her as a “passive patient”. In this sense, case-plans are invested with the potential to “*define and transform* patients, their identities, and their experiences of mental illness” (Barrett 1988, 266, *original emphasis*).

Murray’s work on the “fat body” also unequivocally challenges the “persistence and irrevocability of tacit bodily knowledges that construct us within every context” (2007, 361) that she argues is implicit in objective, medical discourse. Drawing on Foucauldian conceptions of the panoptican and the medical gaze, the case-plan serves multiple purposes: it defines and constructs mental illness, whilst extending the psychiatric gaze (Barrett 1988). The written nature of this document and the established “breach of interviewee etiquette to ‘peek’” (Barrett 1988, 279) renders the subject of such a case-plan detached from their own mental illness experience. Kylee explicitly conveys her frustrations with doctors writing-up her diagnosis without speaking with her about it. Continuing the above interchange, I ask Kylee:

*So who calls you that, like doctors?*

Well, they don’t call it to my face, they write it down.

*Yep, and do you read it?*

[nods head]

*Yeah.*

I found it the other day and read it. Even had ‘morbidly obese’ on it.

*It did?*

[nods head]

Kylee’s non-verbal responses reinforce that peeking at her case-plan is taboo, and she nonetheless disrupts the taken-for-granted objective status of the documentation by explicitly questioning its legitimacy.

## Limitations

Self-identifying as a “free-thinker”, George offers insights into his experiences and the difficulties in conveying these experiences: “If you haven’t experienced [madness and fatness], then it’s really hard to describe what it’s like”. In critiquing my difficulty in understanding his experience, George positions me as an ‘outsider’. However, one’s status as an insider/outsider is “fluid and can change even in the course of a single interview” (Hesse-Biber 2007, 143). Although I was an outsider in the sense that I had never experienced schizophrenia or weight gain like that described by the participants, my outsider positioning away from the psychiatric team also helped me to understand the participants’ experiences of alienation and strangeness. Like the participants, I came to the mental health centre as a stranger, and I reiterated this early in the interviews by explicitly stating: “I am doing research for the University of Adelaide. I am not a doctor and I am not part of the team that works with you. Everything that you say in this room is totally confidential and won’t be repeated outside of this room” (see Appendix 1).

There is significant benefit in straddling the insider/outsider status within qualitative research; it can help us to “take a new look through the lenses of our participants’ eyes” (Holloway & Biley 2011, 972) which can help us to generate theory. My sense of strangeness allowed me to ask questions that surprised the participants, eliciting responses that enriched the data. Following on from my earlier discussion about Kylee being unable to contribute (or, indeed, see) her own case-record, my non-clinician positioning excluded me from also contributing to official documentation. Lucas shows that his own non-clinical status likewise created “distance from the ‘official’ record which facilitated participants’ engagement with the project” (Lucas 1999, 14).

Along with language difficulties, there are other limitations that are inherent in the research of people with experiences of schizophrenia. Many of the participants in this study live with significant cognitive issues. Not only does this hinder their

connections and relationships with others, but it also presents problems for recalling information and past experiences. Some of my research participants, for example, could not recall the specific name of the antipsychotic they take or could not quantify the weight they have gained. A number of strategies were used to overcome these barriers (such as timelining and the use of weight graphs), and some participants drew on strategies to assist with their recall, like Stacey who spontaneously brought to the interview her antipsychotic packaging.

The approach I took with purposeful sampling limited the type of knowledge and insight I accessed about antipsychotic-induced weight gain. All of the participants in this study were institutionalised in the public health care system and were deemed to be 'healthy' enough to participate in the research. Such sampling limited the involvement of those who are not currently taking antipsychotic medication, and although some of the participants I interviewed did have prior experiences of stopping their medication because of the side effects, I may have encountered much stronger views about antipsychotics and side effects had I interviewed people who are not currently seeking psychiatric assistance. However, my earlier discussion about the justification for the NHMRC guidelines showcases the importance placed on the protection of those deemed to have "distinctive vulnerabilities" (NHMRC 2007, 65).

Positivist writing would position all qualitative research as failing to produce research that can be generalised to broader populations. However, the qualitative methodology I employed for this project does not endeavour to explore population-based data, but to instead explore the complexity of the issue investigated. The rigour principle of typicality is one of generalisability and not representationality (Popay *et al* 1998) and, as such, the findings of this research project do not aim to represent all experiences of antipsychotic-induced weight gain. Rigorous qualitative research draws on the notion of typicality to demonstrate its credibility: "The aim is to make logical generalizations to a theoretical understanding of a



similar class of phenomena rather than probabilistic generalizations to a population” (Popay *et al* 1998, 348).

## Summary

Throughout this chapter, I have expanded on the last chapter’s examination of the methodological underpinnings of this thesis to draw specific attention to the methods used to overcome some of the communication barriers for people with diagnoses of schizophrenia. As highlighted by Barrett (1996), Corin (2007) and Lucas (1999; 2004), people with schizophrenia have often developed a strangeness towards, and distrust of, verbal language, and accessing their lives can be difficult. I have demonstrated the importance of using generic language to refer to experiences of schizophrenia and obesity, which not only helped to build rapport with participants, but also set up the participants as “experts” in the subject matter of madness and fatness. Rapport is crucial in the development of trust within the research relationship, and helped overcome some of the communication difficulties of this project. The practice of reflexivity brings awareness to my own privileged position as a researcher and also requires me to explore how this privilege impacts upon the participants’ interview experiences and on the interview data. As reflexivity happens throughout all phases of research – not just during research design and implementation – I will continue to reflect on my own positioning and influence in the following data chapters. In Chapters 2 and 3, I have outlined my reasons for selecting the methodologies and methods for the collation and analysis of data, and in the remaining chapters I explore the lived experiences of antipsychotic-induced weight gain, beginning with the experience of space and ‘heaviness’ in Chapter 4.

# CHAPTER FOUR

## Hungry voices and heavied spatialities

Sitting in a stained waiting room chair when I collect him for our second interview, George rests a paint-splattered and frayed backpack at his feet. Offering him to lead, George hoists the backpack onto his shoulder, walks down the corridor and escorts me into the interview room and, as I follow him, I notice a conspicuously large hardcover book protruding from the half-zipped bag; the book, showcasing the work of Dutch-American abstract expressionist Willem de Kooning (1902–1997), later becomes useful for George in explaining his experiences of schizophrenia and antipsychotic side effects.

I begin by asking George to elaborate on some of the statements he made at our first interview, especially what he meant by his “sense of the physicality of the body” being impacted by schizophrenia. Seemingly anticipating this question, George pulls out the book, explaining that “this might help with the question about bodily boundaries”. Whilst flicking through the book and pointing to pictures of de Kooning’s paintings and sculptures (see Figures 5–7), George describes how, like the figures, the experience of schizophrenia makes bodies seem “mish-mash [and] hickelty-pickelty”:

So that’s like a figure, if you look at it, you can see that there’s an eye and that’s an ear and they’re the extremities ... [But] it’s pretty sort of plishy plashy! The paint style is very, it’s not highly-defined, it’s fairly blurry, but it’s very, um ... plishy plashy ... or splashy ... But in the sculptures, the limbs,

they're not as clean-cut ... That looks a little bit like maybe the experience of somebody with schizophrenia!



**Figure 5:** 'Large Torso'. George shows me a photograph of one of de Kooning's sculptures, constructed in 1974.



**Figure 6:** 'Seated Woman on a Bench'. George flicks to a photograph of one of de Kooning's sculptures, constructed in 1972.



**Figure 7:** 'Cross Legged Figure'. George chooses a photograph of de Kooning's sculpture, constructed in 1972.

George talks explicitly about how schizophrenia renders his “bodily boundaries” as fluid and without finite bodily endings. George uses the term, “floppy”, to describe his perception of bodily borders:

I guess you get to a point where you can't really trust your perceptions, but you don't have anything else to go by. I mean, that's all we have really, isn't it? The way we perceive things is primarily what we are and how we are.

*Does having schizophrenia affect your relationship with your own body?*

Ah, yeah, I guess so.

*Yeah, how does it do that?*

Um, sometimes it's hard to work out where the body ends. I mean, it does, you know. But it's like, sometimes it's more sort of, floppy and sort of, um, more, more like a jelly-fish! [*giggles*] I've had some pretty weird experiences, I have.

Photographs of de Kooning's sculptures and paintings allow George to elaborate on his understandings and perceptions of his own body. Continuing his discussion of his "jelly-fish" body, George hurriedly shifts his chair perpendicular to my own, and bends the spine of the book so that I can better see its contents. Laying the book flat across his legs, George flicks through the pages with reverence, pausing and pointing to particular pictures (see Figures 5–7).

Unfamiliar with abstract art and the work of de Kooning, I struggled to decipher the pictures of unintelligible and blurry figures; a photograph of a sculpture that George reads from the title as a representation of a woman looks to me like two bulbs protruding from a tree trunk:

*Yeah, so me looking at these figures for the first time is bewildering.*

*Is that kind of like –*

They're kind of strange, for sure!

*– is that like what schizophrenia is like to the world?*

Probably, yeah. Strange.

*Everything is made strange?*

Yeah!

These descriptions of bodies illustrate the broader experience of schizophrenia. Pointing to photographs of de Kooning's works, George explains how, like the figures, schizophrenia is "not highly-defined" and "fairly blurry". Artwork is commonly used to explain experiences that are characterised as unexplainable, especially for people with schizophrenia (Lucas 1999).

These lived and embodied experiences will form the basis of this chapter, and I will draw critical attention to space and lived spatialities to integrate experiences of madness and fatness. George's and other participants' experiences of voices and psychoses assault bodily boundaries and taken-for-granted notions of time and space, and I will draw on Lucas' (1999) and Corin's (2007) work on schizophrenia to argue that schizophrenia must be understood within a broader framework that encompasses embodiment and social practice. Contemporary embodiment scholarship (Blackman 2010; Grosz 1994; Williams 1998) is useful in showing how these experiences challenge the autonomous and contained Cartesian body that has become integral to medical and psychiatric thought.

I then expand beyond the participants' experiences of schizophrenia to show how antipsychotics and antipsychotic side effects amplify these disrupting experiences by exacerbating the loss of boundaries. The participants' metaphor of heaviness defies constructions of bodily containment. Such spatial experiences makes bodies, for my research participants, seem heavied, and this heavying experience has three dimensions: the heaviness of bodily motility; the heaviness of emotionality; and the heaviness of extreme exhaustion. The metaphor of heaviness unifies experiences of madness and fatness through its impact on the body's positioning within space. I justify the use of space within analyses of bodies by drawing on contemporary philosophical and sociological literature to argue that spatiotemporalities must always be incorporated into explorations of bodies and bodily experiences (Abrahamsson & Simpson 2011; Duff 2007; Honkasalo 1998; Moran 2012; Thrift 2007; Toombs 2001a & 2001b). This chapter's frame of reference is embodied spatialities and lived space, and the metaphor of heaviness demonstrates how space is constructed by what the body is doing and experiencing.

## **Schizophrenia: edges of bodies, edges of personhood**

The body in embodiment theory – like the participants’ descriptions of their bodies – challenges the possibility of an autonomous and bounded body. The concept of embodiment refuses to think and experience bodies in dualisms, and strives to collapse the Cartesian dichotomies of mind and body, inside and outside, individual and social, and biological and cultural (Blackman 2010; Grosz 1994).

Embodiedness, then, troubles Western scientific and medical paradigms that construct the body as existing “in one specific temporal and spatial location with firmly fixed boundaries, primarily in the form of skin, separating it from its immediate environment” (Mann & Jaye 2007, 184). For this reason, in her essay on the “socio-cultural and bioscientific limits” of the body, Shildrick characterises the embodied body as “highly plastic and rich in the possibility of intercorporeality” (2010, 12).

The intercorporeal body refutes two central components of the Cartesian body: separation and individualism (Blackman 2008). Separation between the self and the Other is a fundamental tenet of Western understandings of personhood, and separation can only occur between “clearly bounded entities” (Blackman 2008, 8). Voices, however, contravene constructs of separate bodies. In her case study of the Hearing Voices Network (HVN), Blackman (2008) argues that, despite the pathology of hearing of voices within modern medicine, evidence suggests that hearing voices is commonly experienced across time and cultures. The recognition that people with experiences of “non-psychiatric explanations ... may live with them quite well” (Blackman 2008, 127) forms the basis of the HVN, an international community alliance between families, carers, professionals and service providers to voice-hearers. Blackman (2008) draws on the HVN to highlight the ways in which the narrow construct of voice-hearing is founded on a conception on the body as defined exclusively within bodily and biological terms. My participants offer complex depictions of the relationships between their voices and their bodies: voices assault bodily borders, and are simultaneously separate from, and inside,



bodies. When asked whether his voices are attached to specific people, Krishna explains that his voices do not have “physical bodies”, but have “separate voices from [him]”. For him, the voices are “internal ... but not different people [with] different entities”.

Krishna concedes that others with schizophrenia may not share his same experience, and voices may instead be experienced as “not really internally ... [and] like someone out there”. Cynthia’s voices fit this description of “someone out there”. For Cynthia, the voices are a separate entity from her own body. In differentiating these voices from her own personal thoughts, Cynthia explains: “I can feel [thoughts] in my heart, whereas the voices upset me in my head”. As the voices are perceived to be separate from her, it is the voices’ transgressive nature that Cynthia finds to be especially distressing. In her study on the theme of privacy for people diagnosed with schizophrenia, Warin also identified the ways in which her participants’ “private worlds” (2000, 116) were transgressed and violated. Drawing on the case study of a young female participant, Kate, whose everyday experiences are exemplified by the experiences of violation and vulnerability, Warin offers an alternative understanding of schizophrenia as “an experience which embodies and reproduces a multiplicity of cultural meanings associated with the concept of privacy” (2000, 115). The openness and lack of privation implicit in the experience of schizophrenia (Warin 2000) has significant implications for how people experience their bodies and bodily boundaries.

Krishna, in particular, offers insights into his understandings of “internal” voices. Intelligent and engaging, Krishna has long considered antipsychotic medications, their side effects, and the pharmaceutical and psychiatric profession’s responsibility for his weight gain; this was revealed by Krishna’s declaration that he is – in his words – “a conspiracy theorist!”. Highlighting the stigma and discrimination directed towards those with schizophrenia, Krishna believes that pharmaceutical companies have created the weight-gain side effect so that “schizophrenics can’t breed” (Krishna believes that the weight gain inhibits

romantic and intimate relationships). Krishna speaks candidly about his experiences of stigma, especially about the amplified stigma of mental illness and obesity: “You have the stigma of mental health, but when you’re overweight and have a mental health problem, it’s twice as bad!”.

As Krishna’s voices are “internal”, they can sense and feel what is happening within his body. Krishna’s voices often comment on his bodily comportment:

*What sort of things did they say?*

Um, they were telling me that my body was too relaxed, my muscles. And I was going to be preyed upon and attacked ‘til I learnt to be completely tense.

*How did they know that you had relaxed muscles?*

I can’t tell you. I wasn’t aware of it, until they started talking about it.

*Like in your shoulders?*

Yeah, yeah. But, year by year, it must have sank into my subconscious because my posture and my tension in my muscles and everything did change how they said I should change it.

In response to the voices’ warnings against being “preyed upon and attacked”, Krishna now suffers from severe muscle tension after years of tensing of his body.

These experiences of voices collapse constructions of individual bodies as separate and isolated entities. Not only do voices transgress bodily boundaries, but they can also cross the borders between multiple bodies, such as the boundaries between Keith and his new dog. Comparing his own position to others who are “at one with the voices”, Keith evinces an antagonistic relationship with the “two idiots talking in [his] head”. Others who are “magnetised” by their voices, in contrast, cannot resist like Keith can. Keith proudly resists the voices’ requests by “do[ing] everything backwards to the voices”, and refuses to eat, shop and wear what the voices want. Another way that Keith contests the voices’ magnetism is by allowing his dog to bite his fingers. Not only does Angel provide him with a great deal of joy

in companionship, but Keith is also proud to describe his voices' apparent dislike of his new puppy, Angel:

The voices don't like her because, all day, she just bites my fingers! And the voices don't like it because someone once told me, they come down to body movements.

*The voices?*

Yeah, [the voices] come down to body movements ... She keeps biting, like all day, mate [*smiles*], she just doesn't quit! [*both laugh*]

Keith explains that when Angel sits on his lap and plays with his fingers, the voices believe that they, too, are getting bitten: "All they can think about is getting bitten by her!".

These are the "extraordinary experiences" of schizophrenia encapsulated in Lucas' (1999) study. These experiences traverse the categories of ordinariness and extraordinariness by conflating experiences that are simultaneously "expected and unexpected, familiar and unknown" (Lucas 1999, 62). Collectively, the extraordinariness of schizophrenia creates experiences that are "disturbing, disorienting, chaotic and hard to grasp" (Lucas 1999, 35).

The disturbing nature of the extraordinariness of schizophrenia is confirmed by another participant in this study, Sam. Immediately after walking into the interview room and before sitting, Sam declares himself to be a "dyslexic, schizophrenic and diabetic". Having a strong sense of self-identity is important for Sam, and he proudly asserts his myriad of roles and identities: "I'm a mechanic", "I'm a cook", "I'm a carer", "I'm a fisherman", "I'm a computer person", "I'm a KISS fan", "I'm a gaming consoler" and "I'm a collector". However, it is his voices' interference with his "worker" status that he finds difficult to cope with:

When I'm talking to someone, I've got to try and think what they're talking about and not what I'm hearing.

*You'd get distracted! Yeah.*

Yeah, it's hard work, too. When I was working ... [my boss would] say 'Hang on a minute, mate, I'm working now. I'll be back with you in a minute'. I'd say 'Alright', '[Boss's name]?'. 'Yeah, I'll be back with you'. 'What?'. 'I'll be back'.

*Oh wow.*

It does get a bit annoying ... it's hard. Even washing cars you think someone's talking to you and that it's in your head. But he [the boss] really is talking to you! The supervisor's talking to you about how to do this job, how to do that job, what jobs to do. But you've got to work out, I'm not saying real to reality, but voices are really strange!.

Sam illustrates the frustrations and repercussions of living with frequent bodily intrusions. The extraordinariness of intrusive voices impedes Sam's ordinary experiences of working and communicating with others and having to distinguish, in his own words, "real to reality", is particularly distressing.

Along with separation, individualism is also pivotal to the construction of bodies within Western thought (Mann & Jaye 2007; Slatman & Widdershoven 2010). The proliferation of individualism, Rose (2003) argues, has had the profound consequence of giving rise to the "fiction of the autonomous self" and the notion of the separate and individual body. As a result, people are now coded almost exclusively in bodily or biological terms:

To be a "somatic" individual, in this sense, is to code one's hopes and fears in terms of this biomedical body, and to try to reform, cure or improve oneself by acting on that body ... What discontents might previously have been mapped onto a psychological space ... are now mapped upon the body ... [or] the brain. (Rose 2003, 54)

Implicit in the notion of "somatic individuality" (Rose 2003, 54) is the Western conception of property. Modern constructions of property seek to draw borders and contain what is within (Williams 1998) and is useful for thinking through the rise of the individual within Western thought. The bounded entity is "a 'container' which protects against and resists external forces, while holding back internal ones from

expansion and extrusion” (Williams 1998, 69). In her work on bodily integrity, Blackman (2010) draws attention to Cohen’s (2009) work on immunity-as-defence, or what she terms as “possessive individualism” (Blackman 2010, 3). Reconceiving the body as a form of property allows for bodies to be constructed as having borders between inside and outside. These borders stand in opposition to “invaders” (Blackman 2010, 2). The notion of voices-as-invaders is too simple a concept for experiences of schizophrenia, and data from my interviews help to contradict notions of bodily integrity and the autonomous body. Blackman problematises the concept of “possessive individualism” to reveal its basis as the notion of the bounded body:

This relates to the idea that a person owns his or her body, that our bodies are objects and, where taking care of our bodies is equivalent to maintaining and increasing our cultural and physical capital ... [and] that our bodies obey natural laws. (2010, 3)

As well as having separate emotions, such as anger, outrage and irritation, the voices also have their own desires. Keith’s voices, for example, “get hungry”. If he did not have voices, Keith believes that he would not need to eat as often as he does: “If it wasn’t for them, you could probably only eat once or twice a day!”. Indeed, if everyone had voices, Keith explains, then everyone would be “mega-fat” because the voices are “just gluttonous”. As he has learnt how to repel his voices’ magnetism, Keith refuses to eat when the voices demand food; he explains that he “can’t feed them all the time”. He giggles when describing how he holds off on eating for as long as possible, “mak[ing] them bitch to one another: ‘When he’s going to cook breakfast?’”.

The voices believe that they can taste Keith’s food. For this reason, the voices are particularly ‘picky’ about the foods they prefer Keith to eat:

They didn’t like me trying Indian food, they didn’t like me trying Italian food ... they just like steak, egg and chips.

*So when you eat, do they act as if they're tasting the food that you're eating?*

Yeah, they'll go 'Ah, that's shit!' or 'Oh, that's off!'.

Keith lives with the voices' continual commentary when eating, and incorporates their preferences into his diet.

As well as having emotions and desires, the voices have memories. Continuing his discussion about foods and eating, Keith illustrates why his voices prefer some foods to others. Rice, for example, reminds the voices of their time as Japanese Prisoners of War, even though Keith has never served in the Australian defence forces:

Whenever I eat rice they talk about being in Changi – 'Remember what Australians got to eat from the Japanese?' That's what they talk about.

That's why I don't eat rice. It's horrible. And they do talk about World War II whenever I eat rice.

Despite these constant criticisms about the foods he is eating, Keith – with his strategy of resisting his magnetising voices' requests – still eats the foods: "And I just force it down!".

Voices also "attack" the participants. Not only do the voices "attack [him] mentally", but they also "attack" Ashley in a physical manner, too. Lucas has similarly documented the "metaphors of assault" (1999, 45) employed and perpetuated by those with experiences of schizophrenia. Examples of bodily assaults vary from forcefulness and covertness, to disorientation and transfiguration (Lucas 1999). For my research participants, the voices are personified as "crawling" and "smothering", making Ashley "off-balance". Ashley details his voices' night-time activities:

I still hear the voices, they attack me in the night-time. When it's real quiet – you know how quiet it is in the night-time? – I get attacked by them all night.

*Even though you're sleeping?*

When I try to sleep, I try to drift off and they attack me. I can't drift off. I go to bed about 12 at night, and I'm still awake at five in the morning. So that's why I'm always sleepy ... When I go to bed, they attack me. My voices attack me and I'm telling them to 'Shut up!' and 'Leave me alone!' and 'Get lost!' and things like that.

*Does that work?*

No, they just attack me all the time so I just have to put up with it. I try to drift off to sleep.

*Do the voices scare you?*

No, I just get angry with them.

*Because they're annoying you?*

I tell them 'Leave me alone, just get out, go somewhere else!'

*And do they come every night?*

Yeah. Every day and every night. I'm arguing with myself and telling them to 'Tick off!' and 'Leave me alone!'

The voices, for Ashley, cross bodily borders in a variety of ways: they "pull" his arm, they yell at him in his own head, and they make his heart beat fast.

Unsurprisingly, the voices' assaults render Ashley unable to sleep: in his words, "It's hard to try to drift off to sleep when someone's yapping inside your brain!".

These experiences mirror the distorted bodily boundaries that George describes with the assistance of de Kooning's artwork. Corin's (2007) study on schizophrenia echoes the extraordinariness (Lucas 1999) of the experience, demonstrating how schizophrenia creates "a sense of porosity and fragility of personal barriers and boundaries" (Corin 2007, 290). George draws on de Kooning's works to reveal the porosity and permeability of his own bodily borders. Asked to elaborate on his perception of his body, George spontaneously declares "that's a boundary thing!". Boundaries, for George, are "like people wearing pyjamas on the street": "It's like a bit of a blur, a blurring experience – where things that are sort of quite obvious to other people are not as clear for a person with schizophrenia." Wearing sleepwear in socially inappropriate settings symbolises the persistent disruption of

schizophrenic experiences. For those whose sense of boundaries has been dismantled, people like George must put in “some effort” to rectify and reset the blurring experiences:

You have to work hard, yeah, to make it work ... You know, what in Buddhism they call it service, they call it devotions. You have to do your service and devotions everyday to make things work. It doesn't just fall into place, there's some effort that's required.

