

**Making Health Agency:**  
**Clozapine, Schizophrenia, and Personal Power**

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I also declare that the intellectual content of this thesis is the product of my own work, except to the extent that assistance from others in the project's design and conception or in style, presentation and linguistic expression is acknowledged.

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## Abstract

This thesis demonstrates how experiences of agency and health persist in spite of confining social and biological circumstances. I take the case of clozapine-treated schizophrenia, where patients are presented with both renewed hope for an independent life at the same time as undertaking an intensive physiological monitoring regimen that prioritises their life in the most immediate sense only. Clozapine patients face a high risk of chronic multi-morbidities that significantly lower their life expectancy, and they are not quite ‘cured’ of their mental disturbances pertaining to chronic schizophrenia. I demonstrate, though, how patients are able to experience a sense of what I term *health agency*, where we might otherwise imagine their well-being to be significantly compromised. Health agency is a feeling of control over one’s well-being, where well-being is defined in one’s own terms. It was remarkable to find it in the clinical contexts in which I was working, where very narrowly constituted definitions of health were ostensibly endorsed and imposed. But in the thick of life in the clozapine clinic, patients and institution did not occupy strict polar positions. My fine grained ethnographic work revealed how patients worked creatively with the clinical circuitries, biomedical imaginaries and temporal underpinnings of clozapine treatment to personalise their experiences and to exert subtle, personal power over their health and future prospects.

My fieldwork was based in the UK and Australia over an 18-month period (2015-2016) between two clozapine clinics. Research participants included 43 people diagnosed with schizophrenia (termed patients, hereafter) and 16 clinical staff at the clozapine clinics (termed clinical caregivers, hereafter). I conducted participant observation and 130 interviews. Drawing on my ethnographic data, this thesis explicates how health agency was available to patients in four central ways. First, health agency was part of a hopeful, personal persistence for holistic health in spite of the ‘physical,’ ‘mental,’ and ‘social’ aspects of health appearing irreconcilable in terms of clinical definitions. Second, patients were able to creatively manipulate and complement the goals of clozapine clinic blood monitoring to actively participate in the aspect of their treatment that is otherwise the furthest from patient control. Third, patients drew on the ambiguities of clozapine and other ‘health’ consumptions or behaviours to negotiate how clozapine impacted their minds and bodies. Fourth, patients utilised the temporalities of clozapine and clinical suspending of non-biological concerns to abundantly “live in the present” and harness focused energies that kept their futures open, while ephemerally suspending clinical symptoms and clozapine side effects. I suggest that

patients' self and social labour, and their quiet everyday efficacies in making their own health, problematise some previous anthropological and clinical conceptions about living with chronic schizophrenia under biomedical treatment models. I make the case for further ethnographic consideration for quiet expressions of agency within highly structured conditions.

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## Introduction

In this thesis I ask: How do experiences of agency and health emerge from within the clinic for clozapine-treated schizophrenia patients? I argue that *health agency* can emerge from the very clinical conditions that might otherwise be seen to define it. People undertaking clozapine treatment for schizophrenia have, for the most part, been given a second chance at life while at the same time facing significantly higher morbidities and intensive biomedical monitoring. I show, though, that patients themselves can make clinical processes and imaginaries their own, in ways that speak to their own power over, and hope for, their health.

In non-medical contexts, Nigel Rapport (2003) has illustrated that if we want to uncover how agency works, we ought to look for it within the most powerful structures. Agency is found not so much in forms of opposition to, nor mere compliance with, the powerful socio-biological structure that is clozapine treatment. Rather, agency issues from within it as clozapine patients rework that which is ostensibly governing their bodies and minds in medical and institutional ways. This is a quiet process that I suggest has been passed over in favour of attendance to the spectacular, elusive or falsifiable-driven aspects of investigating schizophrenia, which I detail in what follows.

Schizophrenia is characterized by a profound disruption in cognition and emotion; ‘a fundamental disorder of thought and feeling’ (Insel 2010:187). In its diagnostic conception, schizophrenia represented a degenerative biological ‘disease,’ implicating experiences of ‘self’ and social functioning. The first clinical observations of the condition, initially labelled ‘dementia praecox’ by German psychiatrist Emile Kraepelin at the turn of the twentieth century, posited that patients experienced: ‘a disease process that isolates and opposes them to Western selfhood’; ‘[t]he resistance to labour, present in every stage in the course of dementia praecox and even in its wake, is not simply a perceived neglect of or disinterest in a particular type of environment; it incorporates a resistance to the labour of self-improvement’ (Woods 2011:42).