The “devotions” in George’s analogy is the “work” that is required to recognise when boundaries have been violated and the “effort” required to make sense of bodily and social borders.

This fluidity of bodily boundaries is theorised within embodiment literature on bodily transgression, which outline alternative ways for thinking through bodies, body parts and bodily borders. Embodiment theory allows bodies to be understood as “extended and multiplied” (Blackman 2010, 1), recognising the inherent and perennial failure of bodies to conform to ‘body laws’. Blackman observes the fallacy that “bodies obey natural laws” (2010, 3) and Grosz likewise refers to the way in which bodies infringe “the laws of nature” (1994, 6). Body laws comprise taken-for-granted understandings about bodies, time and space (Crawford 2013; Blackman 2010; Gupta 2002; Toombs 2001a & 2001b).

Founded on assumptions about spatiotemporalities and bodies, gravity is another example of a body law. When experiencing psychosis, George perceives gravity to be distorting and disorienting:

When I was first unwell, I had a lot of problems with gravity.

*Tell me about that, yeah!*

Okay, well, just the perception of gravity was accentuated. So gravity was really a powerful force, and it was really quite violent on the way that it was perceived and the way that it was happening. The perception of gravity of the body, you know, the body has weight and mass.

*So you felt heavier?*



Really heavy! And the sense of being almost pushed down violently, you know.

*So like every foot, every step?*

Yeah, yeah.

*... So that gravity stuff is pretty –*

Yeah. Well, it's Newton's first law, isn't it?

*Mmm. So schizophrenia kind of mucks up Newton's first law even?*

It does, in a big way! Getting around or doing simple things like having a shower was like a nightmare because everything was so kind of, you know, violently pressed down.

Schizophrenia, for George, confuses the experience of showering: water drops speed up whilst simultaneously landing with extreme force and weight on the body. George relays how one of his friends, who also has a diagnosis of schizophrenia, advocates for understanding gravity in completely different terms to the taken-for-granted: "A guy in [a local psychiatric clinic] said – I don't want to use bad language – but he said 'Fuck gravity and just levitate!'".

Toombs (2001a & 2001b) applies a phenomenological approach to her own experience of living with multiple sclerosis to show how disability has ramifications for perceptions of time and space. Due to the restriction and immobility that she now endures as a result of her impaired motor functioning, Toombs explains that she experiences "a heightened sense of distance between oneself and surrounding things" (2001b, 34). Understandings of time and space are not fixed, but instead changeable and relational.

These illustrations endorse embodied constructions of the body as inherently "transgressive in nature" (Williams & Bendelow 1998, 124) and uncontainable. Like experiences of schizophrenia, Schmied and Lupton's (2001) qualitative study elaborates on ways in which breastfeeding defies the body laws of bounded, discrete and separate bodies. Leaking breasts symbolise the ambiguity between self and Other (Schmied & Lupton 2001) in a similar manner to the blurred

boundaries of self and Other in Keith's anecdote of his voices' relationship to his dog.

## **Heaviness: failed bodily containment**

Building on the bodily transgressions of schizophrenic experiences, antipsychotics and antipsychotic side effects further amplify and exacerbate the unsettling experiences of bodily transgression. Metaphors of containers and containment bring together minds and bodies (and madness and fatness) to theorise the ways in which antipsychotic-induced weight gain impacts on the body's positioning in space. The participants illustrate their weight gain as restricting their sense of spatiality and producing experiences of the 'three heavies': the participants describe a heaviness in terms of bodily movement and motility; a heaviness of numbed emotionality and motivation; and a heaviness of extreme tiredness and dream-states.

The full experience of schizophrenia, antipsychotics and side effects can only be understood within the wider frame of reference of time, space and bodies. Sociological works on embodiment and disability highlight how little biomedical accounts reflect the actual lived experiences of pain, illness and disability (Honkasalo 1998; Paterson & Hughes 2012; Toombs 2001a & 2001b). Toombs explains that she does not experience her illness as lesions in her brain, but instead experiences her illness as "the impossibility of taking a walk around the block, of climbing the stairs to reach the second floor ... or of carrying a cup of coffee from the kitchen to the den" (2001a, 247).

My participants similarly forego biomedical conceptualisations in favour of descriptions of embodied spatiotemporalities to describe their experiences of madness and fatness; schizophrenia, for example, is experienced as ruptured bodily borders (space) and the zooming velocity of disrupted gravity (time). These descriptions align with writings in human geography and philosophy that seek to

bring issues of embodiment into analyses of time and space. After reviewing relevant works in social theory, Moran argues that human geography is positioned at the “intersection of debates over the relationship between time and space” (2012, 308). In her exploration of this relationship in the context of “doing time” within the prison system, Moran asserts: “The embodied experience of time is inextricably bound up with the embodied experience of space, and vice versa” (2012, 310). These sentiments are echoed by Abrahamsson and Simpson who, in their study on the “limits of the body”, draw attention to the interrelationship between bodies, time and space:

the body becomes a matter of concern *because of the ways in which it is relationally coupled with space and time*: it is what constantly changes and still endures; it is part of what we have and part of what we are; it is worked upon from an outside and worked with from an inside; it is done in scientific and everyday practices; it is constituted by socio-cultural inscriptions and by evolutionary-neuronal forces. (2011, 332, *my emphasis*)

Incorporating embodiment into considerations of spatialities allows for understandings of space that it is constituted through the experience of the body (Csordas 1994). Thrift’s (2000; 2007) early theorisations of space and spatial practice conceptualise the body as not only being inhabited by space but also as producing space. The social production of space thus understands space as “not discovered but rather ... [as] socially constructed or produced in the play of events, flows and encounters between individuals, objects and spaces” (Duff 2007, 509).

Conceptualisations of bodily space as heaved support conceptualisations of space as socially constructed. This new way of thinking contradicts traditional understandings of space as “absolute, natural, pre-cultural and continuous” (Duff 2007, 508) that are commonly found in medical discourses. Instead, space is relational, embedded, anti-dualist and inhabited:

And so, space is less a natural property of the world, an inert substance, and more a means of making sense of the world, of negotiating movement

and passages and organising relations and cultural practices. Above all else though, space is continuously evolving and becoming, being made and unmade, contested and settled, territorialised and de-territorialised. (Duff 2007, 509)

This is why analyses of time and space and bodies underpin this thesis: understanding bodies as embodied opens up understandings of time and space as lived (Honkasalo 1998). Unlike the objective and “empty” (Honkasalo 1998, 38) constructs of bodies and spatiotemporalities within medical frameworks, lived time and lived space produce experiences of bodies and time and space that are blurred and ambiguous. The experienced, moving, transgressed spatiotemporalities in pain, disability and illness narratives opens up conceptualisations of lived space, and the metaphor of heaviness exemplifies the participants’ narratives of madness and fatness.

### ***Heavied bodily motility***

The heaviness of the antipsychotic-induced weight gain is exemplified by experiences of immobility: the weight gain literally weighs people down and slows them down. Bodies are spontaneously described as being restricted and “constipated”. Verbal, non-verbal and written forms of communication help the participants to illustrate the everyday experience of living with heaviness.

After greeting Peter in the mental health centre’s waiting room, I invite him to follow me to the interview room; behind me, I hear Peter’s quiet puffs and gasps for air as he follows me slowly down the corridor. It is a warm Australian January day, and his face is still flushed from the outside hot air. Upon walking into the room, Peter deliberately assesses the available chairs in the room, and chooses the one without arm-rests; he pauses, possibly sizing up the chair’s width, before taking a seat and shifting several times to get comfortable. These movements are methodical and unhurried, and carried out with a sense of intention. After briefly

describing my research project, Peter immediately initiates discussion about his own experiences of weight gain, and I take the opportunity to delve further:

*So how do you feel about the weight gain?*

The weight gain? Um, well I suppose, a lot heavier, more to carry around. You know, I'd like to be less, you know what I mean.

*Why would you like it to be less?*

Because you move around and you can get up a lot quicker, and you're more active, you know what I mean. Now I just lounge around.

The metaphor of “loung[ing] around” highlights Peter’s experiences of immobility, boundedness and restricted spatiality, and his slow movements and meticulous assessment of seating arrangements illuminates the everyday experiences of antipsychotic-induced weight gain. Peter enjoys being active; at 48 years of age, his fitness has been integral to his long history of training at gyms and his trade as a fitter and turner. In his own words, Peter draws immense joy and meaning from “doing things”: “concentrating on things ... working on things ... always working on something”. However, because he is now “heavier”, he is not able to be as active as he would like. Another male participant, Dren, laments how the weight gain restricts movement: Dren dislikes how he can no longer exercise because he is “heavy”.

The female participants echo the sentiments of Dren and Peter. After panting her way into the interview room, 61 year old Mary describes how her weight gain “slows [her] down”. Asked to describe how this impacts on her day-to-day activities, Mary explains that the weight hampers her from walking, causes her to “not breathe properly” and forces her to “sit down and get [her] breath” during domestic chores. For Mary, the weight gain explicitly “slows you down, slows you down!”. Although her arthritis presents severe mobility restrictions, 66 year old Josephine nonetheless believes that her weight gain poses further movement issues; despite having to hold our interview in her home due to her difficulties in accessing the mental health centre, Josephine frames her walking troubles in relation to her

weight gain. Like the other participants, Josephine speaks of her weight gain as slowing her down and reducing her activity: “Because when you carry a lot of weight, you’re not moving around as much”. Being slowed down is about being immobile; participants are fixed by their weightiness in the same way that an anchor restricts movement and speed.

Metaphors of heaviness disrupt constructions of the body as a fixed container located within a static spatiotemporal position. Metaphors are intrinsically related to bodies (Lakoff & Johnson 1980; Gibbs *et al* 2004), and bodies thus possess “embodied knowledge” (Johnson 1991), in which all knowledge and ideas are developed through our understandings of the intricacies and activities of our bodies.

The body, as a container, is bordered by skin, and skin thus becomes a metaphor for boundaries (Ahmed & Stacey 2001; Burris & Rempel 2004; Flanagan & Booth 2009). In the introduction to their collection of essays and short stories on skin, Flanagan and Booth describe skin to be “both the boundary and the surface, as well as the place where critical tensions between surface and depth, interior and exterior, are played out” (2009, 6). Skin is “malleable” (Flanagan & Booth 2009, 1), leaky and can be penetrated and intruded upon; skin is characterised by its inherent fluidity (Grosz 1994). Not only do voices cross bodily borders (skin), but so does unwanted weight. As skin is the boundary of the body, anything that crosses it is a threat; voices and weight thus represent threats to the security of the body:

Some degree of vigilance and safeguarding of the skin thus seems normal, rational, and healthy ... the perception of threat associated with violation of the boundary delineated by the skin – the actual or threatened movement from out to in – can evoke powerful, often nonrational, reactions. (Burris & Rempel 2004, 21)

Metaphor theory is useful for understanding the participants’ metaphors of their weight gain as heavying. As metaphors help to “see and understand one thing ...

in terms of another” (Nerlich & Jaspal 2012, 133), the participants’ weight gain is understood with reference to the everyday concepts of anchors and constipation. Stacey explicitly describes her weight as something that gives her a heavy, “constipated” feeling. Wearing walking shoes, comfortable-looking clothing and beaming a large smile, Stacey navigates her shopping trolley around the door and chairs into the interview room. She explains that she plans to do some grocery shopping afterwards, before walking her trolley home in the afternoon. Stacey describes herself as a size 20 and weighing 135 kilograms, and I notice that her round face makes her look younger than her 38 years. In the prior nine years since first being prescribed antipsychotic medication, Stacey has experienced an increase of 70 kilograms. Using her hands to demonstrate her incremental weight increases, Stacey illustrates how she “grew and grew and grew”.

Even though she maintains a positive attitude towards her medications and side effects, Stacey admits to trying to lose weight and that “sometimes” she resents the medication and wishes she could walk more. Asked to describe this weight gain, Stacey surmises it as weighing her down:

*But do you think that if you got off the medications it might be easier for you to lose weight?*

Yep.

*Okay, so why do you think that is?*

Um, probably because it hasn’t got that constant, um – what’s that word?

Oh gee, I can’t find the words. It’s like a weight that’s pulling you down sort of thing, but it’s medication and it’s like feeling constipated and you can’t really get rid of the crap inside of you. Sorry, sorry to say.

In “pulling” her down, Stacey likens her weight gain to the slowed and bloated experiences of constipation. Similarly, in their ethnography of a specialist constipation clinic in England, anthropologists Wainwright and colleagues (2011) investigate the common “disabling” (Wainwright *et al* 2011, 1649) effects of constipation and how they revolve around experiences of immobility: “homeboundedness, isolation and retreat from the working world ... [and] feelings

of low self-esteem” (Wainwright *et al* 2011, 1649). Homeboundness connotes experiences of being ‘stuck’ and restricted to the realm of the home. The participants’ spatially restricted bodies, characterised by “corporeal ambiguity and fluidity” (Shildrick 1999, 78), thus represent sites of disruption and displacement.

### ***Heavied emotions***

As well as manifestations of a physical heaviness, the participants describe a heaviness of emotionality. Metaphors of heavied and flattened emotions contradict constructions of bodies, highlighting the collapse of three-dimensional bodies into two dimensions. Within dualist Cartesian thinking, rationality is afforded status and privilege over emotionality (Williams 1998), in the same way that the mind is privileged over the body. Metaphors of emotion are analogous to metaphors of bodies in that emotions are seen as potentially dangerous and should be the subject of containment (Lakoff & Johnson 1999; Kövecses 2004; Robinson *et al* 2006). Emotions that intrude upon and disrupt such containment consequently traverse and impinge on bodily borders, and is viewed with suspicion.

For Krishna, schizophrenia is experienced as “very strong emotions”, characterised by anger and “very aggressive behaviour”. In contrast, however, the antipsychotics numb and dampen these feelings by making him feel “flat”:

*Do the antipsychotics make you feel differently?*

They make you feel flat emotionally.

*... What does “feeling flat” feel like?*

Slightly down, just empty and not feeling anything.

*So what does “empty” feel like?*

Empty feels like empty and not really feeling anything.

Being “flat” denotes a two-dimensional state. To be “flat” is to be literally close to the ground: heavied, flattened and immobilised. As metaphors are understood with reference to human spatial and bodily comportment, Lakoff and Johnson’s (1980)



orientational metaphors provide a framework for the participants' descriptions of flattened emotions. Spatial metaphors are "rooted in physical and cultural experience" (Lakoff & Johnson 1980, 18), and metaphors of health and sickness arise from having bodies that "function as they do in our physical environment" (Lakoff & Johnson 1980, 14). Spatially, the metaphor of health and life is understood to be "up", whereas sickness and death are culturally understood as "down" (Lakoff & Johnson 1980, 15). This, Lakoff and Johnson argue, may be due to the fact that "serious illness forces us to lie down physically. When you're dead, you are physically down" (1980, 15). Like the common cold being characterised as 'coming down with something', the participants' metaphor of being weighed down is a metaphor for sickness.

Drawing on Lakoff and Johnson's orientational metaphor of "happy is up; sad is down" (1980, 15), Krishna's "empty" is likened to sadness and sickness. Sadness is taken to be 'down', and arises from the physicality of our bodies where "drooping posture typically goes along with sadness" (Lakoff & Johnson 1980, 15). In her work on disability and reflecting on her own experiences, Toombs acknowledges the political repercussions of her loss of motility and mobility: "We assign value to upright position. We applaud the man who can 'stand on his own two feet'. We praise those who are 'upstanding'" (2001a, 255). Sitting or lying positions, however, reorganises and disorients space. Experiencing diminished space or experiencing vulnerability with one's equilibrium reduces social positioning within the broader social hierarchy.

Antipsychotics create experiences of being 'down' through their "dampening", demotivating nature. Describing himself as a "not a thrill-seeker", George appreciates the ways in which his antipsychotics "dampen things down a bit". Although others may like "the more edgy stuff", George instead prefers the feelings of "calm" and "quiet" that come when taking his antipsychotics. Keith similarly describes his antipsychotic medication as making him "lazy". These dampened

emotions fit within Lakoff and Johnson's (1980) orientational metaphor: demotivation is 'down'.

As well as being "flattened" and "dampened", emotions may also be experienced as entirely "numbed". Asked to elaborate on how antipsychotic medication works, Dren offers his experiences:

*So do the drugs work on a specific body part or the whole body?*

Yeah, the whole body, like a numbing feeling. Like I don't get goosebumps, I don't get emotional, like goosebumps from music. It's like I've got no heart!

*What do you mean you don't have any heart?*

No feelings.

*And why is that?*

It's the medication.

*What does the medication do to cause that?*

Makes me numb.

*So it makes your whole body numb?*

Yeah.

Dren identifies the antipsychotics as responsible for numbing his emotions and depriving him of joy. As a musician and a music-lover, Dren notices that he no longer gets goosebumps from music like he previously did.

I met Dren twice and, on both occasions, he wore the same checked shirt, denim shorts, thongs and sunglasses tucked into the front of his shirt. Dren is tall with long greasy hair, and his playful persona makes him seem friendly and helpful. Thirty-two years old and of Croatian heritage, Dren was first diagnosed with schizophrenia as a 21 year old, though he now believes that he is "pretty much getting over it". He gained 20 kilograms in the two-month period following his diagnosis of schizophrenia and commencement of medication and, since then, he has experienced a gradual weight gain of 53 kilograms. Dren says that he is generally "disgusted" when looking in the mirror and that he is "depressed [and] not angry" with his medication. He wishes that he did not have to take the

antipsychotics and emphasises that he does not “want to be on these meds all [of his] life ... [but instead] actually wants to have a life”. A “life” that he aspires for is one in which he could be involved in all of the activities he enjoys: having a job, playing sport, exercising at the gym, creating art, and making music (writing music and playing in a band). Dren explains that the antipsychotics work on “the whole body, like a numbing feeling”, reducing him to a body without a heart.

When drawing on Lakoff and Johnson’s (1980) orientational metaphor, it is important to be careful so as not to perpetuate and extend the Cartesian dualisms of up/down that mirror the dichotomies of mind/body and male/female. Whilst the up/down metaphor is useful for expanding on the heavying experiences of antipsychotic-induced weight gain, the participants avoid categorisations of one-dimensional experiences. Having “no heart” is analogous to Krishna’s description of feeling “empty” and “feel[ing] flat emotionally”. Inverting the orientational metaphor, metaphors of heaviness are juxtaposed with metaphors of elevation. After explaining his “empty” feelings, Krishna further elaborates:

*And what does “happy” feel like?*

Ah, bright feeling.

*What do you mean “bright”?*

Bright and happy and a raised mood, an elevated mood, just feeling good. Some of the things that makes Krishna feel “bright” include his pet cat and his relationships and interactions with others. Spatial metaphors assist in understanding what is meant by “bright” and elevated feelings: in contrast to feeling “flat” as feeling ‘down’, to feel ‘up’ (or “raised” in Krishna’s words) is to feel ‘happy’ (Lakoff & Johnson 1980). Due to the inherent “sensitivity and hiddenness of [emotions] ... within contemporary society” (Froggatt 1998, 333), it is important to understand emotions through the prism of orientational metaphors.

## ***Heavied wakefulness***

The side effect profile of the antipsychotic medication also produces experiences of feeling 'down' through unrelenting fatigue and exhaustion. Ashley uses the metaphor of "sleep heavy" to illustrate his experience of the side effect of extreme tiredness. Metaphors of sleep-induced heaviness, along with contemporary sociologies of sleep (see Williams 2005), reveal "sleeping bodies" (Williams & Crossley 2008) to be open and penetrable, challenging taken-for-granted constructions of contained and enclosed bodies.

"There's no couch [to lie on] in here!", reacts Dren when he walks into the interview room. In line with his playful disposition, this comment highlights the participants' everyday experiences. Throughout our interviews, Dren continually rests his head on his hands and appears to be very tired. Despite my several offers to postpone the interview to another date, Dren refuses, explaining that he would be just as tired at the next interview, too. Dren explicitly speaks of this fatigue as "heavy" and "main brain numb". In fact, throughout our two interviews, Dren uses the word "heavy" 16 times to describe his weight gain and general experience of the antipsychotics. He likens this "heavy feeling" to being "zonked out", "paralysed", as "kind of feel[ing] drugged up like an animal getting tranquilised" and "look[ing] like someone on heroin or something". He relays how his common question when with friends is "Can I just go and sleep on your couch?". This experience, for Dren, is like being "body stoned".

The participants are careful to distinguish their own experiences of the antipsychotic side effects from ordinary tiredness; Ashley explicitly avoids the term, instead describing his experience as "sleep heavy". In their multi-method study on tiredness for people with depression, Canadian nursing researchers Porr and colleagues (2010) similarly argue that tiredness can be conceptualised along a continuum. My participants' characterisations of heaviness fall within these definitions of fatigue and exhaustion. Unlike tiredness, which is categorised as "a

normal response to activity” (Porr *et al* 2010, 1315), fatigue is instead associated with “a gradual loss of energy sooner than expected and the onset of anxiety, an inability to concentrate, insufficient sleep, and the propensity to preserve energy for enjoyable or imperative activities” (Porr *et al* 2010, 1315).

My participants animate the anxiety commonly experienced in fatigue (Porr *et al* 2010), and reveal the blurred distinctions between boundaries of sleep and wakefulness. Kylee describes the distinction between sleep and dreaming, as “you just fall asleep but you don’t dream”. In a subsequent interview, Kylee further elaborates: “It actually renders you unconscious ... it actually freaks you out a bit!”. Afraid to fall asleep, the heavy nature of her experiences of fatigue caused Kylee to stop taking her antipsychotic medication for one month.

Like Kylee’s experience of being “unconscious”, Dren offers a similarly disturbing anecdote. Asked to explain what he means by the antipsychotics making him “body stoned”, Dren answers:

Um, that paralysed feeling ... I get this sensation while I’m sleeping. I don’t know if I’m dreaming it, but it’s like I’m trying to call out and I can’t move or talk ... I don’t know how long it lasts for, probably 10 minutes. I don’t know if I’m actually dreaming it or if I am awake. I can’t move and talk and then eventually I come to. So that’s what being really heavy is like, when my meds kick in.

These side effects have serious health consequences. Suffering from sleep apnoea, Krishna must now sleep with an oxygen pump to keep him from “stop[ping] breathing in the middle of the night”. Krishna explains that the highly sedating side effects of the antipsychotics cause his “airways ... to go lax and compress”.

Further along this scale of tiredness, exhaustion is described as having even more serious health implications, including experiences of “confusion resembling delirium, emotional numbness, change in sleep quality, increased drowsiness and

social withdrawal” (Porr *et al* 2010, 1315). Thwarted sleep patterns is particularly distressing for some participants, and is consistent with Porr and her co-authors’ articulations of fatigue and exhaustion as “insufficient sleep” (2010, 1315) and a “change in sleep quality” (2010, 1315).

Difficulties in achieving deep, satisfying sleep is explicitly understood by Krishna to be “made worse by [his] weight”. This highlights the complex relationship between weight and the increasing prevalence of exhaustion and lack of quality sleep, especially within the busyness of the Western world. Keith and his colleagues find that “less sleep can cause increased body weight” (2006, 1587) and “sleep restriction ... [produces] increased hunger and appetite” (2006, 1587). In her critique of the modern weight-centred health framework of obesity research and treatment, Aphramor draws a link between sleep and weight, asking “Where does sleep debt, for example, fit into the dominant energy-in/energy-out modelling of obesity?” (2005, 322).

The participants draw on metaphors of heaviness, zombies and paralysis to further demonstrate their experiences of sleep heaviness. The fatigue experienced as a result of the antipsychotics, for Rasmey, makes her “act like a zombie”. The metaphor of zombies is particularly illustrative in demonstrating the profoundly sedating nature of the antipsychotic side effects. Populist understandings and popular culture references characterise zombies as being the ‘un-dead’ or the ‘living dead’ – in this sense, zombies simultaneously represent elements of being both alive and dead. By drawing on this metaphor, Rasmey demonstrates the sedating nature of the antipsychotics.

The analytic lens of liminality helps to conceptualise this oscillation between life and death. Behuniak (2011) examines the use of the zombie metaphor within constructions of Alzheimer’s disease. The zombie – like the person with Alzheimer’s – represents the “liminal status between the living and the dead” (Behuniak 2011, 76); the zombie metaphor thus contains “a multitude of meanings,

layers, critiques and fears” (Behuniak 2011, 76). As the ‘living dead’, zombie-hood dehumanises; people with Alzheimer’s disease, or with experiences of extreme tiredness, are accordingly “less than human” (Behuniak 2011, 77). For Hockey and Draper, Alzheimer’s disease represents “the ambiguous relationship between the body and social identity” (2005, 46). In the way that Alzheimer’s disease robs social identity, the concepts of liminality demonstrates how the social withdrawal and isolation of Alzheimer’s disease renders sufferers as “biologically alive, yet social dead” (Hockey & Draper 2005, 47).

Psychologist Sass has had extensive experience in working with people diagnosed with schizophrenia, and he similarly describes people as existing within a “corpse of insomnia” (1992, 8) and entrapped in a “sort of morbid wakefulness and hyperawakeness ... [where they feel] dead yet hyperalert” (1992, 8); they are the “animated corpses” (Behuniak 2011, 72) of Behuniak’s study. The zombie metaphor eloquently illustrates how it feels to be at the border of these two realms; in this sense, the zombie metaphor draws parallels between the intermediate worlds of life and death with the intermediate worlds of wakefulness and sleep. The participants’ illustrations of zombied sleep render them as existing within “liminal status” (Behuniak 2011, 76). For this reason, Rasmey describes the “sleepiness side effect [as] the worst thing”, resulting in her stopping the medication and substituting it for one without such side effects.

Metaphors of heaviness emphasise the paralysing and immobilising nature of antipsychotic side effects. The participants’ difficulty in articulating experiences of fatigue is particularly striking. Instead of using words to describe his experiences of fatigue, Dren augments his verbal descriptions with bodily movements:

*So how do you know when you’re tired?*

Oh, I just feel heavy and tired.

*What does that feel like?*

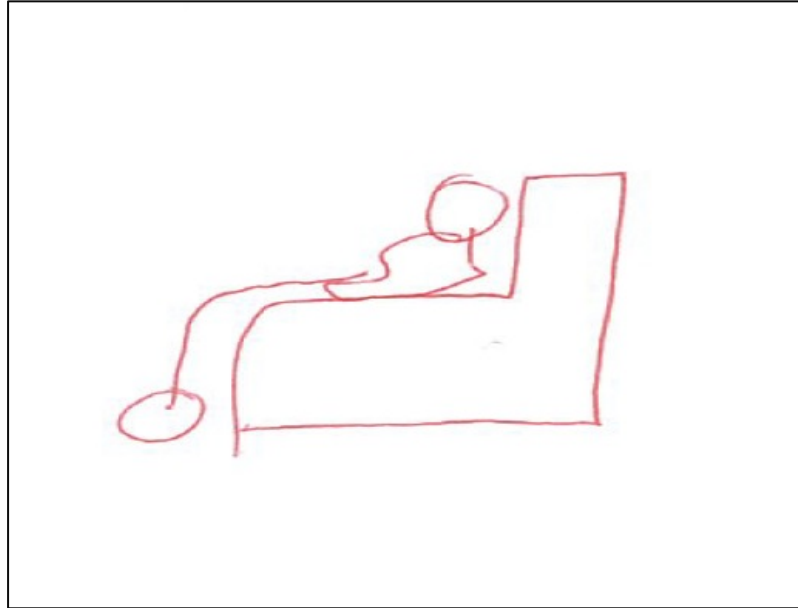
Mmm, just a heavy feeling, like – how can I explain it? I guess it's just too hard to try and sit there, it's like 'arrrr' [*puts head back against top of chair and rolls eyes into back of head as if struggling to keep head up*].

... *How do the medications work on your body?*

Mmm, it kind of looks like I'm on heroin, my mouth's open and I'm just [*flops against back of chair with mouth open and eyes closed*]. Like it looks I'm drugged up ... but it's just really heavy.

Dren's experiences of antipsychotic side effects render him immobile. To further explain his experience of exhaustion, Dren uses a combination of lines and blobs to depict him slumped in a chair: "It's hard for me to get up ... so I need, I need someone to like give me a hand to get off the chair ... So it's like I'm numbed or paralysed" (see Figure 8). In the picture, Dren is a two-dimensional figure, with blobs for his head, torso and feet, and a line to depict his legs. Turning attention to drawings of the person as blobs and lines, Ingold writes that "blobs endow them with mass and volume" (2015, 5) while it is lines that create movement, connection and linking with others. Although part of his body is drawn with a line and represents vivacity and life, most of Dren's body, especially his feet, is drawn with blobs, emphasising his experiences of sedating and immobilising side effects and their disruption to social connectivity.





**Figure 8:** Dren's drawing of being “zonked out”.

Exhibiting resourcefulness and resilience, the participants recount strategies that assist in alleviating their experiences of tiredness; if antipsychotics are understood as rendering the participants as ‘un-dead’, then these strategies help to bring the participants ‘back to life’. One of the most common approaches is to take the sleep-inducing antipsychotics at night-time. Contrary to his psychiatrist’s advice, Ashley now takes his medication at night so that he can “sleep the weariness off”. Indeed, Dren is furious at his psychiatrist for suggesting otherwise:

Well, originally I was meant to pop it in the morning. And like why are they telling me to pop it in the morning when I wake up, when it zonks me out, like a fucking idiot? And I’m like ‘What do you mean?’ I’ve got to pop these tablets at night to put me to sleep! So what’s the point of them telling me to pop it in the morning when I wake up, when I’m going to be zonked out all day anyway? ... And then they were saying ‘You’ve got to take this in the morning’, and I’m like ‘What a load of shit!’.

Other participants talk about the importance of coffee to counteract sedation, as well as cigarettes or, sometimes, a day-time “lie-down”.

Sleep is “a complex, multifaceted, multidimensional phenomenon” (Williams 2005, 169) and, for this reason, Williams calls for an embodied sociology of sleep, what he terms as “this ‘dormant’ third of our lives” (2005, 96). The sleeping body is a useful means to think about human agency, social participation and the “between states” (Blackman 2008, 33) of wakefulness and sleep. Sleep cannot be reduced to a definition of “the closing of our eyes, the partaking of rest, retiring to bed, or even the dreaming of dreams” (Williams 2005, 34). Instead, embodied and phenomenological attention to sleep engenders much more sophisticated and complicated analyses, exemplified by the participants’ illustrations of heaviness and metaphors of paralysis and immobility. Sleep encompasses broader biological, social, cultural, economic and psychological processes (Williams 2005). For the purposes of this analysis, Williams’ phenomenological definition of sleep is useful: “sleep involves a radical shift in the ‘tension’ of consciousness and a spatiotemporal withdrawal from the intersubjective world” (2008, 640).

Collectively, the participants’ use of the heaviness metaphor highlights the intermediate position (Leder 1990) that the sedating side effects occupy. Inherent in being “sleeping as well as waking beings” (Williams 2005, 1) is the oscillations between the states of wakefulness and sleepiness. This has invariably been described as a “between state” (Blackman 2008, 33), an “intersubjective world” (Williams & Crossley 2008, 1) and a “betwixt and between” condition (Williams 2005, 4); sleep is characterised as “hover[ing] somewhere between the voluntary and the involuntary, the purposive and the non-purposive, the learnt and the unlearnt, the conscious and the unconscious, wakefulness and death” (Williams 2007, 314).

Sleep, in other words, both references and contradicts the notion of the autonomous body. Instead, bodies and boundaries are porous, collapsed and open; open body parts represent fluidity between edges and borders. For Ashley, the antipsychotics make him “feel real groggy”. Even though his “body is heavy and wants to sleep”, in Ashley’s words, his “brain is like open to everything”. The notion

of “open” body parts challenges Cartesian dualist understandings of the body, and proffers a uniquely embodied way of thinking about fatigue.

Ashley is a 40 year old male of average height and peaking at a weight of 115 kilograms, and speaks and moves very slowly. Demonstrating an embodied knowledge of the antipsychotics and how they act on his body, Ashley describes how he experiences a “numbness in [his] head” similar to that of a “day dreamy type of state”. Parallels can be drawn here with Dren’s depiction of the “main brain numb[ing]” experience of the antipsychotics. This “day dreamy” state is analogous to the liminal and between states described above. The experience of day dreaming explicitly encapsulates the simultaneous existence within two states: culturally, ‘day’ refers to wakefulness whilst ‘dream’ refers to the state of sleepiness.

Implicit in this state of liminality is the notion of societal withdrawal: sleep is, indeed, the “radical form of severance of withdrawal from the social world” (Williams 2007, 313). Embodiment theorists Williams and Crossley identify sleep as always involving “(partial) withdrawal from the world” (2008, 2). They emphasise the partial nature of sleep because, in their words, “sleep/dream and waking worlds are not entirely closed off to one another” (Williams & Crossley 2008, 2) as sleepers can always be brought back to the realm of wakefulness. Sleep sociologist Lee similarly outlines the “clear threshold between wakefulness and sleep” (2008, 57).

However, the participants’ descriptions of paralysis contradict this notion of partial withdrawal and refute the legitimacy of a “clear threshold” (Lee 2008, 57) between sleep and wakefulness. Liminality, and the embodied experience of the tiredness side effect, entangles and blurs the distinction between experiences of being fully awake and fully asleep. This is highlighted by Dren’s illustrations of being unable to “move or talk”, and Kylee’s descriptions of “unconscious[ness]”.

## Summary

In this chapter I have shown how experiences of antipsychotic side effects amplify the transgressive and disrupting experiences of schizophrenia. The framework of spatialities reveals how the lived experience of schizophrenia contravenes taken-for-granted understandings of the contained body and intact bodily borders. Instead, participants demonstrate the ways in which their experiences can be characterised by a loss of boundaries, and participants use metaphors of the body to show how this loss is exacerbated by the heavying experience of antipsychotics and side effects. Like the participants' descriptions of their experiences of schizophrenia, the participants' descriptions of hungry voices and metaphor of heaviness (and the three heavies) challenges constructions of bodily containment and conceptualisations of the Cartesian body.

The transgressed, fat body is the epitome of the catastrophe of the person. The metaphor of heaviness thus demonstrates the participants' constructions of antipsychotic-induced weight gain as causing immobility and rendering them 'weighted' down, having serious ramifications for their sense of personhood. The next chapter continues to privilege participants' understandings of their bodies through the lens of schizophrenia and antipsychotic medication, and shifts focus from space to experiences of temporalities. Revealing embodied time to be non-linear and multiple, I will demonstrate how the participants' experiences of disrupted temporal experiences have serious implications for health behaviours, rendering participants as "stuck" in time and with no sense of future orientations.

# CHAPTER FIVE

## After the “meds kick in”: disrupted temporal sensibilities

In this chapter, I shift focus away from a spatial frame of reference to a temporal one. I draw on social theory to conceptualise embodied, lived time as multiple and non-linear, and as different from clock time (Elias 1992; Wyllie 2005). These constructions allow for greater insights into the experiences of schizophrenia and antipsychotic side effects, and help to demonstrate the ways in which these experiences transgress taken-for-granted understandings of time. I reveal how participants juxtapose their experiences of the accelerated time embedded in experiences of schizophrenia with both the decelerated temporality of the antipsychotics and the distorted temporal experience of antipsychotic side effects.

I will begin by extending previous works to show how schizophrenia distorts temporal experiences (Corin 1997; Lovell 1997; Lucas 1999), and draw on Flaherty’s (1993; 1999) work on desynchronization to demonstrate how schizophrenia conflicts with clock time. These temporal disturbances make it difficult to share time; as time is socially constructed and institutionalised, people who do not understand or who have different temporal orientations are made to feel strange, alienated and “odd”, in the words of one participant. I then reveal how after the “meds kick in”, perceptions of time are further disrupted: antipsychotics slow down parts of the brain, they delay the sense of passing time, and they slow down and cease bodily mobility (sedation), whilst simultaneously slowing down some bodily internal processes (metabolism) as well as speeding up others (hunger). What marks this population group as different is their simultaneous

experience of all of these temporal distortions, and I demonstrate how the experience of these temporalities has substantial implications for the experience of rapid weight gain.

The experiences of bodily, spatial and temporal transgressions create lived experiences that are bleak and devoid of the potentiality and “new[ness]” of life (Brough 2001, 31; see also Wyllie 2005). I demonstrate how participants perceive their current circumstances, and future opportunities, to be stuck within “the tyranny of ‘forever’” (Seeman & Seeman 2012, 341). I conclude by showing how time-regulators, such as ‘cokes, coffees and smokes’, offer pick-me-ups from heaved existences and help to mark moments throughout the day that are akin to socially-sanctioned understandings of clock time (Fuchs 2005; Klingemann 2001).

## **Schizophrenia and temporal violations**

Bodily transgression comprises both spatial and temporal manifestations. Experiences of schizophrenia disrupt and violate bodily understandings of time as linear, gradual and predictable; instead, embodied experiences of time are non-linear. My participants describe time as hurried, as having “racing” thoughts, and as experiencing sped up temporalities. The failure to share understandings of time renders participants as “a bit odd”, in the words of Krishna; this represents the limitations of sharing time.

Participants described their experiences of schizophrenia in temporal parameters: as “sped up” and “too fast”. Krishna refers back to his high school studies in biology to explain how he understands his experiences:

*How do you experience schizophrenia?*

Nerve endings, the neurons in your brain become overworked and overactive.

*... So schizophrenia is like too many neurons in the brain?*

Yeah, too much activity in some parts of the brain.

*So are they like little things bouncing around in the head?*

They're like a tree with sort of electric signals coming through.

*Sure, and the neurons light up?*

Yeah.

These active neurons make Krishna's thoughts "become racey".

John mirrors these conceptions of "racey" thoughts. For John, the experience of mental illness is represented by his difficulty in sleeping. As well as depicting his experiences of schizophrenia as shakiness and "tingling" of the arms, it is the "racing" and "repeating, repeating, repeating" experiences that causes him the most distress. During long periods of sleeplessness, time is halted and stalled. Despite schizophrenia speeding up everyday experiences of time, the lack of relieve from the continual "racing" thoughts over extended periods of time create experiences of "empty time" (Corin 2007, 281). Within "empty time", time is expanded indefinitely. John's descriptions of "chronic boredom" and drawn-out days of "nothingness" mirror understandings of Corin's (2007) "empty time". As Corin highlights in her ethnographic study into the lives of people with schizophrenia, "empty" temporalities create "feelings of vacuity and boredom" (2007, 281).

The antipsychotic medication that John is prescribed fails to "get through to the relaxation" and fails to relieve John of his experiences of "empty time". John thus frames his antipsychotics as attempting to treat the distorted temporalities of his schizophrenic symptoms, and he draws on temporal constructions to illustrate his desire for the antipsychotics to slow down his thoughts. The failure to do this, in John's terms, prompts him to self-prescribe:

They should relax me, but they don't! ... That's why I've overdosed on them!

To get through to the relaxation, but they just don't get any sleeping power.

*So you take more of them than what you're prescribed?*

Yep ... They can't help you out.

John's characteristic rapid pace of speech mirrors these "mind racing" descriptors. "Overdosing" on his antipsychotic medication highlights John's desperation for sleep and respite from the temporal transgressions of schizophrenia.

When explaining their experiences of schizophrenia, most participants use descriptions of antipsychotic medication to juxtapose the temporal orientations of schizophrenia and antipsychotics: schizophrenia is constructed as being sped up, and antipsychotics are understood as slowing down experiences of schizophrenia. To stabilise his experiences of "too fast", Krishna's medication helps to "slow down" his "brain activity":

*And how do the antipsychotics work?*

Slows them down. I know that some schizophrenics have schizophrenia because the brain activity is too fast.

Other participants echo these concerns about the ubiquitous threat of uncontrollable experiences of schizophrenia. Although not having been diagnosed with schizophrenia until she was 45 years of age (she is now 61), Mary draws on themes of containment to explain how the antipsychotics work:

*So do you consider yourself not sick anymore?*

Ah, it's manageable now with the needle [antipsychotic injection], it keeps me under control. But I could go anytime, I suppose. So, no, I say I'm still sick.

Despite regular antipsychotic injections helping her to remain "under control", Mary articulates her continued vulnerability by self-identifying as "still sick".

Schizophrenia is represented as the continual threat of uncontainment; it is "losing control" or not being "under control".

Other studies have also revealed the temporally transgressive nature of schizophrenia. Sass describes the "destabilized or radically transformed" (1992, 14) time orientations of those with experiences of schizophrenia; indeed, one of Sass' patients characterises himself as a "timeless being" (1992, 14). These



observations are not new, and in her ethnography of those experiencing both schizophrenia and homelessness, Lovell (1997) draws on texts that highlight the temporal disruptions inherent in the experience of schizophrenia (Arieti 1948; Balken 1943; Jameson 1991). My participants likewise experience the temporal distortions of schizophrenia as a violation.

### ***'Oddness' and the repercussions of varieties of time***

Extending the relationship between corporeality and temporality, my research reveals how people who are unable to experience or participate in shared constructions of time are marked out as different. This demonstrates the significant ramifications in failing to understand and adhere to communal or clock time. Social theories of time help to show how simultaneously experiencing a variety of times engenders some people, especially those with schizophrenia, to feel “odd”.

Time and space are intimately and perennially connected; indeed, the concept of clock time draws on the understanding of time as “motion in space” (Lakoff & Johnson 1999, 139). Our understanding of time is developed “through the spatialization of time into periods, numbers, distances” (Schillmeier 2008, 216). Time is literally the movement of the clock-hand around a clock-dial:

As clock-time ‘time’ comes into being through the very absence of time, mere spatial relations define time. In effect, clocks and chronographs become space-giving intermediaries of time. They give space to time as clock-time measurable, calculable, traceable, exact, comparable, dividable, specifiable, etc. Clock-time, then, *isn't* time but *gives* time, and in a very specific, spatialized and embodied sense ... Time-spaces mediate time into space and space into time. It mediates the motility of time and space. Time spatializes and space temporalizes. (Schillmeier 2008, 216, *original emphasis*)

Clock time must be distinguished from lived time. Unlike the socially proscribed nature of clock time (Elias 1992), lived time is defined as the “experience of the embodied human subject ... [and] directed towards the world in terms of bodily potentiality and capability” (Wyllie 2005, 173). In this sense, personal lived time, like the “temporal conscience” (1992, 11) of Elias’ work, is the embodied understanding of sped up time described by my participants. Social theorists agree that lived time, unlike the single, linear and objective nature of clock time, comprises “multiple structured sociocultural dimensions” (Ryan 2005, 838). This lived time is imbued with personal and social meaning, in which “the linearity of physical time [that is, clock time] is reshaped by convention into all manner of ‘unnatural’ forms” (Ryan 2005, 838).

It is only when there is a conflict between these two realms of time – that is, when the juxtaposition between clock time and lived time becomes apparent – that experiences of time are revealed from its inherent taken-for-grantedness. People with experiences of lived time that contradict and rupture taken-for-granted understandings of clock time are thus faced with experiences of time that are otherwise understood to be “absent” (Leder 1990). Although there is a taken-for-granted “rough synchronization between the perception of time and the objective time of clocks and calendars” (Flaherty 1993, 398), when the two realms of time fail to align, desynchronization occurs (Flaherty 1993).

The participants’ descriptions of schizophrenia and its temporal disruptions represent movement away from societal understandings of clock time. When talking about his neighbours, Krishna illustrates the disconnect he feels from them:

*Do you think they know that you have schizophrenia?*

No, but I think they think that I’m a bit odd.

*So do you think you’re odd?*

Yes.

*What does that mean?*

I’ve never learnt normal social behaviours.

*Do you think that's because of the schizophrenia?*

Yeah.

When explaining the reasoning for his oddness and for his difficulties in understanding others, Krishna hypothesises that his experiences of schizophrenia have impeded his learning of certain social understandings and rules.

According to Elias' important text on time, as well serving the "social function" (1992, 2) of orienting and regulating human behaviour, time is also a learnt social process. This aligns with Elias' constructions of "the social institution of time" (1992, 11):

The individual does not invent the concept of time on his own. [One] learns to recognize 'time' as a symbol of a social institution the external compulsion of which the child soon feels at first hand ... [If] a child in such a society does not learn early on how to regulate his behaviour and feelings in keeping with the social institution of time, it will be very difficult, if not impossible, for such a person to take up the position of an adult in this society. (1992, 11)

Social isolation and social deviance are repercussions of failing to learn and embrace clock time, and Lovell documents the "loss of a socially shared sense of time" (1997, 362) in her study. Elaborating on his difficulty in having and maintaining relationships with people, Krishna concedes that his experience of schizophrenia makes him a "bit funny", rendering him – in his own words – not doing "well at understanding relationships". Experiences of disrupted time have flow-on effects for relationships and social interaction. As time is social, the failure to share understandings of time makes interactions, for Krishna, unfamiliar and strange.

Desynchronization – or "personal disjunction" (Flaherty 1999, 3) – has severe implications for one's sense of self and wellbeing, as Krishna explains. In her exploration of ageing, Chernus illustrates the debilitating experience of desynchronization, arguing that "our enslavement to 'clock-time' ... may actually

exert an ongoing, limiting, and perhaps even stressful impact on our degree of contentment” (2011, 335).

## **After the “meds kick in”: extending understandings of distorted temporalities**

As well as the “stressful” repercussions of desynchronization, the antipsychotic side effect profile further adds to the burden of distorted time. The side effects of sedation and hunger simultaneously expand and constrict perceptions of time: sedation and boredom prolong time and interfere with the flow of time; whereas hunger changes and disrupts the taken-for-granted ordering of hunger. The temporal transgressions of the antipsychotics thus produce experiences of varieties of time.

### ***Sedation and boredom***

The sedating side effect of antipsychotic medication has received some critical attention (Jenkins *et al* 2005, 219). As well as producing experiences of heaviness and disrupting the spatial containment of bodies, sedation produces experiences of uncontained and disrupted time. The intimate relationship between sedation and boredom exposes their innate “temporal dimension” (Conrad 1997, 473). Goffman (1968) recognised the ubiquity of boredom to be the fourth characteristic of all ‘total institutions’, and I will later develop how the lack of “temporal oscillation” (Conrad 1997, 473) implicit within the experience of boredom renders my participants as perceiving their future as a “dead ending” (Brissett & Snow 1993, 240).

As illustrated above, when asked to describe how antipsychotics work, my participants drew on explanations that characterise the medications as slowing down, quietening or stopping parts of their brains. To the wrath of his voices, Keith enjoys taking his antipsychotic medication as it helps to slow down his thoughts

where he can “switch [his] mind off ... [and] drift away”. This sense of slowed time is threaded through other participants’ narratives. Josephine depicts the antipsychotics as “relaxing” her so that she “don’t move around much”; Stacey talks about the antipsychotics as “settling” and “stopping” her thoughts; and George explains that after his antipsychotics “kick in”, “things will sort of slow down a bit”. This slowness is analogous to the metaphor of softness and quietness: Sam explains that his antipsychotics prevent the voices from being “so loud in [his] head”, and George explicitly illustrates his medication as “a quiet drug” that is “there, sort of softly”.