Schizophrenia has challenged both clinical and cultural theorists as a ‘subliminal’ category of disorder, with no clear biological determinants nor cures, and may soon cease to be clinically categorisable at all (Woods 2011; Murray 2016). The term itself has come into question because the symptoms and outcomes are not specific to any one disorder (Insel 2010).

Research agendas attempting to better define schizophrenia have not been corroborated, which has produced a ‘discontinuity history’ that further plagues theoretical efforts (Berrios, Loque & Villagran 2003:134). While academic debate about the term being dissolved into something broader, such as ‘psychotic spectrum disorder,’ has been brewing for nearly forty years, the term continues to dominate because ‘there is no other reality without its borders’ (Guloksuv & van Os 2018:238). ‘It is a term with invisible scare quotes, but no other word does its job,’ Luhmann (2016:2) has summarised. I elaborate shortly on what is meant by the label schizophrenia, however I note in the first instance that it is highly elusive.

Anthropologists have looked to humanise the conditions that comprise the term schizophrenia. In 1997, anthropologist Janis Jenkins described schizophrenia as a ‘moral struggle either to maintain or find anew one’s sense of rhythm or involvement in the flow of everyday activities.’ Experiences of living with schizophrenia can indeed be cast as ‘extraordinary’ (Lucas 1999; Jenkins 2015). Jenkins (2004:30) posited that ‘people with schizophrenia are just like everyone else, only more so.’ Drawing on extensive ethnographic evidence of the role of culture and inter-subjective ‘struggles,’ Jenkins (2015:I;12) established an anthropological framework to consider schizophrenia as an ‘extraordinary condition’ that ‘emphasises the nonordinary and spectacular qualities of mental illness in experience and representation’; wherein ‘rather than being dismissed as marginal or abnormal, the extraordinary can be recognized as vital and integral.’ The extraordinary aspects of schizophrenia can be appreciated under conditions where everyday subjectivity suggests an incredible endurance in the face of fundamentally irreconcilable social participations – such as those of strained community connections, acute ‘suffering’ in neoliberal culture, homelessness or peer-led recovery centres (Lucas 1999; Estroff 1981; Jenkins 2015; Luhmann & Marrow 2016; Myers 2015). From a treatment perspective, the question still burgeoning from Kraepelin’s first observations is how to assist patients in living a ‘contributing life’ (Woods 2011; Lourey, Holland & Green 2012), which is now likely to be significantly compromised by pharmaceutical regimens that prompt the onset of lifestyle barriers.

Today, schizophrenia and its treatment are characterised by paradoxes and polarities in terms of how the disorder can be ‘controlled’ – by clinical and social treatments, or by individuals with the diagnosis. The search for biomarkers and improved drug treatments continues apace in biomedical research contexts, while social scientists endeavor to locate cultural

underpinnings.<sup>1</sup> Rod Lucas (2001:97) illuminated how the expectations of reciprocal participation in public life alongside private ‘self management’ can be contradictory for people being pharmacologically treated for schizophrenia. The Recovery Movement in the United States of America overlooks incongruence with wider cultural expectations of what it means to be independent in American society (Hopper 2007; Myers 2015). Even if ‘stable’ on medication, patients face what Jenkins (2010:9) has identified as ‘pharmaceutical paradoxes of lived experience’ that can, ‘ironically create madness and suffering.’ Namely: ‘recovery *without* cure’; ‘stigma *despite* recovery’; ‘the pervasive cultural-clinical trope that a wide array of problems can reductively be defined as “a biochemical imbalance,” which, while no one’s “fault,” enjoins the neoliberal dictum of individual responsibility for one’s own condition even so’; and the “side effects” of antipsychotic drugs ‘that are met with varying degrees of awareness or tolerance of insalubrious effects’ (Jenkins 2010:9). Further, there are the juxtaposed assumptions and experiences in regard to patients’ gender statuses, desires, social needs, along with a ‘felt need for medication *in face of* fears of addiction, toxicity, and chronicity’ (Jenkins 2015:65, original emphasis). The breadth of expectations and experiences of psycho-pharmaceuticals indubitably implicate patients’ subjectivity.