This sense of stillness and soundlessness differs from the participants’ temporal sensibilities of schizophrenia. John’s “racing” thoughts are mirrored in the language of Krishna’s “overworked” brain. The participants emphasise their experiences of the accelerated time embedded in experiences of schizophrenia to contrast their experiences of the antipsychotics as decelerated temporalities.

The implications of slowed time varies between participants. Psychiatrist William explicitly identifies the differing understandings and appreciations of antipsychotic side effects amongst his clients. Sedation, he warns, is “a two-edged sword”. The metaphor of a “two-edged sword” encapsulates the experiences of those who value the sedating nature of the side effects and those who do not. As William explains, some people prioritise “sleeping well” and the reduction in anxiety that sedation provides; whereas others, particularly those studying or in employment, prefer “to have an extra bit of anxiety to have a sharper cognition”.

The case studies of John and Rasmey fall within William’s double-edged descriptions of sedation. As described earlier, John is desperate for sleep and, for him, the antipsychotic medication has failed in slowing down his racing thoughts. Rasmey, on the other, laments the sedation of the medication, unequivocally characterising the side effect as “worse than having the psychotic thoughts”. Like the slowing down analogy used by the other participants, Rasmey illustrates the

“seducing” nature of the antipsychotics. For her, the antipsychotics “seduce you to relax”; they slow down and stop the speeding thoughts. Although she concedes that some “seduction” can be helpful, often the antipsychotics have a detrimental effect on her sense of time:

Those medications seduce you to relax. Like they seduce you to go to sleep ... But when it seduces you to relax, it’s too much, it’s too much of it and I can’t do much! ... And then I stop for awhile, I stop taking medication because the side effect was so bad.

*Really?*

Yeah, really bad so I had to stop.

These drawn out and protracted temporal experiences affected Rasmey’s everyday experiences of time to such an extent that she consequently made the decision to stop taking her antipsychotic medication.

The intersection of boredom with sleep and inactivity interact with food; indeed, many participants talk about “eating out of boredom”. Dren describes himself as “some person that sleeps all day and doesn’t do nothing with his life”. To counteract these feelings, Dren often “wake[s] up and ... eat[s] something”. Nurse Barbara further qualifies the “Catch-22” culminating effects of boredom and weight gain:

And then, of course, it becomes a Catch-22: they sit there and they put on weight, they don’t want to move, they don’t want to walk, they become more sluggish, so then it’s like ‘We’ll just do the same thing again’. And then it just gets to a stage where you have people who are like 150, 200 kilos! How do you get somebody who is 200 kilos moving?

Experiences of boredom cause the passing of time to feel protracted and dragged out<sup>3</sup>. In their depiction of boredom within “contemporary American life” (1993, 238),

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<sup>3</sup> Experiences of bored and slowed time must be distinguished from other alternative time conceptualisations, particularly the phenomenon of slow living. Slow living is the “conscious negotiation of ... different temporalities” (Parkins 2004, 363) which are invested “with significance through attention and deliberation” (Parkins 2004, 364).

Brissett and Snow define boredom as the experience of the “absence of momentum or flow” (1993, 238). Flow is the “participation in the rhythmic experiences of life” (Brissett & Snow 1993, 239) and, as boredom is conceptualised as an “interactional phenomenon” (Brissett & Snow 1993, 238), then boredom is the sense of time as disrupted, disconnected and stopped. As boredom creates perceptions of stilled time, boredom exacerbates experiences of desynchronization (Flaherty 1993; 1999) and conflict between clock time and lived time.

Extreme tiredness and fatigue further connotes notions of loss of time – the many hours that participants describe asleep are, in a sense, lost. Marilyn and Jessica scoff at the devastating effects of the lost time of their antipsychotics, emphasising the lost potential associated with the medications:

It’s a double-whammy, isn’t it? You have this side effect of being demotivated and no energy and feeling tired. So it all just snow-balls really ... And this is something that I think about a lot is – you give anyone on the planet one of those, and see if you can get your ass to college or to work!

The sedating effect of the “heavy-duty” antipsychotics, as Jessica terms them, results in a marked sense of loss of time, and also renders the experience of time as protracted and extended. This reveals the ways in which participants reconcile contradictory modes of time: time is both lost (gone) and extended (more time).

The participants characterise these experiences of lost time within constructions of boredom. Like sedation, boredom distorts time so that it can be felt as tremendously drawn out. Such experiences exacerbate perceptions of the future. For Stacey, she describes her experiences of boredom as her “brain ... not functioning properly”. Experiencing a mis-functioning brain and living with slowed time renders Stacey as living in a perpetual state of immediacy and in an “oppressive-seeming present” (Musharbash 2007, 314).

Brissett and Snow posit boredom as intensified when lives are deemed to be a “dead ending” (1993, 240): “a lifeless future bequeaths a boring presence” (1993, 241). The acute nature of living with schizophrenia and antipsychotic side effects, especially experiences of slowed time, cause time to be felt immediately. The future, for the participants, is assumed to be “dead” (Brissett & Snow 1993, 240) and static, as discussed in more detail later.

### ***Medicated hunger versus “haloumi hunger”***

Another way in which antipsychotic medication disrupts experiences of time is through the transgression of the temporal ordering of hunger. In contrast to the protracted experiences of time in the side effect of sedation, the hunger side effect is distinguished from ordinary hunger (“haloumi hunger”) by its immediate, ravenous and rapid nature (medicated hunger). Temporalities are further disordered by the experiences of sped up hunger and slowed down metabolism.

Marilyn relays her experiences of the ferocious and intense nature of the hunger side effect: “When I was awake enough to notice, I was fucking ravenous! I was like [*in deep voice*] ‘Food, give it to me!’”. Emphasising the distinctive nature of the hunger, participants explicitly differentiate it from ordinary hunger. Now that she takes an antipsychotic without the hunger side effect, Jessica explains the difference between her experiences of “haloumi hunger” (normal hunger) and medicated hunger: “I’m [now] still kind of hungry, but that’s a healthy hunger, I think. Unless there’s haloumi around and then it’s not so helpful! [*laughs*]”. Contrary to what she terms as “healthy hunger” is voracious hunger; Marilyn describes her experience of this hunger as “fucking ravenous”. Hunger is experienced as a result of a sped up appetite.

This hunger is immediate, and the immediacy is illustrated by the instant and urgent response it requires. Time, when hungry, is not experienced like in other circumstances. The sudden pains of hunger require John to “just have a session



on the food”. John describes how he will “grab anything from the cupboard to the fridge and just fill up” in a short space of time. Krishna’s detailed illustrations of hunger help to understand why John binge-eats. Described as a “hollow feeling”, the onset of hunger makes Krishna gag:

*Can you describe the hunger? What does it feel like?*

Just a hollow, almost-nauseous feeling in the stomach... Ah, you feel like you’re about to throw up a little bit, but you’re gagging.

*Gagging. Why are you gagging?*

I’m not sure... Sometimes you do have to eat more because you either get nauseous or you get light-headed.

*... What does the light-headed feel like?*

Not nice. It feels like you’re about to faint.

With experiences of nausea, light-headedness and dry-retching, hunger for Krishna is distressing. The immediacy of such hunger, as highlighted with John’s need to “just fill up”, not only has implications for bodily experiences but also distorts understandings of bodily temporalities.

These temporalities are further complicated by the timing of the onset and retreat of hunger. Contrary to John, for Krishna the sense of hunger slowly and steadily “grows”. However, time is expanded by the drawn-out time the hunger takes to leave Krishna’s body. Characterised as “frustrating”, Krishna’s describes how his “stomach seems to take a long time to register that it’s full”. Despite eating a large meal and knowing he has “eaten enough”, sometimes these nauseating feelings of hunger do not dispel until five or six hours after eating.

As well as the expansion and contraction of time within experiences of hunger, time is further disrupted by what participants referred to as metabolism. As Marilyn describes, “I really noticed my metabolism was really slowed down!”. Asked how antipsychotics make people gain weight, Krishna draws on explanations of slowed metabolisms:

*So do you think that the weight gain is explained by people eating more?*

Ah, I think that's one part of it. From what I've seen, the eating more doesn't last long-term, it's when you first start taking it.

*But the weight gain still continues?*

Yes, so I think the metabolism as well.

*Okay. So what about the metabolism?*

I think it slows down.

*Right, so it can't process the food?*

Can't process the energy, yeah.

Krishna draws together the temporal relationship between accelerated appetite, slowed metabolism and weight gain.

## **Rapid weight gain and its further complications of time**

These experiences of ravenous, medicated hunger are directly linked to rapid weight gain. Along with concurrently experiencing slowed down and sped up time, the participants further experience time as disrupted by the distorted temporality of weight gain. Although experiences of sedation, boredom and hunger are common for many people, the participants of this study are unique in that sedation, boredom and hunger are occurring simultaneously. These experiences contribute to significant weight gain, as well as contributing to the distorted temporal experience of rapid, unrelenting and immediate weight gain.

The surprising and, for some, incomprehensible onset of weight gain characterises its sudden and rapid nature. Marilyn's narrative epitomises most people's transition from a "honeymoon of normality" after first taking antipsychotic medication, to "galloping" and "out of control" weight gain. Marilyn explains that this transition "happened quite quickly":

At first you're just in love with not feeling like shit all the time. 'Hey, remember sleep and not freaking out all the time?' and that's pretty good,

you know! So you have this honeymoon with normality, or a resemblance of it.

Banging her fists against the table to punctuate her words and emphasise the rapid passing of time, Marilyn describes how after this phase, she began to get “fatter [*bangs fist*] and fatter [*bangs fist*] and fatter [*bangs fist*]!”. Like many participants, she first realised that she was gaining weight by her clothes no longer fitting. Despite at first enjoying the opportunity to buy new clothes to fit her expanding body, the accelerated rate at which she was gaining weight meant that these clothes needed to be often replaced:

Then probably, you go ‘Oh, that’s a bit tight, I’ll buy something’. And you think ‘That’s cool, I’m buying new clothes!’. And the second month it’s like ‘I’m buying more clothes’. The third month is like ‘Fuck, this is costing me a bit of money. And those other cool clothes that I just bought, you know, two months ago? I can’t wear anymore!’. I think that was it – when the relatively new clothes that I had bought, I couldn’t wear. It’s like ‘Oh, hang on, hang on, I don’t have shitloads of new clothes, I’ve only got some new new clothes because the other new clothes I can’t wear anymore!’.

Realising how quickly her weight was gaining, Marilyn made a deliberate effort to minimise the gain or – in her words – “maintain it at a level of equilibrium”. However, dieting was a “struggle” for Marilyn, especially because she “loved food”: “I’m not interested in living on a fucking lettuce leaf and carob seeds!”. This distress was exacerbated by the rate at which she put on weight. Although she recognised the initial medicated weight gain and began to put in place strategies to minimise the gain, Marilyn describes how she did not realise its accelerated rate until it was pointed out to her by a colleague. When she gave a presentation about antipsychotics and side effects, Marilyn’s social worker crystallised the extent of her own weight gain:

So we’re having this discussion and ... I was describing my situation and how I was gaining around about a kilogram a month.

*Okay.*

I know, it's a lot!

*Yeah.*

Yeah! What he said was, he just said 'Does that mean ... [that after being] on this drug for 37 months, you will have gained 37 kilos?!?'. And it really hit me! I suddenly thought 'Fuck, this is just not sustainable!'. I had been absolutely struggling to keep a lid on it ... [but] even with making that effort, there was this sort of galloping change. It was just out of control!

Realising the rate at which she was gaining weight, Marilyn decided that it "was not okay [and she had] to get off this!". The three weight graphs in Chapter 3 on pages 72–74 highlight the rapidity of this weight for some participants.

Although not all participants made the same decision as Marilyn to take themselves off their antipsychotic medications, other participants echo her characterisations of the weight gain as sudden and rapid. Jessica points to her abdomen and depicts it as having "really thickened up quickly". When describing her lifetime of weight gain and weight loss, Kylee raises her eyebrows and bears a puzzled facial expression: "I just seem to gain!". Krishna likewise describes having "put weight on so quickly", evidenced by his weight gain of 70 kilograms within an eight-month period.

The participants' bewilderment about the weight is especially evident when asked to chronologically describe and document their weight gain and changing body. Kylee has particular difficulty in charting her weight gain for the weight graph. Although Lovell (1997) argues that narrativization and the construction of timelines and time-graphs are inherently difficult for people with experiences of schizophrenia, these difficulties in documenting their weight changes for the weight graphs demonstrate the ways in which rapid weight gain amplifies and magnifies the temporal disturbances of schizophrenic experiences.

Antipsychotic-induced weight gain interacts with time within constructions of 'stolen' time. The metaphor of stolen time applies to the everyday experiences of

people with disability (Oi 1991; Pagán 2013). Pagán's study extends Oi's (1991) earlier work to show how "disability steals time" (Pagán 2013, 81). The metaphorical stolen time is the extra time required for people with experiences of disability: Oi (1991) reveals the additional time needed for people with disabilities to undertake everyday activities, as well as the additional time needed for medical care and leisure endeavours. The participants in my study similarly describe the extra time required to carry out everyday care. For Kylee, showering and dressing have been affected by her weight gain, as has putting on leggings for which she now needs her husband's help: "I can't bend over far enough, to hold them to put my legs in". The participants extend beyond understandings of stolen time to articulate how sedating side effects and slowed time renders large amounts of time as utterly lost. The everyday experiences of weight gain takes up and consumes time: participants are required to expend more time on everyday activities, such as Kylee's example of getting dressed. This shows the ways in which weight gain impacts on how participants perform what might ordinarily be assumed to be simple acts of everyday living.

For Marilyn, and for the other women in this study, not only does clothing help to identify and mark weight, but clothing also has complex emotional and gendered consequences. The emotional relationship between women, clothing and their bodies has received some critical attention (Colls 2004), and Marilyn's discussion about clothing draws together these themes with time:

You know, [buying new clothes] raises all kinds of issues and distress and 'Oh my god, my body is disgusting and I'm so out of control!' and that kind of stuff. So, anyhow, I was noticing this ... At least your bust looks okay and that's the only thing that benefits from getting fatter and fatter!

By describing her body as "disgusting" and "out of control", Marilyn connects the emotional experiences of clothing with the distorting temporal effects of her weight gain. Colls calls for shifting the analysis of women's emotional engagement with clothing consumption beyond the "labelling of emotions as either positive and/or negative" (2004, 584) as doing so will render highly-fruitful understandings of

women's relationships with clothes, including their temporal experiences of clothing.

The narrow possibility of clothing styles for women after gaining weight causes further distress amongst the women participants in this research: Mary, for example, laments that bigger-sized clothing “don't go for glamour!”. Colls has found similar concerns in her own research, recognising that the “clothing that is available is understood as baggy and unfashionable and designed to cover up the space of the body rather than reveal its material form” (2004, 591).

The use of clothing to recognise weight gain demonstrates its unpredictability and the ways in which medicated weight gain fails to align with culturally established understandings of gradual weight gain – or what Crossley characterises as “creepy” (2004, 242) weight gain. The “creepy factor” (Crossley 2004, 242) depicts the familiar perception of weight gain as something that “‘creeps on’, largely unnoticed, coming as something of a shock to the agent when it is noticed” (Crossley 2004, 242). However, experiences commonly found in popular accounts and confessional pieces on diet and weight loss are markedly different to the accounts given by my participants. Instead, the weight gain is unexpected and rapid, and contradicts conventional understandings of weight gain as slow and steady.

### **“Stuck” in time and static futures**

Antipsychotic side effects further disrupt participants' temporalities by distorting their sense of the future. After the conclusion of our second interview and without prompting, Dren spontaneously exclaims “I can't have a life!”. This declaration encapsulates the ways in which the participants frame their understandings of schizophrenia, reliance on antipsychotic medication and resultant side effects as stagnant and without temporal movement. Although everyday experiences of time are disordered, most participants nonetheless accept that they will be on their

antipsychotic medication 'for life' and speak of their diagnosis of schizophrenia and antipsychotic side effects with a sense of permanence.

Participants described their futures as static and fixed. Along with boredom rendering the participants' sense of future as a "dead ending" (Brissett & Snow 1993, 240), disrupted temporalities further disconnects participants from their futures. Despite their lists of complex and varied side effects, when asked to elaborate on why they continue to take antipsychotic medication, the participants consistently described medication-free futures of "getting sick", "going crazy" or "going too loopy", committing self-harm, being on their own, or detained in hospital.

Recognising the deeply rooted nature of time within everyday activities and understandings, contemporary social theory understands experiences of lived time to be elastic and continually "new" (Brough 2001, 31). The perennial new-ness of time constantly brings new opportunities: "the temporal perspective continually changes: a "new" now replaces the old now; what appeared as now comes to appear as past" (Brough 2001, 31). The future, then, is exemplified by "openness to change and movement" (Wyllie 2005, 173).

However, people with mental illness often evince characterisations of "temporal dissonance" (Lucas 1999, 117) and experiences of time as unchanging and still, which are then reflected in perceptions of the future. In his ethnography, Lucas draws distinctions between his own temporalities that are compulsory for doctorate writing and completion, which are "predicated on progress and closure" (1999, 118), and the "remarkably static" (1999, 118) temporalities of his participants:

Their circumstances and conditions did not change as rapidly. Such stasis made it difficult to maintain relationships because of the disparities it highlighted and the reticence it caused between us, there being a social value attached to progress and change – achievements which are presumed to be inhibited by schizophrenia as a 'chronic' illness. (1999, 118–9)

Chronicity is intrinsically temporal; unlike 'acute' illness, 'chronic' illness is long-term, ongoing and enduring.

Like many participants, Dren equates his increased likelihood of a shortened lifetime with schizophrenia and antipsychotic side effects:

*Are you worried about what the weight gain will do to your body?*

Ah, it's already happened! I'm probably going to die of a heart attack soon!

*Why do you think that?*

I've got high cholesterol and high blood pressure.

*And that's related to the weight?*

It's related to the medication. The medication's done it all, it's made me put on weight! ... No-one takes me seriously.

*Why is that?*

Because I'm just some person that sleeps all day and doesn't do nothing with his life, and, so yeah, I'm just a joke to everyone I suppose.

At 44 years of age, Kylee also predicts a lifetime shorter than the average: "I had a feeling that I'd die before I was 45". When asked why she believed this, Kylee answered that it is due to the "many physical things wrong with [her]" and because she is "so badly overweight". In their qualitative research on taking antipsychotic medication (something that they describe as akin to the "quest for well-being"), Carrick and her colleagues (2004) similarly found that participants were troubled about the future and their long-term health, explicitly relaying anxieties about the impact of the medication side effects and weight gain.

Despite the possibilities for future change that comes with constructions of time as "new" (Brough 2001, 31), my participants articulate bleak futures. Exploring the lives of those with mental illness, Wyllie draws parallels between this lack of openness with a "static and deterministic" (2005, 173) future which, in turn, renders those experiencing it as having "a sense of hopelessness" (2005, 173) and experiencing "eternal suffering" (2005, 173).



One of the key characteristics of this “absence of openness” (Wyllie 2005, 173) is the acceptance that “things will not get better” (Wyllie 2005, 173). My participants accept the impossibility of future improvement. Although their current experiences of antipsychotic side effects are distressing, particularly in the ways in which the side effects disrupt spatial and temporal taken-for-granted understandings, my participants articulate the devastating repercussions of ceasing to take their antipsychotics. The participants overwhelmingly designate non-medicated futures the same sense of hopelessness: suffering, abandonment, detention, and worsening of mental illness.

Dren illustrates a strong sense of pessimism towards his current state of health and general life:

I can't have a job because of [the antipsychotic medications]! ... And it's given me weight gain and, because of the weight gain, I've got high blood pressure and high cholesterol ... I've got to try and exercise it off. Mmm, I don't see it happening!

This despair is not only limited to the taking of the antipsychotics; Dren also reveals a cynical perspective towards his future life. Due to his schizophrenia and antipsychotic-induced weight gain, Dren explains that he “can't have a life”. He continues, claiming that he will never marry and have a family, especially because he has decided not to have children that will “grow up being a victim of [his] stupid, fucking brain!”.

In their literature review on research conducted into the meaning of antipsychotic medication, Seeman and Seeman characterise the “unremitting nature of chronic medication” (2012, 341) as “the tyranny of ‘forever’” (2012, 341). Dren wishes that he did not have to take the antipsychotics, and his rejections of the possibility of a fulfilling future epitomises futures that are stuck and fixed in time. Like Wyllie’s “absence of openness” (2005, 173), this “tyranny” renders those who take antipsychotics as victims, and the medication consequently “becomes the tool of victimization” (Seeman & Seeman 2012, 341). Embracing this model of victimhood,

Kylee echoes Dren when talking about her experiences of the antipsychotics. Not only does this sense of a bleak future have an impact on how she views her current life, it also impacts on her recovery potential:

I want to come off of all psych medication.

*Why is that?*

... I am just trying to patch my life back together, you know what I mean?

*So you don't think you can do that on medication?*

Things I have to do to ... live life, survive life ... I'm willing to ignore the voices and the things that I see so that I can actually get things done.

## **Managing time and time-markers**

Where time is experienced as distorted, disordered and disrupted, participants employ practices of temporal benchmarking. Time-markers help to provide comfort and transportation to – in Ashley's words – the "other world", and lessen the impact of distorted temporal experiences. Barbara laughs when she notes that the "three things that ... [she] finds mostly" consumed amongst her clients are a "coke, coffee or a smoke". Not only do cokes, coffees and smokes demarcate and signify specific parts of the day that are akin clock time, but they also combat the distorting temporal experiences of schizophrenia and antipsychotic side effects. As participants encounter experiences of desynchronization, these "resynchronizing measures" (Fuchs 2005, 196) and routines help to provide comfort and restore balance (or "homeostasis" (Fuchs 2005, 196)) to temporalities.

Snacks, in the form of regular small meals, are paramount for George. Recognising that a "good diet [is] important", George eats at least four or five times a day, thus breaking up his everyday meal experiences into fixed and discrete units of time. George's snacking is different to the once or twice daily meals eaten by other participants. Although for some, this may be for weight loss, eating only one meal a day may also be compatible with the everyday experiences of disrupted time.

The participants speak of food, coffee and cigarettes in similar terms, describing them as “nice”, “good” and “better”. Dren explains that food “feels nice in [his] belly” and “just feels good in there”, and similarly coffee “makes [him] feel better”. The ways in which coffee makes Dren “feel better” is twofold: it helps to isolate specific parts of the day (such as having his customary ‘morning coffee’ upon waking), and also relieves the sedating side effects of the antipsychotics. Countering the way in which the antipsychotic medication draws out time by causing sedation, coffee speeds up Dren’s sense of time: “I feel good drinking black coffee, it wakes me up!”. For Dren, coffee provides a positive experience that it helps to provide balance to his distorted temporal sensibilities; in this sense, coffee re-establishes some stability to the distorting temporal and spatial experiences of schizophrenia and side effects.

Although most of the participants mention the public health campaigns against smoking, they nonetheless emphasise the importance of cigarette-smoking throughout their day. Ruth, for example, responds to social workers’ pleas to quit smoking by reasoning that “You can’t be hard on yourself ... We have to have a bit of enjoyment!”. Importantly, the benefits of cigarettes can be felt even when schizophrenia and side effects alter the experience of smoking. Qualifying that although the antipsychotic medication can be “very helpful”, Krishna explains that “things can get quite strange”. One of these “frustrating” side effects is a distorted sense of smell and taste, which makes “everything smell [and taste] like flowers”, particularly warping the taste of foods, cigarettes and coffee. Despite what he terms as this “hallucination of taste”, Krishna continues to receive benefits from the regularity of cigarette-smoking.

When simultaneously experiencing sedation, boredom, hunger and immobility, Peter describes how cigarette-smoking provides for him “something to do” with his (otherwise idle) hands:

It helps out, love.

*What does it help?*

Well, it's something to do with your hands. Do you know what I mean?

*Yeah, yeah, okay.*

... And makes you feel better, you know. I don't mind it, I like smoking.

The characterisation of cigarettes as 'helping out' demonstrates their capacity to distinguish blocks of time, and time is thus felt as moving between sped up experiences of schizophrenia, protracted experiences of boredom and managed with slowing-down strategies.

Keith explicitly draws an association between his cigarette-smoking and time. Asked to elaborate on why he has "always loved cigarettes", Keith explains: "Ah, like when schizophrenia is really bad, you smoke every 10 or 15 minutes". In a state of psychosis – characterised in his words as "really bad" and "your head is zooming" – smoking not only staves off hunger, but also allows Keith to count 10 minute blocks of clock time by having a cigarette at each interval. This practice of constant smoking continues throughout the day and night, for at least seven or eight days until Keith can fall sleep. Integral to maintaining a sense of time that aligns with societal clock time, Keith elaborates on these temporal strategies, explaining how he ensures that they coincide with cycles of monetary payment:

Oh, it's just like, you get your pay – I get my pay because I'm not under the guardianship board or nothing – I get my pay and I'd spend ... 140, 160 bucks on cigarettes. I'd get two cartons and a few pouches. And then I'd just be up, I'd be up ... seven, eight days out of ten. And then I'd have a huge sleep, then I'd be alright for a couple of days.

Being prepared ensures that Keith has enough cigarettes and tobacco to last him the cycle of the wakefulness of his psychosis.

Parallels can be drawn between these time-markers and the theoretical understandings of "temporal benchmarks" (Klingemann 2001, 314). The "abundance of time" (Klingemann 2001, 314) held by the patients of an alcohol and drug treatment centre in Klingemann's study has a similar effect of protracted time as the participants' descriptions of boredom. To fill their time, Klingemann argues

that people “need to mark time” (2001, 314), a process that he describes as temporal benchmarking. The regularity of eating and smoking are forms of temporal benchmarks, in that these activities help to determine the respective part of the day according to clock time.

Like the mothers of severely ill infants in McKeever *et al*'s (2002) study, ordinary markers of time – such as lunch-breaks, weekdays, weekends and the change of seasons – are irrelevant and indecipherable for the participants in my research. McKeever and colleagues apply qualitative research principles to explore the way in which these mothers navigate the “space/time conundrums” (2002, 1027) of mothering infants who are in prolonged protective isolation. In these isolation rooms, a sense of daily (and oftentimes, monthly and yearly) life is absent, and the women thus “orient themselves temporarily using daily routines” (McKeever *et al* 2002, 1027).

My participants zealously expound the importance of “daily routines”; where time is expanded and disrupted, routinised activities are comforting. The everyday regularity of food, coffee and cigarettes provide for the participants a “sense of comfort”, as described by George. “When things aren’t always what you think they’re going to be”, explains George, “a very strict routine” of repetition and familiarity are integral. Incorporated into his “routine” are food, cigarettes, medication, music and artwork (painting, sculpting and drawing). George explicitly defines comfort as “not being troubled by one’s thoughts ... [and] being able to understand the things around you”, highlighting the ways in which activities that provide comfort help to displace the sense of estrangement and alienation of temporal disordering.

Merilyn describes a friend with schizophrenia who adheres to a similar routine as George. Despite the distorting temporalities of schizophrenia and antipsychotic side effects, George and Merilyn’s friend both find a great degree of comfort in maintaining routines. Realising the sedating effect of the medication, Merilyn’s

friend now takes the antipsychotics at night-time and, even though he sleeps for 16 hours, he nonetheless has “some quality of life during the day”. Marilyn explicitly articulates the importance of routine:

He’s a very organised and orderly kind of person. I find him quite inspiring actually! *[laughs]* ... *[And]* this kind of thing about schizophrenia being disorderly ... I look at him, and to cope with it, he has to lead a really ordered life and he imposes that order on it, he does it, you know. And probably not many people could live with that discipline! *[laughs]*

Although George emphasises the importance of routines in managing disordered experiences of time, the concept of routine is given broader meaning than its taken-for-granted understanding. Conceptualisations of routines for the participants are – like Williams and his colleagues’ understanding of emotions – “personal, embodied, situated, practical and interpretative” (2001, 60). In this sense, the notion of routine is given embodied and personal meanings, rather than objective understandings. Although constructions of routines ordinarily entail notions of order, regularity and predictability, the participants’ illustrations of their own routines are markedly different.

For the participants in this study, routines do not necessarily revolve around clock time and the attached assumptions about day and night activities. Instead, George schedules his routine around the weather and the availability of outside space. As his artwork involves working with materials that require ventilation, George must work outside. However, due to the extremes of the Australian weather, George must coordinate his working hours around parts of the day that are not too sweltering. These parts of the day must be balanced with hours that bear enough sunlight to see and work. It is for this reason that George adheres to routines that he characterises as “very strict ... as strict as a monk would have it in a monastery, self-imposed”, even though these routines vary on a seasonal and, often, daily basis. As creating art and identifying as an artist are very important for George, then the development of routines are integral in managing his experiences of time.

The construction of such routines, strategies to “get control over the situation and over what is to be done” (Hellström 2001, 85), is often given weight (or priority) for people with chronic illness (Hellström 2001).

In contrast to those with experiences of schizophrenia, the health practitioners I interviewed continue to define routines within conventional terms. Julia’s notion of “routines of eating” is an example of this, and these routines revolve around societal expectations about appropriate times and foods to eat. Although my participants highlight the importance of routines, Julia instead suggests that such routines are impeded by the realities of most people’s lives and the “poor economy” in which they live. For Julia, “routines of eating” stipulate what, how and when to eat, but people who have developed schizophrenia at a young age have often missed out on learning these lessons. The voracious antipsychotic-induced hunger wreaks havoc on Ashley’s everyday experiences of routines around mealtimes, and he describes how he is often so hungry that eats throughout the night, despite having a full meal at dinner-time. The onset of hunger during clock time’s hours of sleep-time infringes on Ashley’s temporal experiences. These disordered eating patterns highlight the repercussions of the antipsychotic side effects on the participants’ sense of routine: sleep comes and goes at times that do not align with the appropriate sleeping-hours of clock time, further distorted by experiences of hunger outside of taken-for-granted (day and night) hours.

## Summary

Time permeates our everyday existence and experiences; our daily lives are “soaked with time” (Brough 2001, 29). This is true for the participants despite their experiences of time being significantly different to the understandings of institutionalised and societal time – or, clock time (Elias 1992; Wyllie 2005). Within experiences of schizophrenia, time is sped up; antipsychotics create experiences of slowed-down sedation and ravenous, immediate hunger that produce temporal disruptions.

These experiences are further complicated by the violently rapid nature of antipsychotic-induced weight gain, where the sudden weight gain defies understandings of bodies and time as linear, predictable and containable. Instead, time is simultaneously expanded and constricted, violating everyday temporal understandings. I have shown how experiencing these varieties of time render this population group as distinctive, and having these temporal orientations make the participants feel alienated and “odd”. Feelings of oddness render time as fixed, and these perceptions engender short-term behaviours that mirror static futures. To alleviate contradictory experiences of time, the participants employ mechanisms of time-regulation to bring some degree of comfort to their everyday lives: a “coke, coffee and smoke” offer respite to lives that are marred by experiences of disordered time.

Although clock time and lived time are constructed as separate concepts, the two mostly always align within everyday temporal orientations. However, when there is conflict between societal and lived time, flow is interrupted and desynchronization occurs. The next chapter extends analyses of desynchronization and draws on health professionals’ narratives to explore what happens when there is conflict between (embodied) transgression and (medical, objective) containment. The example of Webster-paks offers a clear illustration of the disjuncture between temporalities, and how medical attempts to contain bodies, time and space preserves cultural conceptualisations of madness and fatness as transgressive, fragmenting and disrupting.



# CHAPTER SIX

## **“If you exercise harder and eat better, then maybe you won’t be a fat bastard!”: between understandings of madness and fatness**

Oh, I just thought of something else – the drug companies, I mean they’re really, really aware of this issue [antipsychotic-induced weight gain] and they’re really aggressive marketers ... Because they’ve got a captive audience, particularly in people who are on legal orders to take particular medications and they’ve got absolutely no interest in anything that looks like a functional cure.

They have done things like, their efforts were so pathetic ... one of the drug companies, had this thing ... they wanted to do this thing about healthy living and they wanted some ‘Consumer Champions’ ... with some little booklets to hand out to people about healthy eating and exercise.

That’s all well and good but there was no acknowledgement of the role of the drugs in it! It was all ‘If you just exercise harder and eat better, then maybe you won’t be a fat bastard!’ ... There’s really conflicting agendas!

(Marilyn)

This chapter shifts focus away from the lived experience of antipsychotic-induced weight gain to the relations between understandings of antipsychotic-induced weight gain. As highlighted by Marilyn above, there are many meanings used to explain and understand antipsychotic medications, side effects and weight gain. This thesis is grounded in the epistemological explorations of how people come to represent and know madness and fatness, and the last two chapters have shown the difficulties people have in living with these experiences. Weight gain is understood to be unique as it is caused by medications. This explanation is contrasted with how some health professionals understand the weight as something that can be prevented and overcome by 'exercising harder and eating better'.

This chapter explores the disjuncture between those experiencing antipsychotic-induced weight gain and the health professionals involved in their clinical care. I take inspiration from Mol's work to explore the "relations between ... practices" (2002, 5). Although Mol's (2002) work is ontological, her work is useful in highlighting the multiplicity of ways for knowing bodies and the things that happen to bodies. Mol investigates the enactment of atherosclerosis: how atherosclerosis is 'done' or practised. This work forms the basis of her treatise that bodily experiences are bound up in practices and knowledges that cross medical and lived experiences.

Instead of understanding the different meanings of madness and fatness as abstract, sitting in isolation, disconnected, I draw on Mol's work to argue that "multiple objects tend to hang together somehow" (Mol 2002, 5). Understanding how differing knowledges of antipsychotic-induced weight gain "hang together" privileges the interrelationship between practices, experiences and knowledges. Not only does Mol's enactment of bodies open up the thinking of bodies as "multiple", but it also opens up the thinking about health experiences and health outcomes along a "spectrum of knowledge(s)" (McClellan & Shaw 2005, 729).

When we begin to look at the interrelationships – the connections and the disconnections – between understandings of antipsychotic-induced weight gain, we access insights into how health professionals seek containment through medication. Whereas people were once contained in asylums, the transition to deinstitutionalisation in the Western world has created different forms of containment. I show how the ways in which health professionals conceptualise schizophrenia reflects their conceptualisations of antipsychotics. For some, psychotic thoughts represent a spilling over or crossing of boundaries; within this conceptualisation, antipsychotics reduce and curtail this spillage.

People with schizophrenia are now contained in communities; antipsychotic medication (temporarily) contains through the burden of medication compliance and (spatially) through the burden of self-surveillance. I use the example of Webster-paks and pharmaceutical time to highlight some of the tensions that arise when embodied experiences of bodily transgression interact with medical imperatives of containment. I then show how the imperative for compliance requires medications to be taken ‘on time’, containing the disrupted temporal sensibilities of madness and fatness. Carrying out practices of self-regulation and being “on the look out” are similarly mandatory, containing through restraint of the fat, transgressive body. Attempts to contain bodies through time and space preserve and propagate sociocultural constructions of schizophrenia and fatness as transgressive.

### **Webster-paks: an example of differing knowledges**

Webster-paks, or “medication management systems” (Webstercare 2014), offer a good example of differing (and competing) knowledges; they represent the dominance of pharmaceutical time over the lived time of those prescribed them. Tu, the first of the two pharmacists I interviewed during my fieldwork, draws out the problem of differing temporalities and the usage of Webster-paks to bridge this gap. Scheduling our interview on a Friday morning when the pharmacy would be

“fairly quiet”, Tu invited me to follow him to the staff room, and we sat on stools at a large stainless-steel bench. The expansive staff room was relatively quiet, apart from the hum of six specially-monitored fridges on one side of the room, and was large enough to store several shelves of prescriptions. The placement of these shelves prompted Tu to refer to them during our discussion. Had Tu not invited me to hold the interview in this space, then he may not have spontaneously pointed out the medication packs:

It's pretty hard ... if they're not taking [their antipsychotic medication] properly. [*looks around staff room*] And that's why we do the Webster-paks! [*points to shelves of medication packs*]

*Yeah, right. So do you do this for pretty much everyone on antipsychotics?*

Um, not everyone, a lot ... [Mostly] people who go down to [the] mental health [centre]. It's either they're on this or they're on injections.

Mid-interview, Tu swings around to look at the shelves (see Figure 9) and beams. Tu explains that his clients' tendency to inadequately take their medications has resulted in Tu's pharmacy offering the service of bundling people's medications into packs.



**Figure 9:** Shelves of Webster-paks in Tu's staff room.

As described on the Webstercare website, the packs are “medication management systems” (Webstercare 2014) that are “designed to help people take their medication correctly, according to their doctor’s orders” (Webstercare 2014). Certain groups can often need assistance in taking medication: usually populations who are deemed as having difficulty in understanding clinical directions, such as the aged; indigenous Australians; people from culturally and linguistically diverse backgrounds and people with English as their second language; and those diagnosed with mental illness (Bajramovic *et al* 2004; Swain & Barclay 2013). Webster-paks are thus aimed at populations who are unable to take, or have difficulty in taking medications at specific, regular intervals; the packs are a response to people’s supposed inability to self-care and self-manage. Dose

Administration Aids, commonly-used in Australian pharmacies, are individual blister packages organised into weekly cards (see Figure 10).



**Figure 10:** An example of the ‘Community’ Webster-pak. (Webstercare 2014)

Webster-paks denote precise measurements of pharmaceutical clock-time. The weekly calendar packs comprise of separate blister compartments for the seven days of the week; the photograph of Josephine’s Webster-pack provides more detail (see Figure 11). Each day is divided into four times: “breakfast” is represented by a rising sun, “lunch” is represented by a full sun, “dinner” is represented by a setting sun, and “bedtime” is represented by a moon. The packs are based on popular (and medical) assumptions and knowledge about food, sleep and days, and understandings of time that contrast with the participants’ temporal sensibilities outlined in Chapter 5.



**Figure 11:** Josephine's Webster-pak

Sam explains his deference to the assumptions implicit within the Webster-paks. Asked when he takes his medications, Sam mirrors the language and temporal orientations of the medication packs:

*And when do you take your medications?*

Um, morning, dinner and at bed-time.

*So dinner as in night-time?*

Yes, at dinner. Dinner-time I take my tablets. I take my morning tablets and I also take my night-time tablets, which I have quite a lot of tablets for schizophrenia which I have. I take about four or five clozapine and I'm diabetic, too, so I have to take metformin and diamicon, and that's all I think.

Aligning his medication-taking with the labelled blisters of the packs, Sam explains that he takes his medications in the morning, at night and just before bed. The

antipsychotics disturb sleeping patterns, sometimes making Sam sleep for over 16 hours a day. Despite this disrupted sleep conflicting with ordinary understandings of morning-time and bed-time, Sam nonetheless mimics the temporalities marked by the medication packs.

Tensions arise when taken-for-granted assumptions about meal-times, sleep-times and specific times of the day directly conflict with lived temporal experiences. Sam's recent hospitalisation after forgetting to take his antipsychotic medication – and (mis)use of his Webster-pak – demonstrates the repercussions of the health practitioners' attempts to manage the time of their clients. My first interview with Sam was delayed as he had, in his words, “mucked up” his medication, and was subsequently hospitalised for three weeks. Having experienced dyslexia from a young age, Sam admits to often being confused about his medications. However, it is not only his dyslexia that causes him to misunderstand his medication. A month prior to our interview, Sam called the police to tell them about the “bikies after [him]”. In response to his phone call, the police realised that Sam had failed to take his medication:

And the cops [came to my house and] just saw all my medication and they said ‘You haven't been taking your medication properly’. I said ‘Yeah, I've missed a few days’. And he goes ‘You've missed four or five days!’. He said ‘You've got a month's supply of pills here and they're not even’ – you know you've got one for breakfast, lunch and tea – ‘you've got five or six missing here, six missing there’. I said ‘Alright’.

Webster-paks allow for the easy identification of failure of medication-taking by those who are in tune with the established temporalities of clock-time. Although the Webster-paks ostensibly endeavour to combat some of the problems inherent in experiences of confused and distorted temporalities, they are nonetheless designed within a temporal framework that conflicts with the lived experience of schizophrenia and antipsychotics. In doing so, the health professionals may



inadvertently provoke and cause additional confusion, further burdening the participants' lives.

## **A 'new' form of containment**

The innovation of Webster-paks speaks to the need within public health for strategies to assist people to take their medication with regularity and consistency. The import of medication-taking reflects the health profession's conceptualisations of schizophrenia: antipsychotics offer a means with which to contain through medication.

Antipsychotic medication is the basis of the rationale for deinstitutionalisation (Rose 2003). The classic histories of asylums and madness demonstrate the ways in which people were once contained in asylums (Foucault 1967; Goffman 1962). We have experienced a key shift in psychiatric services: a move away from institutions (hospitals, asylums) to the community (Barrett 1996; Lucas 2001). As shown in my discussion of the history of madness and modern psychiatry in Chapter 1, the treatment method used in asylums prior to the twentieth century on those who became known as the mentally ill was predominantly the restriction of bodily movement, though restraint of the mind through sedation was a common technique used, too. Bell (2003) provides a history of South Australian public psychiatry, and documents the dramatic shift in psychiatric care after introduction of first generation antipsychotics in the mid-1950s. The use of these antipsychotics, or what he terms as "tranquilizing drugs" (Bell 2003, 82), improved the lives of people with schizophrenia. Such improvement meant that many could leave long-term psychiatric institutions and "contemplate survival in the outside world" (Bell 2003, 82). Although some historians dispute the assumption that the introduction of antipsychotics resulted in the immediate release of people from long-term, residential psychiatric facilities (for an overview, see Moncrieff 1999), many psychiatric practitioners and writers nonetheless see one of the reasons for the

profession's move away from institutionalisation relating to the use of antipsychotics.

'Deinstitutionalisation' thus represents the transition of containment of bodies (restrained in asylums) to the containment of minds (medicated in the community). As Lucas points out in his study on people with schizophrenia living "at home", "psychiatric illness has a new location – 'the community'" (2001, 95). Experiences of schizophrenia, however, amplify the "uncanniness of ordinary places" (Lucas 2001, 98). 'The home' and 'the community' thus become, for people with experiences of distorted psychotic thoughts, "not necessarily inviolate" (Lucas 2001, 100). Lucas argues that these locations amplify the "extraordinary" experiences of schizophrenia, and the violation of privacy that comes with these experiences reconfigures the locations as a "watchful extension of the state executive" (2001, 100).

The community has not only been rendered as strange and disordered, but so too has the body. Nurse Julia describes modern psychiatry's transition to community care as being "fabulous". However, she also raises concerns with some of the practical ramifications of this transition, particularly as the separation of formal healthcare and mental healthcare has had negative consequences:

Now, we've moved out to the community ... but it doesn't always work for everybody and a lot of things are really difficult and get missed and one of those things is physical health ... For a consumer, it can be that they lose 20 years of their life. So, it's just not good, is it?

*No.*

Unnecessary ... And people don't routinely [get health check-ups] ... The last thing a lot of consumers want is to be poked and prodded around as well, you know ... Particularly if you're a bit paranoid about something, you need time to get that relationship happening and build that trust. You can't do that in a 15-minute interview with a GP, so things do get overlooked. And

the GP can't know what the problem is if the person's not expressing it either. So it's very tricky.

Julia highlights the pragmatic difficulties of people with schizophrenia now having to access medical practitioners at multiple locations. Julia also alludes to how bodies being rendered strange by schizophrenic experiences has implications for healthcare:

Because the thing too with mental illness, some people, they lose that connection with their body, they're not quite aware. Some of the antipsychotics can reduce pain, so that they're not aware that they're having such a great pain. When they do attend a doctor or an ED, the person may not be able to get across to the person what the problem is. The examiner's looking at them thinking they've got a mental illness and focusing on that, so the physical health side of things can get discounted again.

The panoptic gaze of the "watchful" (Lucas 2001, 100) contemporary community setting is augmented by the "sheer force of [antipsychotics'] chemistry" (Desjarlais 1997, 118). In his ethnography of shelters for people living with mental illness, *Shelter Blues*, Desjarlais highlights how:

[t]he use of medications enabled the state to monitor people in ways distinct from an earlier era of psychiatric care ... The use of such medications helps to explain the decreasing utility of panoptic models of enclosure and surveillance ... With this medicalization of surveillance, the meds governed a person's actions through the sheer force of their chemistry. (1997, 118)

Desjarlais (1997) shows that these experiences are not only contained through the dominant medical paradigm of medication compliance, but also through the medications (and side effects) themselves. Barrett similarly draws on Foucault's work to argue that although institutional powers and surveillance since deinstitutionalisation have dispersed, they are as "pervasive in the lives of the mentally ill in the new regime as they were in the old" (1996, xi). Although they were once contained in asylums, this does not mean people are uncontained in the

community – people with schizophrenia now experience a different type of containment through medication.

Although one psychiatrist I interviewed explains that there is no “black and white agreement” about the understanding of schizophrenia within the health profession, the health practitioners in this study understand antipsychotic medication to be containing the psychotic thoughts that are conceptualised as spilling out of the body. Asked how antipsychotics work in the treatment of schizophrenia, William draws on biomedical language to explain schizophrenia as a “neurological dysfunction in the brain” which results in “an excess, or a relative excess, of dopamine”. Antipsychotics thus reduce (or contain) excessive “dopamine activity”. This is encapsulated in psychiatrist Gopal’s explanation of the “dopamine hypothesis”, described as when someone “who has psychosis has more dopamine so let’s cut down the dopamine and see what happens”.

Juxtaposing these understandings, the mental health nurses almost entirely avoided biomedical constructions to describe schizophrenia. When with clients, Gary seeks to understand the nature of the psychotic experience:

*So how do you understand schizophrenia, like what is it?*

It can be positives and negatives which can be like how much energy they have, how much energy they don’t have, whether they want to do things, such as if they’re hearing voices. What are the voices telling them? Do they have good voices? Do they have bad voices? I always try and break it down and say ‘Okay, are you hearing things?’. ‘Yes’. ‘Are they telling you good things or are they telling you bad things?’ If they’re telling you good things, then I’ll say ‘Okay, try and hone in on the good things’.

Gary admits that psychiatric intervention is “never going to get rid of the voices”, so instead seeks to equip clients with strategies for “overcoming” distressing schizophrenic symptoms. These strategies incorporate antipsychotic medication to “reduce” voices, as well as individual techniques so that clients “can actually cope” with experiences of psychosis.

Despite these differing explanations for schizophrenia, the psychiatrists and nurses similarly construct people with schizophrenic experiences as transgressive. For Gary, people with schizophrenia are characterised as “unstable” and a “threat”. The seemingly unpredictability of the schizophrenic experience produces societal understandings of people with schizophrenia as uncontained. Gary illustrates how people with schizophrenia are commonly characterised as “threats to the community”, resulting in public calls for people with schizophrenia to be “locked up and the keys thrown away”. Experiences of transgression are thus met with calls for containment. Some studies highlight how people with schizophrenia are discursively constructed as dangerous and threatening (Barrett 1996; Rose 1998 & 2000). Rose draws on contemporary prison statistics to demonstrate the implications of such cultural constructions: those who are deemed to be dangerous are often restrained and contained. Governments, argues Rose, are increasingly introducing new measures for preventive detention for those “thought to present a threat to the public” (2000, 355).