While the intention has been to situate the subjectivity of schizophrenia patients along a human continuum, there has been much emphasis on how psycho-pharmaceutically medicated patients’ agency manifests – like schizophrenia – in quite remarkable ways. Institutional and biochemical powers are often critiqued for what they do to the agent, producing ‘pharmaceutical reason’ (Lakoff 2005), ‘neurochemical selves’ (Rose 2003), a ‘pharmaceutical self’ (Jenkins 2010) or a ‘pharmaceutical personality’ (Martin 2009). Meanwhile, when looking at non-psychiatric health conditions, people have been found to subtly and effectively take part in their clinical management (Mol 2008), in ways that may sit unnoticed in light of larger regimes of ‘biological citizenship’ (Petryna 2004). It is thus critical to think about how experiences of anti-psychotic drug regimens that downplay the ‘extraordinary’ conditions of schizophrenia, by introducing routine *non-psychiatric* monitoring, may shape agency and health.

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<sup>1</sup> The most recent biological hypothesis at the time of writing this thesis is that schizophrenia may be a ‘multi-system disorder’ involving inflammation of the whole body, such that psycho-pharmaceutical ‘brain’ treatments with ‘physical’ side effects may not be the central contributor to co-morbidities (Pillinger et al. 2018).

In the biomedical treatments contexts of Australia and the UK where I conducted fieldwork, the antipsychotic drug clozapine offers chronic schizophrenia patients the most stability and hope, while at the same time requiring rigorous physiological monitoring. Clozapine is associated with a plethora of imminently life-threatening side effects and chronic ‘physical’ health conditions that shorten life expectancy. The reason for taking clozapine in the first place, however, is often a matter of life or death (suicidal, and sometimes homicidal, behaviours tend to land people in the situation of being given this ‘last resort’ but ‘wonder’ drug). People taking clozapine as part of their management regimen become ‘clozapine patients’ beyond their status of having schizophrenia.

Ethnographic research has not previously attended specifically to the clinical monitoring experiences of those undertaking and overseeing clozapine treatment for schizophrenia, nor has health or subjective well-being in the clozapine context been explored beyond clinical measurements. Thus, the purpose of my ethnographic research was to investigate what clozapine-treated schizophrenia patients and their clinical caregivers make of ‘health’ during clozapine treatment, and to what degree a more commonplace agency can be experienced. Before returning to the greater context of schizophrenia and its biomedical treatment and what clozapine introduces to people’s lives, I elaborate on the central themes of ‘agency’ and ‘hope’ embedded in clozapine treatment experiences. I then outline four manifestations of health agency that I observed, comprising the four thesis chapters that follow.

### Agency

I draw on notions of agency as an active and relational practice; an embodying experience that grounds people in present activity and gives subjective meaning to the world, to the self and others. Subjectivity refers to how ‘actors ‘enact,’ ‘resist’ or ‘negotiate’ the world as given, and in doing so, ‘make’ the world’ (Ortner in Jenkins & Barrett 2004:9). Drawing on Gregory Bateson’s ideas about how people manage their lives around ‘negative entropy’ and Amos Rapoport’s observation that ‘all living things organize space’ *in* their own ‘personal space,’ Nigel Rapport (2003:224-225) suggested that individuals feel an influence over their environments and selectively draw from those environments, depending on their personal goals. I take the clozapine clinic as the central social space in which agents were operating and selectively making their worlds and executing personal goals, toward health, where it might be otherwise assumed that they have no such agency. Moreover, I take the theoretical

frictions between ‘structure’ and ‘agency’ to be about how both concepts are ‘affectively interconnected, rather than diametrically opposed’ (Biehl & Moran-Thomas 2009:276). There are numerous theoretical frameworks about the interplay between agency and social structures to which my ethnographic findings speak.

First, agents continually operate within permeable and changing structures that have been otherwise nominalised. ‘Agency refers to doing,’ wrote Giddens (1984:10). Giddens posited that ‘ordinary human agents’ possess ‘controlled alertness’ that gives rise ‘[t]o reflexive monitoring of action, in contexts of co-presence’ (1984:79).<sup>2</sup> As Archer (2004:308) asserted in her social realism approach to understanding agency in context, there are ‘causal powers proper to agency itself.’ These powers ‘enable people to reflect upon their social context, and to act reflexively towards it, either individually or collectively’ (Archer 2004:308). This does not preclude experiences of struggle. In the context of schizophrenia, Jenkins (2015:92) posited ‘struggle as central to the daily and long-term experience of mental illness is intended as a frame to identify the quality of experience as an active process.’ Experiences of agency that are both threatened and endorsed by the presence of structures/others also involve the more elusive *power* of agents to imagine more for themselves.

Agency may be seen as a creative process of ‘becoming’ something yet to be known. Biehl and Locke (2010:322) have argued for individual power over institutional power of agents, picking up on Deleuze’s notions of ‘becoming’ – where ‘society is something that is constantly escaping in every direction.’ The ‘anthropology of becoming’ explores ‘the motions of becoming different and moments of impasse or plateaus of stabilization,’ wherein ‘the work of becoming is inherently a work of creation’ (Biehl & Locke 2017:6;9). Similarly, Ingold situates humankind as ‘a singular locus of creative growth within a continually unfolding field of relationships’ (2011:4-5). In terms of the ‘skills’ that humans develop and express in their environments, he notes that ‘a mixture of improvisation and imitation’ are critical (Ingold 2011:401). My ethnographic data attests to both the ‘becoming’ and creative competence of agents. The imaginative dimensions of agency and power need to be carefully considered, particularly in circumstances that invite existential struggles and imaginaries.

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<sup>2</sup> Giddens (1984:16) theory of ‘structuration’ – wherein ‘structure is not “external” to individuals’ and agency is comprised of a ‘duality’ that ‘is always both constraining and enabling’ – was at first appealing for my analysis, until I realised the limitations of this theory when it came to explaining the individual and ‘existential power’ (Rapport 2003) embodied by clozapine patients in my research.

The active imagination of all human beings is part of our agency and we project ‘the capability, the power, to be the source and originator of acts’ (Rapport & Overing 2001:1). The degree of attention granted to us as individual selves and bodies within an inter-personal context invites different degrees of *projectable* agency. The deployment of what Rapport (2003:16) described as ‘existential power’ and a ‘self-intensity’ (*Machtegefühl*) is accessible to ‘Everyperson.’ The creativity exemplified in ‘an imaginative self is not a luxury but an ontology, an inevitable aspect of our embodiment’ (Rapport 2003:54), and agency need not be a matter of *resistance* to sociocultural constraints (Mahmood 2005; Jackson 2005; Biehl 2010). Biehl, Good and Kleinman (2013:348) conceived of subjectivity in the context of psychiatric treatment as, ‘a continuous process of experimentation – inner, familial, medico-scientific, and political.’ While the ideas put forward in this thesis speak to individual creativities, agentic creativities also work with institutional and biochemical goals. To take one example, UK patient Luke, 45, told me when I asked if there was anything he would change about his health, that he would “improve it, make it better – that’s what I’m here for isn’t it ... *survive* the schizophrenia not just, ah, you know, *succumb* to schizophrenia” (original emphasis).<sup>3</sup> Luke imagined that it would take him another “twenty years” to “recover” completely, by him simply “carry[ing] on doing what I’m doing.”

There is an intentionality in how both patients and clinical caregivers maximise the desirable effects of clozapine and minimise the undesirable side effects, such that patients can pursue life without suffering. The term ‘intentionality’ builds on both Foucault’s attention to ‘governmentality’ – ‘a mode of action upon the actions of others’ through ‘the social and ethical contexts in which one’s will is realised’ (Jackson 2005:90), but also a more immediate and reflexive ‘operative intentionality’ whereby agents make meaning out of given situations in their immediacy (Merleau-Ponty (2005[1962]:498). Rapport (2003:225) argued that an individual’s ‘life project’ – afforded by embodied personalisation of circumstances – is ‘a practice which procures an extended environmental homeostasis: the maintenance of a set of life-conditions within which the self continues to flourish and has its objectives met.’ Although schizophrenia is largely associated with ‘social *defeat*’ in Western societies (Luhmann 2007; Luhrmann & Marrow 2016, my emphasis), I observed that the structures of clozapine treated schizophrenia can, to some extent, redress experiences of social defeat

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<sup>3</sup> Pseudonyms have been assigned to all participants: clinical caregivers and patients, and also patients’ hallucinatory presences when they pertain to a particular person. All emphasis used in quotes from participants in this thesis henceforth pertain to original emphasis.

because the clozapine clinic does not, in the lived experiences of patients, subject people to a predominantly subordinate social role. Patients can subtly exert their social agency, too.