## **Taking medications ‘on time’: the temporal burden of compliance**

The contemporary medical containment of madness and fatness imposes two burdens on those experiencing antipsychotic-induced weight gain: people must take their antipsychotics ‘on time’, and they must constrain weight gain. These imperatives are couched in a broader discourse of compliance: drawing on Foucauldian concepts of biomedicine and governmentality, the “ascetic subject of compliance” (Whitmarsh 2013) succumbs to the notion that health outcomes are linked to health behaviour. Those working within the constraints of the public health paradigm see their role as bringing their clients closer to a non-compliant subjectivity:

Compliance as a problem area calls for an extension of the biomedical medical perspective (recognizing there is a problem, knowing the risks,

getting a diagnosis, understanding the significance of taking medication and eating and drinking appropriately, valuing health, acting in healthy ways). (Whitmarsh 2013, 305)

Despite the health profession being a broad church and encompassing various understandings of schizophrenia, health practitioners tend to hold uniform attitudes towards people “own[ing] the decision” to follow medical advice. The “decision” to take medication is deemed to be both personal and within the realm of individual volition. For this reason, William does not hesitate to provide clients with information about antipsychotic medication and side effects:

I think it's vital that ... [we, as practitioners] don't run away from it and that you don't hide it, because the person has to own the decision. Otherwise they're not going to stick with it! And I make no bones about the side effect profile, especially with clozapine. But a person at that stage, they've got to be really committed to being on it so they've got to see that those risks are worthwhile given the quality of life they've got at the moment. So, yeah, don't pull any punches about that!

People must consider potential medication side effects and weigh up whether the risks are “worthwhile”. This reflects a valorisation of the search for information. For nurse Gary, “ownership” means “looking at ... medication” and “looking at side effects” and having the initiative to ask questions about the medication. The biomedical model takes antipsychotic medication as the ultimate “gold standard of treatment” (Gordon 2010, 51). This approach posits medicine to be the only appropriate treatment option so, once a person learns more about their options, this logic sets out that medication will always be chosen.

Gary stresses the importance of self-control and self-discipline, lamenting some clients' attitude of “passive-resistance” towards their medications. The purpose of the mental health centre, for Gary, is to help clients achieve and maintain mental health, or “to keep them well”. “Keeping ... well” means achieving the containment

of psychotic thoughts and hallucinations. To accomplish this, clients must take their antipsychotics:

Our thing is to keep them well. How do we do that? What ways can we do it to keep them well? ... You try and encourage them to be aware of the medication of what they're taking. And some of them say 'Oh, I just don't care. I've got an illness, I've got to take my medication'. It's, in some ways it's passive-resistance. You know, 'I'm on the medication. I don't like taking it. I don't care if I have side effects. You've brought these side effects on, you've put me onto this medication'. Whereas if they took ownership, to me, they'd be looking at their medication, looking at side effects.

People are compelled to “take ownership” of their medications. For the health practitioners, the only acceptable attitude of their clients' is one of absolute engagement and interest. The clients who exemplify “passive-resistance” are deemed to be culpable for all adverse repercussions.

The health practitioners' attitudes towards medication compliance carries the “asceticism” that Whitmarsh (2013) describes in his treatise on the role of compliance in the twenty first century's global health focus on diseases of “lifestyle”. William's and Gary's obligation of 'taking ownership' echoes Whitmarsh's commentary on the imperative of “knowing oneself biomedically” (2013, 310), in which learning “the health risks, the treatments, the proper course of action ... is posited as available to anyone, and so becomes a labor expected of everyone” (2013, 310). Like the biological citizen, or “biocitizen”, in Rose and Novas' (2004) work, people are required to not only follow medical advice and expertise, but to also know oneself through the prism of biomedicine and what modern medicine deems to be 'good for you'. The repudiation for failing to do so – allegations of being passive-resistant – demonstrates the relationship between compliance and biomedicine:

Accordingly, the discourse of 'compliance' attempts to replace discernment of a patient's wants and needs with a pragmatics of getting a patient to act in healthy ways ... Asceticism runs throughout the notion of compliance in

biomedicine: the daily betterment of the self is each individual's calling, a coming together of *I must* and *I desire*; the patient must not only continually learn, he [sic] must want to learn. (Whitmarsh 2013, 310, *original emphasis*)

The participants engage in an asceticism of compliance despite failing to understand and consent to the public health reasons for taking antipsychotics. As highlighted in Chapter 5, the participants sense their future to be fixed, static and a “dead ending” (Brissett & Snow 1993, 240). Asked to elaborate on why he continues to take his medication even though it renders distorted and confused spatial and temporal experiences, Dado explains: “If you muck around with your tablets, you end up in hospital!”. Dado is a 50 year old man diagnosed with “chronic schizophrenia” (in William’s words), who has taken antipsychotic medication and has had regular electroconvulsive therapy since his diagnosis as a 34 year old.

Complaining about the weight gain he has noticed as a result of the antipsychotics, I asked Dado if the weight would ever induce him to stop the medication, to which he emphatically answers “No!”. To justify the taking of his antipsychotics, Dado normalises the medication and equates his life with his medication (“My whole life, my medication”):

I will never stop my medications. I’ll go too loopy.

*Go too loopy. What’s bad about being too loopy?*

Harm yourself. You got to take your medication. [*inaudible*] If you’ve got to take it, you’ve got to take it.

*Say that again?*

I’ve always taken it my whole life. My whole life, my medication. [*inaudible*] Better than being on my own.

*... So you think that if you stop taking your medication your mum wouldn’t let you live with her anymore?*

Mmm. Yeah, she’s really on about taking my tablets.

*... Why would your mum be mad at you if you stopped taking?*



You go bad if you don't take your medications.

Dado's future, as well as the other participants' alternative to antipsychotics as "getting sick", "going crazy" or committing self-harm, demonstrates the dominance of the biomedical paradigm. Krishna, for example, concedes that the drastic repercussions of him not taking his antipsychotic medication removes any possibility for an alternative to medication-compliance: "When I'm psychotic, they have to strap me down and inject me regularly". Sighing, Krishna murmurs, "[It's] just something you have to accept". If Ashley had the choice, he admits that he would not take the medication. Recognising "there's not really many good bits that come" from taking the antipsychotics, Ashley explains that he continues to do so or else "they'll lock [him] up in [a psychiatric hospital] and then [he will] have to stay".

The compliance paradigm draws on discourses of 'patient empowerment' (Confortini & Krong 2015; Whitmarsh 2013): people must engage in practices of self-control, understand medical information, and adhere to expert, biomedical advice. The participants' narratives above do not resonate with empowered narratives; instead, the participants explain their commitment to compliance in relation to how their lives would be without the medication.

### ***Compliance and depot medications***

Reactions to societal perceptions of schizophrenia as transgressive (and dangerous) are often met with demands of containment. These calls are placated by psychiatry's use of state-sanctioned depot medications. "Depots" administer antipsychotic medication in the form of injections at two-weekly or four-weekly intervals. Although the use of depots can be framed as the failure to achieve compliance, the health practitioners I interviewed provide a complex picture of why depots are used and how depots help to overcome some of the repercussions of distorted temporalities brought to light in the case study of Webster-paks.

Wearing yellow-lensed glasses and with a markedly black sense of humour, Gary brings a colourful exuberance to the 135 clients he works with. He is the centre's 'depot nurse', and he explains that for some of his clients, regularly taking oral medications can be difficult. This difficulty arises from, and can be amplified by, the distorted temporalities of the schizophrenic experience, which is made worse by the consumption of antipsychotics and resultant side effects. For people like Sam, whose 'mucking up' of his medication resulted in him being hospitalised, the psychiatric practice can use depots in two ways: psychiatrists can decide to prescribe depot antipsychotics based on risks of non-compliance; and psychiatrists, working with the broader psychiatric team, petition to have a Continuing Treatment Order (CTO) brought against people believed to be a risk to themselves or others should they discontinue the use of antipsychotics.

Whitmarsh argues that compliance requires "not to surrender to some authority, but to come to see the value *to the self* of being compliant" (2013, 313, *original emphasis*). Having psychiatrists or CTOs prescribe depot antipsychotics thus defies the responsibilities implicit within compliance models of biomedicine. People must take antipsychotic medication not because they have 'surrendered' to the authority of their psychiatrists, but because they recognise the importance of taking their medications to their self as self-regulating, responsible individuals. Thus, when patients have "insight" into their illness, they can turn the gaze inward and self-monitor.

However, Gary concedes that the majority of clients request to have their antipsychotic medications administered via injections. As William explains:

One of the major things is compliance and so the availability of a depot formulation comes into [decisions about which antipsychotic to prescribe] ... Very often it's the cognitive problems that you forget to take it, you're too disorganised to take it. And so, the majority of people who are on depots do so voluntarily. They want to be on depots because it's easier for remembering.

Having “insight” into one’s illness is a common psychiatric term and means that people have a level of understanding that allows them to be compliant and to practice modalities of self-surveillance.

William’s clients have internalised biomedical demands for medication-compliance, but also know themselves well enough to raise concerns about their capacity to take medications at the prescribed regularity of “breakfast”, “lunch”, “dinner” and “bedtime”. If compliance requires the active participation in biomedical ways of understanding health and health practices, then depots are an example of this form of compliance.

This is despite Seeman and Seeman finding in their study on the meaning of antipsychotics for people diagnosed with schizophrenia that “needles make them feel passive” (2012, 342). Gary attempts to invert cultural connotations of passivity by incorporating what he calls “choices” into the depot process. Clients are encouraged to decide how they want the medication injected and in which body part they want the injection; as Gary explains: “I give them the choice about whether they want to be standing, sitting or laying down”. As he explicitly describes, “I give them choices, I don’t give them the answers, I give them choices and they can take up whatever choice they want to take up”. Giving “choices”, as Gary describes it, challenges cultural constructs of mentally unwell people as unable to make decisions and without cognitive capacity.

Not all of the health professionals see the value in challenging these cultural constructs, though; some health practitioners I interviewed were more cautious in providing the full information required to know oneself biomedically. The pharmacists in this study adopt a “selective” process in providing clients with information about side effects. Vien is careful when deciding with whom to explain medication side effects:

The condition itself already warrants us to be very selective and be very precise. We have to be extra careful in dealing with those patients.

### *How do you do that?*

By making sure that we obviously gauge and see how they react and whether they would talk normally or whether they become a lot more sensitive ... So we've got to make sure we engage them, we've got to make sure they understand it. From the moment we start talking, they look a bit lost, and a bit too much, so we've got to step back.

## ***Critiquing compliance***

Many writers have offered critiques of compliance to show how the paradigm discounts the lived experience of medication-taking (see Segal 2005; 2007). These works argue that compliance discourses are “one-way doctor-to-patient instructions rather than two-way interactions” (Seeman & Seeman 2012, 345). Segal outlines five key reasons why a re-evaluation of the compliance model is required:

1. Patients deserve more respect than they are typically afforded in a compliance model.
2. Physicians and patients often think differently about and have different preferences in medical outcomes and the means of achieving them.
3. Patients are often well informed about medical matters in general and knowledgeable about their own health in particular ... They, therefore, may be well-qualified partners in decision-making.
4. ... [N]ow patients, increasingly subjected to direct-to-consumer advertising for prescription pharmaceuticals, can and do order prescription medications directly over the Internet ... Patients, that is, are capable of acting without the authority of their physicians.
5. Compliance denotes obedience to someone else's wishes. (2005, 141)

As for this last point, the conception of compliance does not align with constructions of people accessing health services as the “active patients” (Pryce 2000) required within neoliberal health discourses. As Segal illustrates, “[c]ompliance is a bad fit with the idea of patient as client” (2005, 141). Gary signals the importance of treating the people who access the centre as ‘clients’, as

the term is frequently used by the nurses I interviewed. I asked Gary why he uses this phrase, and he tersely replies, “Patients go to hospital and clients come here”.

Some writers and researchers have called for alternative models of compliance: adherence, concordance and nudging (for a brief overview, see Bajramovic *et al* 2004). These three alternate models imply a greater inclusion of both parties involved in the health experience. Adherence, for example, relies on the belief that “people choose freely” (Bajramovic *et al* 2004, 222) about their health, and encapsulates a collaborative involvement. The concordance approach extends adherence by explicitly outlining “an agreement or partnership between patient and prescriber” (Bajramovic *et al* 2004, 222). However, Segal offers a critical view of these models, noting that they are “full of contradiction ... [and] harbors an ideology of compliance” (2007, 81).

The concept of nudging supposedly provides a middle-ground approach to medical interactions, and has been the subject of much attention from within academic and health settings. Drawing on philosophies of libertarian paternalism, Thaler and Sunstein created the term, nudging, to describe an intervention that promotes welfare-enhancement whilst also preserving individual autonomy: “To count as a mere nudge, the intervention must be easy and cheap to avoid. Nudges are not mandates. Putting the fruit at eye level counts as a nudge. Banning junk food does not” (2008, 6). Since its inception in 2008, nudging has received both positive and negative attention: some lament its “fuzzy” definition (Marteau *et al* 2011, 263), its narrow focus on individuals, and its inherent oxymoronic nature of encapsulating libertarian and paternalistic values; while others see “choice architects” (Vallgård 2012, 201) achieving the balance of allowing people the capacity to make their own choices (Ménard 2010; Vallgård 2012).

Nonetheless, nudging – like the aforementioned models of compliance, adherence and concordance – all continue to revolve around a responsible individual who

seeks out and heeds health advice, and the implicit power disparities of neoliberal health continue to go unchallenged. Greenhalgh argues that:

the entrenched social determinants of health are readily overcome ... [and that] all you have to do is choose the healthy option at every node in the decision tree. You may of course need a nudge to do it these days. (2012, 96)

Despite discussions around alternative modes of compliance, people with schizophrenia describe experiences that Usher terms as “imposed compliance” (2001, 151): the motivation for taking antipsychotic medication arises from the influence of others. People with schizophrenia, in particular, often describe perceiving pressure from family, friends and clinicians to take their antipsychotic medication, or perceive that they have no other choice (Seeman & Seeman 2012; Usher 2001).

## **Being “on the look out”: the spatial burden of self-surveillance**

As well as constraining through the body’s position in time, the health profession constrains spatially through the requirement of being “on the look out” for weight gain. As I’ve argued throughout this thesis, the medical imperative for weight loss seeks containment of the fat, transgressive body (Lupton 2012) through self-regulation and self-surveillance and the imperative to contain spatially-expanding bodies. Drawing on Foucault’s critical contributions on power and governmentality, these imperatives demonstrate the embeddedness of what Foucault terms as ‘technologies of self’ in contemporary psychiatric practice. Extending Whitmarsh’s (2013) “ascetic subject of compliance”, the health profession imposes the requirement for people to not only obey medical advice, but to also proactively and rigorously monitor their own body for possible weight-gain side effects and to participate in weight loss strategies, the responsibility of which lies wholly with individuals.

## ***“Taking ownership” and technologies of self***

The imperative to “take ownership” is sermonised by Gary and his colleagues; taking “ownership” means both conforming to the temporal constraints of taking medications on time, as well as preventing and curtailing the expansion of the body. The health professions exhort being “on the look out” for potential side effects, especially weight gain; and, if weight gain has occurred, actively engaging with weight loss strategies.

Taking “ownership” means engaging in the self-surveilling practice of “looking” for side effects. William implores his clients to be “mindful”, “careful” and “aware” of potential weight gain:

*So do you explain the weight gain before prescribing?*

Yep.

*So what sort of information do you give people?*

Well, I basically just sort of say that, you know, ‘Here are the good points and the bad points. And the bad points are that you can gain weight’. And I really say that you’ve got to be on the look out for it and do whatever you can do to not put on the weight.

*... And is there a protocol for dealing with weight gain?*

And, as I said, before we start it, especially with the olanzapine, before we start it, I go into quite some detail that ‘This is a risk and you need to anticipate it and do other things to minimise weight gain’ and try and sort of come back to that and support that.

Being on the “look out” for weight gain also includes doing “whatever [individuals] can do to not put on the weight”. Acknowledging that this is “easier said than done”, William nonetheless endorses “the need to anticipate [the weight gain] and do other things to minimise weight gain”. William highlights the importance of undertaking activities and practices to prevent weight gain. “Doing things” include “sticking to a strict diet” and substituting foods (such as “eating vegetables instead

of high-carbohydrate things”); increasing water intake and eliminating soft drinks; and increasing physical activity. Barbara draws on similar individualistic health promotion discourses, imploring clients to make “right choices” over “easy options”. This includes particular types of foods (“salads, fresh fruits, veggies”), portion sizes (small), and activities (walking instead of sitting in front of the television). Compliance is thus about both “minimizing [the] unhealthy attitudes, desires, and behaviors” (Whitmarsh 2013, 309) towards certain foods and drinks, and promoting other foods, drinks and exercise.

Responsibility for looking for weight-gain side effects unequivocally lies with those taking antipsychotic medication. The prescriptions made for the “ascetic subject of compliance” (Whitmarsh 2013) is increasingly framed within a narrative of “patient empowerment” (Whitmarsh 2013, 310). Whitmarsh (2013) chronicles the focus on patient autonomy that has come out of the social movements of the 1960s and 1970s that strove to reinsert the needs and wants of patients into medical discourses. Now, this focus has shifted to obligations on patients to self-advocate, of which the failure to do so results in “a failure of discipline” (Whitmarsh 2013, 310).

Barbara’s descriptions of her interactions with Kylee epitomise the framing of Kylee as empowered to make the choice to subscribe to biomedical prescriptions:

If I know that somebody isn’t doing the right things and, you know, they’ll say ‘I’m putting on weight, but I’ve done this, that and another’. And I’ll say ‘Well, what did you have last night for tea?’. And they’ll say ... ‘It’s your fault, you know, the medication’.

In response to assertions that the weight gain is entirely medication-induced, Barbara responds:

And I went ‘No, no. Who ate all these things? Who ate the lollies? Who ate the cream doughnuts and whatever else?’. And it’s like ‘Well, I did’. ‘So who did that? Who made you eat that?’. ‘Well, because I wanted to’. I said ‘Did someone hold a gun to your head?’. ‘No’. ‘So who made you?’. ‘Oh, I



suppose it was me'. 'Well, okay'. You sort of make them try and take responsibility. Because they have to.

Modern health discourses and health promotion draw on practices of self-surveillance and self-regulation to produce modern subjects (Crawford 2006; Foucault 1980). Foucault's (1978; 1980) work of governmentality theorises how the modern state governs its citizens: technologies of power and technologies of self-organise populations and produce self-regulating subjects. Requirements for biomedical compliance produce technologies of self: institutions discipline individuals (and their bodies) through techniques of (bodily) surveillance, both real and perceived (Foucault 1980).

The health practitioners' requirements for self-regulating compliance is tied to specific forms of neoliberal governmentality. Biopower, as a form of technology of power, is a political technology that manages and controls large populations through practices associated with the body. The global 'obesity epidemic' highlights the pervasiveness of biopower within a medical-political context: particular practices and particular bodies have been normalised to generate concerns over 'obesity' and fat bodies (Evans & Colls 2009; Wright 2009). Biopower has thus been used to critique obesity, because modern obesity practices:

not only place individuals under constant surveillance, but also press them towards increasingly monitoring themselves, often through increasing their knowledge around 'obesity' related risks, and 'instructing' them on how to eat healthily, and stay active. (Wright 2009, 2)

Health promotion is a practice of governance in that it produces modern subjects: it defines health, whilst also supervising and advising on how to achieve it (Coveney 1998; Crawford 2006). The health professionals' guidance of avoiding weight gain, such as modifications to diet and exercise, governs how clients can achieve health. In their UK study on the "limitations of a biomedical framing" for South Asian women with experiences of breast cancer, Confortini and Krong articulate how

compliance is achieved through “self-control, the understanding of ‘proper’ information (devoid of ‘harmful’ cultural and social ideas) and the adherence to (expert) biomedical guidance” (2015, 4). When these prescriptions are abided, clients become ‘empowered’ (and thus compliant).

### ***Critiquing “lifestyle” interventions***

Responsibility lies with individuals to not only “be on the look out” for weight gain, but to also engage in weight loss strategies should weight gain occur; if individuals have failed to self-surveil in the prevention of weight loss and have gained weight, then individuals must employ technologies of the self to lose weight. William describes the “problem” of “people not owning their fat”. Some health practitioners have drawn on neoliberal ideology to encourage clients to not only “own” their medication, but to also “own” their weight gain (and subsequent weight loss endeavours).

Barbara describes her frustrations with Kylee’s refusal to take responsibility for her weight gain and weight loss. Barbara believes that weight gain can be combated with “(self) motivation”. Fundamentally, clients have “got to want to change ... If they don’t want to change, there’s nothing that you can do [that] is going to change it”. Barbara counsels Kylee after she becomes discouraged about her lack of weight loss:

‘So, you can’t be doing all the things that you say you’re doing’. ‘Oh, I am, I am’. I said ‘Well, you need to prove it because, at this stage, it’s not showing’, and I said ‘If you’re following everything to the letter ‘T’ and actually doing everything that you’ve been told to do, you should be losing weight’, I said ‘But you’re not. So that tells me you’re not doing it’.

For Barbara, her suspicions are confirmed when, a month after her reproach of Kylee, Kylee is weighed and registered as having lost weight. Asked why the weight loss occurred this time (and not the month earlier), Barbara exclaims:

Oh, she wasn't doing what she was said she was doing! She was telling me she was, but I would daresay she was eating extra stuff. I don't think that she was having enough water, and she wasn't walking as much as what she said she was.

Barbara develops a hierarchy between clients who “actually want to lose weight” and those who do not. As the head of the Clozapine Clinic, Barbara is responsible for the “metabolic monitoring” of about 90 clients on clozapine, as well as the monitoring of the other side effects of the medication, including low white blood cell counts. She is also involved in the Clozapine Working Group, a group of doctors and nurses across the State working towards reducing the weight-gain side effect profile of clozapine: one of the important roles of this group, Barbara explains, is to answer the question, “How do we actually get this weight down, especially with people with a BMI over 40?”.

Only those falling in the first category of “wanting to change” are selected to participate in Barbara’s “added bonus” program: intended as a “motivational thing” to help lose weight, these clients are given the option of being weighed on a weekly basis. The 15-minute Friday sessions usually involve the weighing of the client and Barbara asking questions in relation to the week’s potential weight loss: “their diet ... how they’re going ... how did they think the week went, have they done any exercise ... where did you go wrong this week?”. Barbara also provides clients with a coloured excel graph of clients’ weight loss, “so they can actually see it going down”.

This approach reflects what Barbara and Julia describe as “motivational interviewing”. As the transgressive experiences of schizophrenia and weight gain create distorted spatiotemporalities and produce heavying experiences that make people feel ‘down’ (as demonstrated in Chapter 4), then motivational interviewing helps to get people back ‘up’. Developed by clinical psychologists and first coined in their textbook of the same name, Miller and Rollnick describe motivational

interviewing as inherently “conversations about change” (2013, 3). They argue that language primarily serves to, in their words, “motivate [and] to influence each other’s behaviour” (2013, 3), and the principles of motivational interviewing help to “strengthen motivation for change” (2013, 12).

Despite attempts to collaborate between health practitioners and clients, motivational interviewing is limited in extending beyond the neoliberal discourse of choice. Julia describes motivational interviewing as helping clients set goals that “they can achieve without depending on anyone else”. She does this by first asking clients “Now what’s the most important thing that you want to do?”. This approach resonates with Miller and Rollnick’s third principle of motivational interviewing of autonomy: “a radical acceptance recognizing that ultimately whether change happens is each person’s own choice, an autonomy that cannot be taken away no matter how much one might wish to at time” (2013, viii).

Motivational interviewing and self-motivation pervade all aspects of personal and social life. Julia describes the diverse ways in which she compels clients to carry out technologies of self:

I emphasise ... simple things: you’ve got 32 teeth in your mouth, chew your food 32 times; always sit and have a meal; eat regularly. All the little hints, you know, that we’re taught right from being toddlers: you wake up in the morning, before you have that first cigarette, have some breakfast; extend your smoking habit, keep putting it off, 10 minutes, 15 minutes; have a glass of water, fill your stomach with water; grated carrot is another one I tell people to have, if you’re looking to fill your plate a little bit more, think about some grated carrots, they’re inexpensive, they are really filling; celery, it’s good in other ways, too, you know, good for your kidneys, diuretics.

Motivational interviewing also draws on scientific rituals and imperatives of confession (Pryce 2000). Foucault (1978) understood the Christian principles of confession and penance to be the precursor to the modern technologies of self,

self-regulation and self-surveillance (cf. Coveney 1998). These Christian practices developed through the organisation and operation of disciplinary knowledge. Barbara's weekly weigh-ins and subsequent questions of "Where did you go wrong this week?" highlight the burdens placed on clients to explain the discrepancies between their weight gain or lack of weight loss, and their recorded weekly practices of diet and exercise. Clients are impelled to declare and confess how they "went wrong". Such practices constitute "scientific modes of incitement to confess" (Pryce 2000, 106).

As well as eating more vegetables and drinking less soft drink, some of the health professionals encourage clients to "teach" themselves to think differently about meal sizes and personal satiety. Although clients argue that the technologies of self for weight loss render them hungry, Julia implores clients to enact self-discipline:

You may not feel satisfied with that meal, but you have to teach yourself 'This is a plate of food that is sufficient for me and therefore I'm going to maybe have a glass of water or stretch out the time that I take to eat that meal'. But in a psychological way, you're going to have to learn to eat a smaller amount.

These prescriptions are couched in moral frameworks, challenging people's perceptions of bodily hunger and sense of fullness. In his exploration of the "government of girth", Coveney (2008) uncovers the morality embedded within modern nutritional science. Coveney draws on a critical fat approach to demonstrate how the fat body is now conceptualised as a "state of moral pathology" (2008, 199). Food and food choices, argues Coveney, are governed in two ways: first, by scientific knowledge that manage the eating habits of populations; and second, "as a form of moral correction" (1999, 23) which problematise personal food choices. In the governmentality of the self, nutritional science is established through the self-regulation and self-scrutiny of individual dietary habits.

Traditional weight loss strategies align with understandings of weight gain as resulting from the “Big Two” (Keith *et al* 2006, 1585) of diet and exercise, and the health professionals in my study frequently refer to “lifestyle factors”. Advocating for these modes of weight loss contradicts my participants’ understandings of ‘unique fatness’. Unlike constructions of weight gain as “not fat”, the health practitioners understand it differently. When his clients refute their culpability in the weight gain and say “it’s not fat”, Gary responds unequivocally:

I say ‘Sorry, dear, it’s fat!’ ... You can’t say ‘This is happening but it’s not [my fault] ... I’ve gained weight but it’s not due to me overeating’. ‘Sorry, it is! It’s due to you overeating but it’s also due to your medication as well’. So we’ve got to look at both things.

The import placed on lifestyle factors (and “lifestyle diseases” (Whitmarsh 2013, 305)) has received recent critical attention. Glass and McAttee bring to light the heightened focus within public health on “individual health-related behaviors (or ‘lifestyles’), without due consideration of the social context in which health behaviors occur and become socially patterned” (2006, 1651). Epidemiologists Keith and his colleagues highlight some plausible mechanisms for increased rates of obesity within the wider population, including “sleep debt” (2006, 1587), reductions in ambient temperatures, declines in cigarette-smoking, and an increase in the ages that women give birth. Along with these other factors, Keith *et al* (2006) draw correlations between the increased use of many types of pharmaceuticals, including antipsychotic medication, and the rise of obesity rates.

In Chapter 1, I highlighted other researchers’ concerns about the “hegemony” (Keith *et al* 2006, 1585) of diet and exercise in obesity research, including proponents of the Health At Every Size (HAES) movement and writers from critical dietetics. Aphramor writes within the dietetics academy and challenges the ‘energy balance’ theories of obesity and weight gain, describing the narrow focus as “epidemic of truncated theorizing” (2005, 334). She further argues:

The reductionist assumptions of current theories of adiposity, its implications and significance for health, have failed to flesh out the real issues. By vilifying fatness, promoting dietary restraint, conflating slenderness with well-being, glorifying thinness, cementing gender-inequity, hiding violence, fuelling shame and perpetuating narrow biomedical understanding of health mainstream nutrition discourse marshals our thoughts and keeps the obesity generals fed with troops. (Aphramor 2005, 331)

Traditional understandings of weight gain neglect these “real issues” of fatness due to their biomedical and reductionist framework: the energy in/out equation fails to see beyond individualistic actions taken on individual bodies. Adhering to neoliberal ideology that positions individuals as responsible for “owning” their weight (gain and loss) thus restricts broader explorations of weight experiences, especially the lived experiences of weight stigma.

### ***Containment and the achievement of ‘self’***

Crawford’s “imperative of health” (2006, 403) mirrors medical imperatives of containment: to achieve health, bodily transgressions of illness must be contained. Metaphors of illness and containment are central to discourses that place the responsibility of one’s health with the individual (Sontag 1978). “Health is metaphorical” (Crawford 2006, 405), and warfare metaphors emphasise the importance of ‘fighting off’ intruding germs and diseases: individuals ‘battle’ cancer with potent antibiotics that act as ‘big guns’ to ‘kill the bugs’ that infect (‘invade’), and after a ‘long and valiant battle’, the individual may be overcome with ‘defeat’. In his treatise on the modern “Age of Immunology”, Napier maps out the emergence of contemporary immunological practices and sciences, and how immunological metaphors has influenced the ways in which individuals understand themselves and what he terms the “not-self”, the “pathogen” (2003, 2). The result of these metaphors and this way of thinking created “The Enlightenment, the Age of Discovery, the homogenization and elimination of difference that has brought us ... into our “immunological” world” (Napier 2003, 2).

The popular narrative around the AIDS epidemic extends the relationship between illness and containment (Crawford 1994). Western cultural understandings of AIDS epitomises the assault of the healthy self by an unhealthy Other (Crawford 1994):

The 'diseased' Other who 'carries' and metonymically comes to represent the feared disease, whose invisible presence contaminates the pure space of health, must be physically and culturally isolated. The presence of disease and 'the diseased' is a nearness that threatens by reminding the healthy that their health is tenuous. It is a threat that must be contained by making 'the diseased' different and disease the property of the Other.

(Crawford 2006, 414)

Self-control and self-containment are essential in staving off the "diseased Other". Health is thus conceptualised as contingent on how well the individual maintains self-boundaries and perpetuates "ideal(s) of personal control" (Crawford 2006, 419).

Modern constructions of healthfulness are founded in moral discourses and imperatives: in our "health-valuing culture" (Crawford 2006, 402), individuals abide by moral codes of corporeality and surveillance to achieve health. Modern healthism recognises health to be central to all aspects of life (Henderson *et al* 2009), and the achievement of health is contingent on self-discipline and the regulation of the self.

The "meta-narrative ... [of] the Western notion of selfhood" (Greenhalgh *et al* 2015, 9) revolves around the success of the individual to navigate prescribed choices and behaviours. Models of morality are encoded in narratives of responsibility and citizenship: Crawford argues that health is "widely considered the *sine qua non* of individual autonomy and good citizenship" (2006, 402). Selfhood and citizenship are defined by how well people succeed or fail in adopting prescribed self-surveilling practices and health behaviours (Crawford 2006). Modern frameworks



of health establish and demonstrate how to be a good citizen, and Rose (2000) argues that these models are based on reciprocal obligation.

In return for the nation-state providing the “conditions of the good life” (Rose 2000, 1398), individuals must exercise “active responsible citizenship” (Rose 2000, 1398). A mutual obligation takes place, in which responsible citizens are required to actively partake in the prevention and maintenance of their own health, in order to ‘repay’ the support they receive from society. The preservation of good health is thus one of the obligations of citizenship within contemporary society (Petersen & Lupton 1996), and Galvin (2002, 112) maps out how modern constructions of health have transitioned from a right to a duty.

Neoliberal ideologies of health require individuals to actively seek out, and act on, relevant health advice, rendering individuals responsible for their own health. Petersen (1996) chronicles the shift away from the state protection of health in the 1970s to the modern expectation of citizens to ensure their own physical and psychological wellbeing. What has emerged is an ‘age of neoliberal health’. As Coveney recognises, the fundamental feature of a society in which neoliberalism is “successful” is “a self-reflective, self-regulating individual with the correct concern for themselves” (1998, 464). Similarly, Petersen describes the “endless” processes of “self-examination, self-care, and self-improvement” (1996, 48) required of neoliberal individuals.

The achievement of health – and its connotations of containment and wholeness – is intimately connected to Western constructions of the self. Not only are technologies of self the means by which health is achieved, but health has also become “a symbol, and vehicle for, demonstrating self-discipline” (Henderson *et al* 2009, 11). The self is characterised as the “ideal of personal control” (Crawford 2006, 419), and those who fail to achieve this ideal accordingly fail to achieve the status of selfhood and full citizenship. Personhood is defined by how well people succeed or fail in being healthful:

Accordingly, both the conventionally understood means of achieving health and the social state of being designated as 'healthy' are qualities that define the self. They become features of modern identity. Moreover, health and the qualities of personhood associated with its achievement are key metaphors traversing the moral terrain of contemporary societies. (Crawford 2006, 402)

Fat bodies signal failure in achieving discipline and control – fatness thus denotes loss of health and citizenship. Parallels can be drawn between the transgressive fat body and Crawford's (2006) example of the AIDs epidemic: the healthy self sits in opposition to the unhealthy and deviant Other.

## **The impact of differing knowledges**

The differences between medical and patient understandings of time, space and bodies highlight the conflicts between medical imperatives for containment and participants' lived experiences of medicated weight gain. A spatiotemporal lens draws attention to these conflicting discourses by showing how the attempted containment of the transgressed experiences of schizophrenia produces weight-gain side effects that amplify perceptions and experiences of time and space. Rather than setting up these discourses as opposing dichotomies, exploring the space between these understandings opens up the possibilities of understanding the "relations between ... practices" (Mol 2002, 5) and between health practitioners and clients, and achieving insights about health as complex, personal and transformative.

Understandings of antipsychotic-induced weight gain as 'unique fatness' highlights how meanings of medicine and science can be saturated with, and transformed by, personal understandings and lived experiences. Some health researchers have pointed out the common mistake in health research of overlooking the ways in which individual meaningfulness is applied to experiences of health: personal understandings are "deeply personal and therefore infinitely varied" (Crawford 2006, 404). Crawford cautions researchers against this tendency:

In the quest for generalization, sociologists, myself included, often lose sight of the fact that health is imagined and taken up as a practice in the life-worlds of individuals who have uniquely personal reasons about why health has become important to them. (2006, 404)

Failing to recognise the “spectrum of knowledge(s)” (McClellan & Shaw 2005, 729) of health narrows alternative understandings of health, especially experiences of antipsychotic-induced weight gain. In her critique on the limitations of health research that relies on evidence based medicine, Greenhalgh argues that the repercussions of research that fails to take into account lived health experiences is the production and perpetuation of the “bounded, linear, predictive” (2012, 96) health paradigm. Such a framework sets up the “lay-expert divide” (McClellan & Shaw 2005, 729), positioning lay lived understandings (like ‘unique fatness’) as inferior.

However, health is a social practice and what Popay and Williams term as “lay expert knowledge” (1996, 760) must be incorporated into all health research. Popay and her colleagues (2003) document the ways in which early understandings of lay perspectives were conceptualised as separate from formal understandings of health and illness, something that social science writings on health have tried to rectify by including these perspectives in their works. These developments have created the appetite for a broader debate about the integration of lay knowledges into medical practice and health policy (Napier *et al* 2014; Weiner 2009).

Complexity exists not only in people’s everyday understandings of their health, but also in health practitioners’ knowledges and experiences of health practice. Not only is there disjuncture and conflicts between healthcare and lived health experiences, there is also conflict within the broad church of the health profession. This is especially evident not only in the differing views on the causes of schizophrenia and the way in which antipsychotic medication works in the

treatment of psychosis, but also amongst the health profession about the prevalence and cause of weight gain. Indeed, the two pharmacists involved in this study both explicitly deny the prevalence of antipsychotic-induced weight gain and the role of the medication in the weight. Vien describes the weight-gain side effect as “not a big thing” and not a “major side effect”; Tu similarly asserts that “there’s not many people who are overweight [from antipsychotics]”. When people do experience weight gain, Tu claims that he does not “see the influence of the drug in the aspect of weight gain” as he has also “seen a lot of skinny patients” who have taken the antipsychotics.

Highlighting the different approaches taken within the medical profession, other health practitioners hold different versions about the weight gain. Gopal deems there to be “multiple mechanisms” for the weight gain:

Number one, in very simple terms ... the medication might increase the appetite and the patients may end up eating more ... Natural to the illness, if the person has a lot of negative symptoms, already he or she is vulnerable to the side effects ... So they may take the medication, sit and watch TV all day, or smoke and watch TV all day, so that makes them vulnerable to weight gain ... [Also] 45% of the Australian population is obese or overweight, so again, we have to remember that the general population is at an increased risk of being overweight.

*Okay.*

So there are multiple mechanisms in which people gain weight. But I feel that ... it’s a combination of taking medications that make them vulnerable to weight gain, having negative symptoms that prevents them from going out and being active too, and having comorbidities like diabetes or depression, for example, that prevents them from doing anything.

Gary conveys similar knowledge of the weight gain, recognising that some weight gain is due to the antipsychotic medication, but that it is also “due to other things that are happening as well”. As I’ve shown, despite acknowledgement of different

causes for the weight gain, the health practitioners almost universally agree on the solution for the weight as within the responsibility of individuals.

These conflicting knowledges can have serious implications. Despite recent clinical evidence highlighting the poor health experienced by people with mental illness, specifically schizophrenia (Allison *et al* 2003; Lowe & Lubos 2008), broader health experiences have not been incorporated into mental healthcare models. Julia laments that the “whole medical model” is pervasive. This dominance, Julia explains, is bound up in the funding of the modern medical system: “It’s all about money and beds!”. She illustrates how each diagnosis is attached to a pool of money, which is then allocated for specific tests, treatments and care.

Within this biomedical framework, social or psychological interventions are undervalued and overlooked; as Julia explains: “They’re not going to give us a packet of money because we say we will set up an exercise group and society would benefit!”. Julia’s daily task of “finding beds” not only brings to light the hierarchical nature of contemporary medical practice, but also shows how the focus on containment (hospitalisation) comes at the expense of other possible health practices:

So they go by diagnosis and that’s how, you know, our whole service operates now. 9.30 in the morning, there’s a phone call between all the different community sites: ‘Who’s going to be hospitalised?, Who’s not going to be hospitalised?’ ... That’s the whole focus, every day. We don’t have a meeting every day saying, you know, ‘So-and-so is going to put on a group activity today about mindfulness’ or something.

### ***The centrality of embodiment and experiences of side effects***

Despite this biomedical paradigm positioning the treatment of schizophrenia as fundamental and side effects as peripheral, we know that side effects (especially weight-gain side effects) are central to experiences of health (Jenkins & Carpenter-

Song 2008; Seeman & Seeman 2012; Vandyk & Baker 2012). The data presented in the last two chapters shows that medical attempts at containment result in amplified spatiotemporal distortions; recognising the centrality of all embodied experiences, disrupted spatiotemporalities are fundamental experiences and not experienced as unimportant.

As someone who has experienced weight gain, Barbara straddles the boundary of embracing the medical narrative that advocates for weight loss at all costs, while empathising with clients who struggle to lose weight. Barbara brings into consultations her own experience of having a large body and of undergoing weight loss surgery. At times during our two interviews, Barbara evinces a compassionate attitude towards her clients, an attitude that may have resulted from identifying with experiences of weight gain and weight loss attempts. However, framing the success of her surgery within terms of the self-discipline practices of motivation and adherence to her treatment regime, Barbara's history of weight loss surgery imposes limits on the empathy she has for her clients.

Embodiment scholar Throsby (2008) has researched the lives and experiences of those who have undergone weight loss surgery. For her participants, surgery dates connote "re-birth dates" (Throsby 2008, 118): "re-birthdays" celebrate the identity of the "re-born post-surgical 'new me'" (Throsby 2008, 118). The "new me" is differentiated from life prior to surgery; after surgery, a "more authentic, socially legitimized, disciplined self" (Throsby 2008, 129) is rescued and revealed.

Barbara has developed a narrative that cements her own weight loss as resulting from the personality traits and behaviours (that is, self-regulation and self-surveillance) of her "new me". Looking at photographs of herself prior to surgery, Barbara distinguishes her "new me" from her prior self:

In actual fact, I was just going through photos over the weekend with my sister – because we're actually doing a photo book for my dad for his 80th

and we're going over in August – and I came across some of the photos and I went 'Oh my god, have a look at *that!* How fat was I in that photo?'

Although she ostensibly recognises the role of the antipsychotic medication in her clients' weight gain, Barbara asserts an homogenous view of weight gain and loss by conceptualising it almost exclusively within the narrow neoliberal terms of self-motivation. This view of weight-gain side effects conflicts with the participants' descriptions of the weight as 'unique' and something that is 'not fat', and medical directions and advice that fail to take into account these understandings will fail to connect with their target audience.

### ***The futility of health behaviours***

Not only are these differences in knowledges problematic because they fail to incorporate lived experiences of medicated fatness into public health narratives, but they also promote individualistic behavioural changes. An emerging body of literature has offered critiques on the effectiveness of self-regulation in health practices (Baum & Fisher 2014; Confortini & Krong 2015; Greenhalgh *et al* 2015), demonstrating how public health initiatives that focus exclusively on the health behaviour of individuals are “doomed to fail” (Greenhalgh *et al* 2015, 11). Despite some health professionals acknowledging the cause the weight gain as medication-induced, they continue to promote particular individualistic health behaviours.

Encouraging these behaviours frames health and health experiences as entirely produced by individuals, removing social context and biology from these understandings. Some of the practitioners I interviewed did draw attention to the people who access the centre as being, as described earlier, “the worst of the worst”. Julia links many of her clients' weight gain with their high consumption of sugar, fat and salt and lack of cooking skills. This social context is complemented

by Gopal's "combination" of factors to explain the weight gain, including the medical conditions of diabetes and depression and having specific genetic factors.

Despite recognising these explanations for the weight gain, the practitioners exclusively relegate the responsibility for weight loss with clients. This position is predicated on the 'education about risks' paradigm that posits 'lifestyle' prerogatives as entirely free choices that are unconstrained by broader socioeconomic factors and, given appropriate information about lifestyle risks, individuals can and will make choices that result in good health outcomes. In promoting diet and exercise, health practitioners rely on the proposition that they are within the reach of the clients, that they will result in weight loss, and that weight loss promotes good health (cf. Aphramor *et al* 2013).

Baum and Fisher, however, draw attention to how social determinants of health, not health behaviours, play a significant role in health:

When people behave in ways that are not good for their health it is generally not because they are unaware of the risk but rather that the constraints of their life and accumulated dispositions over the life-course means they are unable or unwilling to change their behaviour. (2014, 216)

To promote health behaviour that puts the onus onto people with schizophrenia denies the social constraints of their lives: lives that are "the worst of the worst" and often marred by social disadvantage, poverty, isolation, stigma, and multiple medical conditions.

Not only does this approach deny the social context of their clients' lives, but it also denies the complexity of the weight gain. Using the case study of obesity, Huang and Glass (2008) challenge the ways in which it is represented as an imbalance of the energy consumption/energy expenditure equation. Instead, obesity is "a medical manifestation of the complex interplay of biology and social change" (Huang & Glass 2008, 1811); Huang and Glass argue that obesity research must pay attention to "larger changes in the social, physical, economic, and policy



environments” (2008, 1811). Likewise, medical conditions and diseases are “produced through a complex and interrelated set of factors that are not reducible to a simple cause–effect explanation” (Confortini & Krong 2015, 3). Cause–effect explanations underpin the behaviour change paradigm.

The spatiotemporal lens used on the phenomenon of antipsychotic-induced weight gain expands understandings beyond individual health behaviour and the cause–effect of the energy equation. Space and time are severely distorted, magnified and constricted by the taking of antipsychotics and side effects, and health promotion strategies must attend to these experiences to achieve successful public health outcomes. If public health continues to ignore the specific experiences of antipsychotic-induced weight gain and bundles the experiences with broader narratives about weight and obesity, then they will continue to be “largely ineffective and unsustainable” (Huang & Glass 2008, 1811).

In their study on the everyday experience of schizophrenia and medicated weight gain, Vandyke and Baker highlight the failure of psychiatry and public health to consider the lived perspective when formulating weight loss advice and programs; this is why “successful, long-term weight loss interventions are not yet available” (2012, 349). This lack of integration of individual experience defies the evidence showing that weight gain often leads to the drastic repercussions of discontinuation of antipsychotics and possible psychiatric relapse. Seeman and Seeman (2012) draw on a variety of studies on schizophrenia throughout the US, UK and Australia to approximate that between 20% and 89% of people with schizophrenia have not taken their antipsychotic at one time throughout their diagnosis. A majority of the participants similarly described discontinuing their use of medications, whether because they had difficulty in taking their medications ‘on time’, or in the cases of Kylee and Rasmey, the side effects were too distressing and, for them, outweighed the benefits of their antipsychotics.

## Summary

Kylee's and Rasmey's stories of medication-discontinuation highlight the repercussions of psychiatry's attempt at containment, in which antipsychotic medications exacerbate experiences of transgression to produce distressing experiences of transgressed bodies and time and space. For health practitioners, clients like Kylee and Rasmey are required to constantly attend to and surveil their body and bodily practices, and the imperative of health requires the identification of potential dangers (Crawford 2006). Drawing on Douglas' (1970) work on "matter out of place", Crawford (2006) illustrates how health is built on the symbolism of danger (transgression) and control (containment). The obligation of self-surveillance is directed towards the "preservation of sociocultural boundaries" (Crawford 2006, 402), and any transgressions or deviations from the norm must be surveilled, regulated and contained.

Critics of "'behaviour change' interventions" (Greenhalgh *et al* 2015, 1) understand health and health outcomes to be a complex interplay of a broad range of factors. These critiques have given rise to increased social and medical interest in lay knowledges, creating opportunities for weight-gain side effects to be conceptualised outside of the simplistic energy in/energy out equation, and instead understand medicated fatness to have come about from the failed containment of transgression. Lay understandings of health are imbued with layers of meanings of biomedicine, institutional authority, metaphor and social phenomenon (Crawford 2006). As Crawford explains:

Lay conceptions of health – including ideas about causal pathways of disease ('lay epidemiology'), strategies of protection and related commentary on individuals, situations, environments and medical recommendations – are elaborate and intricate. (2006, 402)

Understanding health as a "meaningful social practice" (Crawford 2006) allows for deconstructions of health practices and knowledges and, together with the

application of a spatiotemporal lens, thus offers insight into the lived experience of antipsychotic-induced weight gain.

# CHAPTER SEVEN

## Conclusions

This thesis has examined the relationships between medication, madness and fatness. The case study of antipsychotic-induced weight gain, exemplified by the Eli Lilly court case introduced at the beginning of this study, reveals the ways in which the creation of one condition (fatness) has been caused by the medication management of another (schizophrenia). Throughout this thesis, I have drawn on theories of embodiment and spatiotemporalities to expand on the major themes surrounding the phenomenon of antipsychotic-induced weight gain: bodily boundedness, containment and the transgression of bodily and social boundaries. The spatiotemporal framework extends analyses of bodies to understand bodies as inherently transgressive and unable to be contained (Blackman 2010; Williams 1998).

Theories of bodies, time and space bring together a series of related fields to understand the complexity of simultaneous experiences of being fat and mad. Starting with empirical literature that illuminates the ways in which experiences of schizophrenia produces experiences of transgression and loss of boundaries (Barrett 1996; Corin 2007; Lucas 1999), I expanded constructions of schizophrenia to show how weight-gain side effects align with its representations as “the broken brain” (Kleinman 2004, xv). In conceptualising schizophrenia as located exclusively in the head, medication is designed to contain the ‘symptoms’ of schizophrenia: antipsychotics thus contain the ‘uncontainable’ thoughts and experiences of schizophrenia.