Clozapine treatment offers up social participations and may become part of a ‘life project’ of sorts (Rapport 2003). GH Mead (1932:194) suggested that, ‘any self is a social self, but it is restricted to the group whose roles it assumes, and it will never abandon this self until it finds itself entering in the larger society and maintaining itself there.’ On the one hand, clozapine patients may participate minimally in the social system of the clozapine clinic whereby their ‘role’ is simply continuing the regimen, with varying degrees of observable engagement. For some, the social worlds pertaining to residual delusions may yield more prominent roles for them to negotiate. Other patients may more explicitly incorporate both their active roles in clozapine treatment and also ‘larger society’ – the social worlds beyond clozapine clinic visits and non-shared (hallucinatory) social experiences. In both cases, patients express their agency without the assumed necessity of person-centred psychotherapy.

Because clozapine patients receive attention from others that is not premised primarily on their mental illness status, practices of agency were not confined to the disempowerment that may have been previously felt when talking with a clinician about their diagnosis. Critically, the two clozapine clinics included in my research did not involve any formal psychotherapy treatments; the focus was rather on the patient as one of many clozapine patients undergoing primarily physiological monitoring. Biomedical treatments without some provisioned psychodynamic therapies have been critiqued by ethnographers for their dearth of opportunities for personal engagement between patient and clinical caregiver (Luhmann 2000; Jenkins 2015). Further, Kirmayer (2007:238) has noted that the purpose of psychotherapies in Western culture is that ‘patient and therapist are engaged in an active process of moral choice’ and ‘the invocation of the ‘true self’ that is thus socially contingent.’<sup>4</sup> Of course, ‘[w]ithout the attention of others we are nobody and nothing’; ‘[w]e have no social self’ (Aylwin 1985:115). As I demonstrate throughout this thesis, clozapine patients were nonetheless able to interact with clinical caregivers and aspects of their treatment monitoring to achieve socially meaningful and personally virtuous goals.

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<sup>4</sup> Kirmayer cautioned that for psychotherapy to work, the therapist must consider 1) whether the patient can ‘continue either the coherent construction of the private experience of self or the social interaction that sustains their self in community, and 2) that ‘individual psychotherapy may then be in fundamental opposition to traditional socially integrated personhood’ (2007:243).

The final aspect of agency that this thesis builds upon, then, is that of socio-moral participations. Schizophrenia ‘patients are not just passive targets’ (Myers, Lester and Hopper 2016:422). Neely Myers (2016:428) drew on Blacksher’s attention to accountability to others and Mattingly’s observation about all social settings being ‘moral laboratories’, whereby ‘with action, humans are able to create something new’ and ‘[t]o make possible intimacy with others in such social spaces, a person’s actions must be recognised by others as “moral”.’ In the context of ‘recovery’ from schizophrenia, Myers (2016:435), continued, ‘[m]oral agency means having the wherewithal to aspire, and the intentions and necessary resources to achieve what one understands to be a ‘good life’.’ Being able ‘to be held accountable ... makes for possible stronger connections to others’ (Myers 2016:435). Myers (2015;2016) suggested this moral agency to be largely dependent on participation in wider social worlds beyond those tied to psychiatric patient-hood. I suggest that both ‘moral struggle’ (Jenkins 1997) as well as moral agency productively merge with much potentiality for clozapine patients *despite* patients having not, for the most part, reintegrated into a wider social world.

The above aspects of agency are brought to bear on what I term *health agency*, which I sketch out in greater detail in Chapter One. In short, health agency concerns feelings of personal control over one’s own well-being and how one’s well-being is creatively defined in relation to structural forces. Another central under-pinning of it, in the context of clozapine treatment, is a particular but fundamentally human expedition of *hope*.

## Hope

The arguments in this thesis are in many ways premised on manifestations of hope, and the value of exploring the fluctuations of ‘hope’ as it manifests for chronic schizophrenia patients and their clinical caregivers in clozapine clinics. The imagination for a fruitful life to come becomes more available than it has perhaps ever been for patients. As Australian nurse Zoya, explained to me, the clozapine regimen has “given hope to some people that don’t have hope.” Even when ‘improvements’ were less clear – evoking questions along the lines of what Australian psychiatrist Adam posited to me: “if people don’t respond to clozapine, why do we keep people on it?” – clozapine patients lived through the hopeful reality of not returning to acute psychosis and feeling an overwhelming dependence on others.

Patients' imaginaries of clozapine as a drug of 'hope' were personal; clozapine became a critical part of an individual's world beyond structural and clinical expectations. This is not, therefore, just a matter of enacting Foucauldian 'techniques of the molecular self,' where 'the capacity to modify one's self through conscious intervention is exercised at the price of identifying with the gaze of the scientist' (Rose 1999:37) (although this 'gaze' was a little less fixed in clozapine treatment). Clozapine patients worked with the structures of their treatment to exert more mundane forms of power. While I do loosely attend to 'hope and its paradoxes' that constitute 'a force for personal and social change emergent in interpersonal events, in personal and family lives, in communities' (Mattingly 2010:219), in the clinics where I was based, clinical caregivers were, no matter how dis-intimately, involved in the projects to stem disintegrations of hope for patients more than family members were.

UK neuropsychiatrist George told me that he was drawn to clozapine-treated schizophrenia because, "I liked those cases, since I was a trainee, that no one was interested in anymore, and that they had no *hope* – because I'm always getting the impression that there's something else that can be done". He wanted "to look after these people that, historically, nobody ... has been looking after them in a continuous way." George continued, "I have plenty of cases who are full time working and have quite a successful life – fulfilling that, I cannot see why it should not be the initial goal with *all* the clients ... in general, I have seen a lot of miracles with this illness." Since taking on a combined research and clinical role in the clozapine clinic three years earlier, "expanding the *activity*" of the clozapine clinic had been George's ambition. This was specially in regard to addressing clozapine's side effects: "I think it's a wonderful medication with an *awful* amount of side effects that we should be better at tackling."

"If I was psychotic," George considered, "with all my knowledge, I would be taking clozapine *immediately*, and I would probably try to *stop* clozapine immediately, or to *reduce* to a... to a... nothing – 25 milligrams per day ... to have that feeling of control, back to controlling your own life – I completely understand this." He would not stop taking clozapine entirely because, "the evidence also suggests the risk of a relapse is *high*." I queried, "and how much of that do you think is to do with the symptomatic nature of these drugs, such that if you take something your chemical balance changes, so when you *stop* taking it you're going to have withdrawals of some kind and exhibit symptoms anyway?" George responded, "I have no clue... basically, because we don't even know how clozapine

works, I don't know.” As Del Vecchio Good (2007:364) pointed out, ‘[e]nthusiasm for medicine’s possibilities arises not necessarily from products with therapeutic efficacy, but through the production of ideas with potential but as-yet known unproven therapeutic efficacy.’

While the therapeutic efficacy of clozapine was evident, the ‘as-yet known unproven’ precise workings and quest for ideas to explore this add to what Rose and Abi-Rached (2013) outline as hope for a potential specific, and neuroscientific, evidence base. George elaborated, “I think that we will have *surprises* in the future as to how clozapine works, I think that there are *many* other mechanisms, that they are *useful* mechanisms; I think it’s much more complex.” He conceded that:

There’re a lot of symptoms that cannot be controlled by pharmacology, so, we don’t know how to control cognitive symptoms ... It’s the same for negative symptoms – the ability to communicate emotionally with others, or the ability to have motivation for doing activities – there is no medication for this. There’s the social – all the social problems associated with this, and the increasingly, *brutally* competitive society as we have, now you need to perform *full* time, a hundred per cent of the time, doing well, you know. These people ... *most* of them, might need more support, more help, and there is this a lack of where to place these people, where they can be in less... *demanding* jobs ... I always find that the best outcomes are the people whose family have a job, or a workshop, or a shop that people can just link in ... it’s easier for them to be integrated in that more, *slightly* protected environment ... they can engage in a slower pace, at least *initially* ... that’s my old-fashioned view.

George’s “old-fashioned view,” resonated with what modern anthropologists have observed (see Jenkins & Barret 2004; Luhrmann & Marrow 2016). Alas, George admitted, “50 percent of them, we know, will not respond” (to clozapine). I asked what proportion of patients were in the “optimal situation” he had described. He replied, “no more than ten per cent, for sure, which is very low.” Throughout my fieldwork, I met only a handful of people who had fulfilled this particular story of hope for socio-economic independence and contributions, whom George categorised as ‘good outcomes on clozapine patients.’ One example, included in this thesis, was Martin.