However, a contradiction arises in that in its containment of the head, antipsychotics cause rapid weight gain on the body, amplifying the loss of boundaries and distorted experiences of bodies, space and time. I have shown that despite its attempt to contain thoughts and activities of the mind, antipsychotics do the opposite to the body: bodies are expanded and bodily boundaries are transgressed. Reflecting prevailing psychiatric discourse, the weight gain is considered to be a 'side' effect of the antipsychotic medication and is unattended to as it occurs in the body and sits outside of the purview of psychiatry.

In spite of treating psychosis so that symptoms can be dampened and functioning in everyday life is improved, the side effect profile of antipsychotics mark people as different. Extending Estroff's (1981) classic work on extrapyramidal symptoms of earlier antipsychotics, in treating and attempting to hide the overt 'anti-social' symptoms of schizophrenia (talking back to voices, responding to visual hallucinations), the uniquely rapid nature of antipsychotic-induced weight gain identifies and marks those with schizophrenia to reveal their identity as 'crazy'. Nurse Julia acknowledges the irony that what is commonly characterised as "pretty scary" about people with schizophrenia – the large bodies, the smell, the walk, the drawling – is actually caused by the antipsychotic side effect profile: "most of what we see is the side effects of the medications ... it's not the illness!". Unlike the primary symptoms of schizophrenia (hallucinations and delusions, for example), which Julia believes can be "hidden", antipsychotic side effects cannot.

In exploring the relationship between madness and fatness, my study has revealed its inherent complexity: antipsychotic medication creates experiences of transgressions beyond those that the medication attempts to contain. Participants' descriptions of the weight gain reflects its spatial and temporal transgressions: antipsychotic-induced weight gain expands, heavies and immobilises bodies, and violates experiences of time and the ordering of everyday experiences, rendering bodies as distorted, disrupted and uncontained.

## Transgression and a loss of personhood

Antipsychotic-induced weight gain extends understandings of schizophrenia to show the ways in which the cumulative experience of madness and fatness amplify disruptions of bodies and bodily boundaries. Extending Barrett's (1996) pivotal work on the construction of schizophrenia as the fragmentation of Western constructions of personhood, this weight gain creates experiences of distorted, uncontained bodies and everyday experiences. The participants (literally) consume the antipsychotic medication, and the medication in turn (metaphorically) consumes them, their life and what it means to be a person and a citizen within Western society.

The ill, disabled or pained body is often coded as “dysfunctional” (Leder 1990; Toombs 2001a & 2001b). My research has drawn parallels between the participants' experiences of antipsychotic-induced weight gain and the dysfunctional body; both straddle the boundaries of health and ill-health, and both reflect bodies in transgression. Antipsychotic-induced weight gain straddles these boundaries by producing experiences of disrupted and distorted space and time. Bodies that are conceptualised as heavied and amorphous demonstrate how the experiences limit movement and connection (Ingold 2015). Contrary to the contained bodies of Cartesian thinking, permeable bodily borders challenges conceptualisations of personhood and self. The ‘undead zombie’ describes participants' understandings of liminality and how transgressive experiences reflect a loss of personhood. Zombies signify “a terrifying threat to the social order” (Behuniak 2011, 72); they are “a non-person” (Behuniak 2011, 74) on the borders of life and death, never fully belonging to either state.

Experiences that intersect at the margins revoke individuals' entitlement to autonomy, highlighted by the metaphors of liminality (‘the walking dead’) and sleep (Lee 2008). These metaphors extend Barrett's work that schizophrenia is constructed as “a basic flaw in the core attributes of personhood” (1996, 216).

Disintegrated and disrupted experiences contradict constructions of personhood as “unified, coherent, bounded, whole” (Barrett 1996, 216); transgression, therefore, represents failure to achieve wholeness and personhood.

As well as transgressed spatialities having implications for how participants understand their weight gain and their sense of personhood, the lens of temporalities draws attention to the relationship between time and health. Despite time being a taken-for-granted fixed entity, when experiences of time contradict clock time and flow is interrupted, time becomes acutely apparent and present. When time is experienced as immediate, the future is fixed; the participants characterise their futures as “the tyranny of ‘forever’” (Seeman & Seeman 2012, 341) and articulate it in deterministic and bleak terms.

Negative future outlooks encourage short-term views and risk-taking behaviour. George explicitly justifies how, “when your life gets to that point” and the future is “not so rosy”, then it is “okay” to drink alcohol, eat take-away food and “have a few cigarettes”. These behaviours are immediate forms of gratification that brings pleasure to lives marked by acute hardships (Graham *et al* 2006; Johns 2011). In their study on the meanings of obesity prevention programs for people living disadvantaged lives, Warin and her colleagues develop the analytic concept of “short horizons” to argue that “obesity prevention programs have limited relevance to the immediacy of poverty, contingencies and survival that mark people's day to day lives” (2015, 309). For those with lives marred by disadvantage and danger, time (and the future) is not linear and predictable.

My participants emphasise the importance of generating and maintaining a sense of hope when faced with everyday experiences and futures that are bleak and unpleasant. For George, “hope is enormously powerful” in helping people believe that “things can improve”. Hellström has likewise found hope to be important in countering negative future perceptions: “To have something to strive for, to have dreams, to have something waiting in the future proved to carry a quality of survival

value” (2001, 88). Popular constructions of hope have often reflected the individualistic orientation of modern healthcare, evidenced by an increasing use of the language of empowerment in health discourses (Petersen & Wilkinson 2014). Recognising the complex and ambiguous meanings of hope, Petersen and Wilkinson call for a sociology of hope that will:

eschew efforts to neatly conceptualize hope and its meanings, but rather seek to elucidate the tensions, multiple interpretations, and “in situ” experiences of hoping, through empirical analyses of the workings of the politics of hope in different contexts and in regard to specific conditions. (Petersen & Wilkinson 2014, 116)

Greater understandings of hope draw attention to its interactions within individual experiences of health, medicine and healthcare and its operations with the health relationship. As well as the lived experience of hope, research could explore how hope works within medical discourses and medical practice, and potential uses of hope at the level of health policy.

## **Unique fatness and implications for public health messaging**

The participants’ constructions of medicated and non-medicated fatness alert researchers to the hierarchies of fatness. Descriptions of unique fatness reveals the multiple and complex meanings the participants attribute to fat and its causes; bodies and bodily processes are understood and experienced as differently constituted from ‘ordinary’ or non-medicated bodies. As well as being linked entirely to medication, experiences of unique fatness produce distinctive spatiotemporal experiences; not only does the medication slow down bodies while speeding up hunger, medicated fatness also creates distinctive experiences of time and space. In this sense, antipsychotic-induced weight gain is out of the participants’ control. In contrast, the participants described non-medicated bodies



as able to exhibit 'self-control': ordinary bodies can "exercise harder and eat better" and effectively lose weight.

What the participants describe as "not fat" is still fat in a physiological sense, but rather the meanings of the fat are not individualised or seen as a consequence of one's responsibility – it is not the same type of fat. The fat of non-medicated and medicated bodies is (materially and morally) qualitatively different.

Characterisations of the participants' weight contradicts taken-for-granted understandings of weight gain as a result of poor lifestyle choices – of excess food and not enough physical activity – and thus challenge popular understandings that tend to homogenise obesity within a discourse of individual blame.

The failure of recognising these constructions of unique fatness has implications for public health messaging and initiatives. Although some research has exposed the differing ways in which people understand their own weight (Lewis *et al* 2010; Warin *et al* 2008), the interactions of these understandings with medicine and public health have received little interest. Hierarchies of fatness reveal the inadequacies of contemporary health promotion practices and policies that rely on "simplistic and individualistic" (Warin *et al* 2008, 108) understandings of weight gain and solutions to weight loss. Despite the "smorgasboard" (Banwell *et al* 2005, 568) of ways for understanding weight and obesity, mainstream public health continues to draw on simplistic caloric in/out equations for weight loss advice (Baum & Fisher 2014; Keith *et al* 2006). As such, public health initiatives that aim to promote healthy eating and physical activity characterise the body as a universal entity, failing to acknowledge the ways in which bodies are influenced by particular pharmacological (and socioeconomic) circumstances. Health promotion materials that target all large people as being overweight or obese exclude alternative constructions of fatness and those who do not identify as obese, and who instead articulate their weight in terms of iatrogenic effects.

My research offers credence to those health researchers and practitioners who have begun to expand constructions of weight and challenge weight-centric assumptions within medical imperatives of containment. A “wellbeing oriented paradigm” (Provincial Health Services Authority 2013) advocates for weight-neutral and non-dieting approaches to health, and incorporates both scientific and “experiential knowledge” (Aphramor *et al* 2013, 94) to offer safe and feasible weight-loss alternatives. The wellbeing paradigm incorporates features of Health At Every Size (HAES), a movement that re-frames health away from pathology. Emerging from the second wave of feminism in the 1960s and 1970s, HAES first exposed the way in which women, especially women’s bodies, were targeted, and the trans-disciplinary movement has since grown in popularity (Bacon & Aphramor 2011; Robison *et al* 2007).

Experiences of madness and fatness do not occur in a “in a socio-cultural vacuum” (Greenhalgh *et al* 2015, 1), and any understandings and treatments that are designed without acknowledgment of socio-cultural considerations are deeply flawed. Further research can help to shed light on how meaningful integration of lived and clinical understandings of medicated fatness can achieve a “multilevel” approach to antipsychotic-induced weight gain (Baum & Fisher 2014; Greenhalgh *et al* 2015; Mol 2002). Not only must this approach acknowledge social as well as biological influences, but all health models must seek to address and remedy social disadvantage.

Health promotion policies are effective most when they are meaningful for those whom they target. For those experiencing antipsychotic-induced weight gain, further research is needed into how public health can incorporate conceptualisations of transgressed bodily boundaries, disrupted temporal ordering, and distorted spatialities. The framework of spatiotemporalities offers a useful paradigm for seeking and achieving meaningful engagement with what it means to experience madness and fatness.

## The broad church of the health profession

These conclusions emphasise the importance of carrying out research that investigates all layers of health practices, experiences and knowledges, and their interrelationships, especially how they “hang together” (Mol 2002, 5). In designing a research project that draws on the key people involved in the experience of antipsychotic-induced weight gain – including those taking antipsychotic medications, and the psychiatrists, nurses and pharmacists involved in medication prescription – I have revealed the varied ways for understanding the weight gain. I have argued that the notion of a “spectrum of knowledge(s)” (McClellan & Shaw 2005, 729) challenges the assumption that the understandings of all health professionals can be grouped together in one homogenous category. Not only is there a “spectrum of knowledge(s)” (McClellan & Shaw 2005, 729) between health practitioners and their clients, but there is also a “spectrum of knowledge(s)” within the broad church of the health profession, illustrating the inadequacy of any blanket description of the profession.

Acknowledging the limitations of the evidence-based paradigm, some of the health practitioners in this study recognise the differences in knowledge and experiences between themselves and their clients, and draw on a variety of practices to reconcile these differing perspectives. After relaying some of my initial conclusions about the participants’ articulations of their weight gain as unique, psychiatrist William sighs, raises his eyebrows and exclaims that he is “quite intrigued”. Attempting to understand and bridge differences is, in William’s words, part of the centre’s “philosophy”:

If people have that perception that ‘Oh, it’s medication-related weight gain – it doesn’t matter!’ ... then that would sort of lead us to re-evaluate how to do that education, and it may be worth factoring that back and slightly altering how clear we are about things. So what is it about these people who are not receiving that message and how can we do it differently? Because that certainly is quite a big part of our philosophy.

This highlights how health practitioners – especially those I interviewed – draw on a “wider menu of metaphors and models” (Greenhalgh & Wieringa 2011, 508) within their everyday practice, including approaches as diverse as motivational interviewing, language games, practical wisdom and mindlines. In their ethnographic study of how general practitioners and nurses made healthcare decisions, for example, Gabbay and le May found that clinicians relied on mindlines: “collectively reinforced, internalized, tacit guidelines” (2004, 1014). Instead of using clinical knowledge that encourages “rigid cookbook adherence to codified knowledge” (Gabbay & le May 2004, 1015), the clinicians in this study incorporated a broad suite of sources into their clinical understandings. The role that informal interactions play in decision-making processes is an under-researched but significant factor. In answering a question about pharmaceutical marketing, Gopal shifts the direction of the interview to explain that he is “in touch with various ... researchers”, and that colleagues and friends are “who you actually get more valuable information from”. Being “in touch” is like the “communities of practice” (2004, 44) in Gabbay and le May’s study: mindlines become refined “by acquiring tacit knowledge from trusted sources” (2004, 1014).

Further research may demonstrate how, and with what means, health practitioners engage with and understand their clients’ experiences. Mindlines and other alternative practices offer scope for changing clinical attitudes, and there would be value in learning how these informal interactions and practices influence decision-making. Always transforming and never static, mindlines offers a particularly innovative model for medical practice; mindlines are continually modified and tweaked to incorporate new information and alternative viewpoints. Although the potential for mindlines to challenge the established “lay-expert divide” (McClellan & Shaw 2005, 729) has not yet been fully explored, the breadth of sources incorporated into mindlines may include experiential accounts and lived health experiences like those developed in this study. This is why research is warranted for the ways in which these models work both on an individual and on a broader

scale, as well as how they can be expanded to incorporate lay knowledge and lived experiences.

My work on unique fatness highlights the gap between lay and expert knowledges, and the importance of understanding these differences. Failing to recognise these differences has significant (and, sometimes, unintended) implications for public health messaging. Further research is required into how constructions of unique fatness can be incorporated into mainstream medical understandings and health promotion initiatives around obesity and the individualistic, behavioural imperatives to “exercise harder and eat better”.

This thesis has provided insights into how explorations of the lived experiences of health and illness can unlock theoretical insights into sociological constructions of transgression and containment. The themes of transgression and containment are underpinned by conceptualisations of time and space. Further research is warranted into the lived, everyday understandings of time and space and how these understandings impact on a range of health conditions and experiences. Spatiotemporalities provide a framework for thinking not only *about* a health condition, but also *across* health conditions, and further research could thus explore how bodies are experienced through time and space for two or more interacting health experiences.

The use of space and time as an analytical lens has allowed me to expand my analysis on madness and fatness beyond taken-for-granted foci on the ‘mental’. This has generated insights into antipsychotic-induced weight gain that demonstrate the unique experiences of medicated fatness and failed containment. Using analyses of time and space brings to light the lived, embodied experience of transgression, and highlights the tensions between these lived experiences and medical imperatives of containment. Instead of setting up a dichotomy between the framing of the mind in psychiatry and the framing of the body in public health, medication side effects expose the relationship between the two; this thesis shows

how the embodied experience of madness and fatness collapses the Cartesian dualisms of mind/body, inside/outside, private/public and contained/uncontained. In focusing on experiences of embodiment, this research provides valuable insights into the ways in which medication side effects are indeed not 'side effects', but exacerbate core symptoms of classic diagnostic criteria and further extend bodily transgressions. In turn, this research offers something new and innovative to the literature on medication and weight.

# APPENDICES

## Appendix 1: Interview schedule for those with experiences of antipsychotic-induced weight gain

### INTERVIEW SCHEDULE

#### For those with experiences of schizophrenia and antipsychotics

##### Introduction:

- Thank you so much for agreeing to participate in this research, I really appreciate it.
- As you read in the Information Sheet, I am doing research for the University of Adelaide. I am not a doctor and I am not part of the team that works with you.
- Everything that you say in this room is totally confidential and won't be repeated outside of this room.
- Do you have any questions about the Information Sheet?
- Before we met today, I asked around at the centre who would be a good person to speak with for this research and you were recommended. Your <key worker/doctor> has signed this Consent Form to say that you understand what this research is about.
- To prove that you understand what was said in the Information Sheet, the University of Adelaide Human Research Ethics Committee says that you need to sign a Consent Form.
- I have two copies of the Consent Form – one for you and for me to keep.
- Now that you have consented to participating in this research, do you also consent to recording our conversation? No one else besides me will hear the recording but it will be used for me to listen to our conversation later and make notes.

##### Background

- Okay, so as you know, my research is exploring the experience of gaining weight from taking antipsychotic drugs. For my research, I'm interested in hearing about your story, your experiences and your opinions, and I'm very interested in hearing what you have to say. I'm not the expert here, but you are the expert because it is *your* experiences that I would like to hear about.
- Throughout the interview, I will guide you with some questions but please feel free to raise any issue that's important to you as we go along.
- When I write up the material from these interviews, I will allocate you a pseudonym, or a fake name. Before we begin, I was wondering if there is a particular name that you would like me to use for you?

#### Schizophrenia

- So can you start by telling me your story? Tell me about how you came to be accessing this service.
- *Follow-up: When were you diagnosed with schizophrenia? How?*
- What treatments were available?
- What types of medication have you tried?

#### Now

- And what about now – do you take any medication now?
- If so, what types?
- Do you take the medication voluntarily or is it part of a treatment order?
- Do you have a community support worker?
- How tall are you?
- Are you a smoker?

#### Atypical antipsychotics

- What is your experience of atypical antipsychotics?
- *Follow-up: Medications like olanzapine (Zyprexa), clozapine (Clozaril), risperidone (Risperdal), quetiapine (Seroquel), ziprasidone (Zeldox)...*
- How long did you take them for?
- What did you know about these drugs before taking them?
- What did your doctor or psychiatrist tell you about them?
- *Follow-up: How did your psychiatrist explain how the drugs work?*

#### Schizophrenia

- What do you think schizophrenia is?
- What causes schizophrenia?
- What was schizophrenia for you? How did it affect/impact you?



- DRAW: What schizophrenia does to your body
- Voices? – If so, what do they say? What do they look like? Do they comment when eating? Do they have bodies?

#### How the drugs work

- Do the drugs slow parts of the brain down? relaxes it? numbs it? stops it? blocks it?
- When the doctor prescribed the drugs, did they give you a story of how they work?
- Can you imagine what happens to the tablet when you put it in your mouth? When it dissolves in your body?
- DRAW – Which part of the body do the drugs work on? Which part of the body do the drugs make bigger?

#### Side effects

- Have you experienced effects from any of the treatments or medications?
- *Follow-up: How did you feel about these effects? What were they?*
- Have you experienced any effects from the atypical antipsychotics?
- *Follow-up: How did you feel about these effects? What were they?*
- Who would you usually speak with about these effects?
- *Follow-up: GP, caseworker, psychiatrist?*
- Did you speak with them about any of these effects?

#### Hunger / food / eating

- Describe hunger
- What is 'appetite'?
- What satisfies the hunger?
- Describe being satisfied – What does it feel like?
- Does the hunger come and go? all the time? are certain times worse?
- What sorts of foods are you eating? When?
- Yesterday - what did you eat? when? were you hungry?

#### Tiredness

- What is tiredness like? – can you describe it?
- What is your sleep like?

#### Antipsychotic-induced weight gain

- Atypical antipsychotics can cause weight gain in some people. Have you encountered this?
- If so, how much weight gain?

- Have you been diagnosed with Type II diabetes?
- Do you think there are reasons other than the drugs that have made you gain the weight?
- *Follow-up: Excess food intake, lack of exercise?*
- How did you feel about this weight gain?
- Has the weight gain changed what you do on a day-to-day basis?
- *Follow-up: If so, how? Give examples.*
- Are you worried about what the weight gain will do to your bodies?
- Did you tell your <GP, caseworker, psychiatrist> about this weight gain?
- *Follow-up: Why or why not? Were you worried that they wouldn't think of it as a problem?*
- How do you balance the benefits of the drugs compared to any disagreeable side-effects?
- Have you tried anything to reduce the weight?
- What is the weight? – fat? fluid? muscle?

#### Gender and weight

- Do you think that weight gain is more or less of a concern for women as opposed to men?

#### Stigma

- Have you experienced discrimination because of your diagnosis of schizophrenia?
- If so, what forms of discrimination?
- *Follow-up: How did this make you feel? How did you react?*
- Has anyone ever said anything to you about your diagnosis? or called you a name?
- Have you experienced discrimination because of your weight gain?
- If so, what forms of discrimination?
- *Follow-up: How did this make you feel? How did you react?*
- How do you think about other people who are overweight?
- Do you ever feel like there is somewhere you can't go? Or can't go because you feel uncomfortable?
- Has anyone ever said anything to you about your weight? or called you a name?
- How do you know that you are being stigmatised?

#### Solutions

- What do you think is the solution for this type of weight gain?
- *Follow-up: What should people do about this weight gain?*

- Who or what do you blame for the weight gain?
- *Follow-up: Do you think the weight gain is totally due to the antipsychotics?*

#### Conclusion

- That's been really useful – thank you! I'm just going to look over the topics that I wanted to cover today. Whilst I'm doing that, can you think about whether there is anything else you wanted to talk about?
- *Thank you!* Thanks so much for being interviewed. It really is that you're prepared to do this and will mean a lot for people down the track.

#### Debrief

- How was that for you? How do you feel?
- How has it been talking to me? Is there anything I can do differently/improve?
- Do you have any questions?

# Appendix 2: Interview schedule for health professionals

## INTERVIEW SCHEDULE

### For health professionals

#### Antipsychotics

- Can you tell me how you understand schizophrenia?
- *Follow-up: What are the symptoms? How does it affect people? Why does it happen to some people and not others?*
  
- Do you believe that there is a schizophrenia 'gene'?
  
- Is there a relationship between schizophrenia and emotions?
  
- How do you think antipsychotics work for schizophrenia?
- *Follow-up: Does it work by relieving symptoms or actually treating the 'cause' of schizophrenia?*
  
- What is your understanding of the newer, atypical antipsychotics?
- *Follow-up: How do they differ from the typical antipsychotics?*

#### Side effects or adverse effects

- What is meant by this term, 'side effect'?
  
- How are side effects or adverse effects determined?
- *Follow-up: Does it have to occur so many times, etc.?*

#### Antipsychotic-induced weight gain

- Weight gain is a common side effect of the atypical antipsychotics. Why does this weight gain happen?
  
- What role does the medication play in the weight gain?
  
- One person thought that sedation as a side effect caused the weight gain, and that the weight gain is not a direct consequence of the medication – what do you think?
  
- Why does weight gain happen to some patients and not others?
  
- Is there a protocol for dealing with weight gain?
- What do you do? i.e. refer on?

- What is the weight? – fat? muscle? liquid/fluid?
- How do most people respond to the weight gain?
- Do some people complain more about the weight gain than others?
- Does gender play a role in these responses?
- Some people I've spoken to differentiate between antipsychotic-induced weight gain and 'obesity'. What are your thoughts about that?
- The clients here seem to receive lots of information and explanations for the weight (such as genetics, lifestyle, medication), how do they take on board all this information?

#### *Weight gain and concern*

- Have you seen differences between men and women and their concerns about weight?
- Are women more interested?
- Who tends to have the more motivation?
- How do people react when their BMI keeps going up?
- How do they react when it goes down?
- Does age play a factor in people's concerns?

#### *Weight loss*

- How do you promote weight loss?
- What is successful?
- Do you promote or see value in medical forms of weight loss? (surgery, medication)

#### *Mental health versus health weight*

- Do you think that psychiatry places more importance on mental health, whereas other doctors might be more concerned with healthy weight?
- *Follow-up: For example, obesity specialists might think that weight gain is important enough to discontinue atypical antipsychotic medication...*
- Different priorities between different medical specialties?

#### *Compliance*

- What do you think is the relationship between compliance and side effects?
- Does weight gain develop slowly?

- Does weight gain (and side effects generally) affect compliance?

Solutions

- Do you think there is a solution for this type of weight gain?
- *Follow-up: What should people do about this weight gain?*
  
- Who or what do you blame for the weight gain?
- *Follow-up: Do you think the weight gain is totally due to the antipsychotics?*

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