UK patient Martin, 51, reminded me of many English males of his age. Always attending the clozapine clinic before his afternoon work shift, he wore neatly tucked in business shirts, had neatly combed grey hair, and a clean-shaven face. He was ebullient, well-spoken, with great

knowledge of English literature and computer programming. Martin worked nine afternoons a fortnight (“pretty much half part-time and half full-time”) in an administrative job that he had had for fourteen years. He travelled around the countryside most weekends for bridge and croquet tournaments, and went on occasional international holidays. Martin lived alone, had “not really” ever had a romantic partner, but socialised at the pub most evenings playing snooker and backgammon with his croquet friends. Martin was on 250 milligrams of clozapine, and slept for ten hours each night, about which he had no qualms. From a clinical point of view, the only concern was his weight gain. But Martin was not so fussed about this. The experience of occasionally wetting the bed troubled him more. Although he did not mind me observing his clinical consultations concerning such matters, his face blushed with embarrassment when the issue came up during one of our interview times. Martin seemed similarly uncomfortable when we saw each other at his (very public) workplace one day. The clinic was the most productive space for us to interact, so long as we talked about matters beyond clozapine side effects during interviews.

Martin said that his job “keeps me sane,” along with the simultaneous enjoyment and challenge he got from his croquet and social commitments. He relished the days when it was “warm and sunny.” Clozapine and these activities, he said, help him to “whittle through.” Having financed his own flat by working and then paying off the mortgage with an inheritance from his father, Martin, unlike most patients, was financially secure. Martin enjoyed drinking beer most evenings, and ate mostly takeaway foods. Takeaway containers and dirty dishes were often stacked up, he explained, overwhelming him at times, along with many piles of unopened mail. When I asked what had changed for him since he had been diagnosed with schizophrenia twenty years earlier and being put on clozapine a few years later, he replied, “What’s *changed*... that’s a difficult question... I guess it must have *slightly* changed, you know, my, my perception of myself... I suppose, I mean, I’ve sort of got this *label* now... which I didn’t have before. I don’t know whether it’s a good thing or a bad thing; I’m not complaining!” He laughed, “I can blame the untidiness on my illness – though, as I said, it’s probably nothing to do with it, it’s just the way I am ... I’m the same person! ... I’m not sure there’s necessarily a before and after.”

Martin had his first ‘psychotic episode’ at the age of 31, in the middle of a croquet tournament. Martin had been working for his step-brother, who he spoke highly of, at a lucrative computer company, after a period of “failing to become an accountant” and facing

unemployment in his late twenties. During this time, his mother had died from Alzheimer's Disease. While Martin confided he "was struggling" because his mother did not recognise him by the time she passed away, when I suggested, "that must have been really hard," he replied, timidly and hesitantly, "yes, well, it was hard on my *Dad* really." Like most patients I spoke with, Martin did not feel sorry for himself. Rather, he had simply "chucked in" his job with his step-brother because this had "coincided with my diagnosis." Martin also once had a biological brother. "I think he had what I have, schizophrenia, and clozapine wasn't around then, so... he died.... He was 24, probably – I was 8 or 9." "It's never really been *discussed* but, he... he killed himself." When I offered my condolences, Martin said, again dismissively, "it didn't really affect *me*, you know, in terms of *my* life, it didn't really affect me at all, I just wondered why my mum was crying when she told me, and I didn't really understand that, to be honest." Martin understood schizophrenia to be "genetic or hereditary, or whatever the term is," and "one of those things that you probably always have." I asked if he "felt" different as a kid, and he replied, "I don't *think* so ... maybe, I mean... I was quite, um, I went to quite an academic school and I was quite *good* academically, in maths, but other subjects too, but maybe... *emotionally*, or whatever you like to call it, not so... not so smart." He chuckled nervously. His cheerful manner and current social life suggested, conversely, that Martin had plenty of ability to connect with others. Returning to the possibility of finding a romantic partner, he shrugged with a both solemn and resolute smile, "I am where I am now, so." Over the year or so I knew him for, his main goal for the future was to simply get his flat "in order" so that he could at least have his croquet friends come to stay with him.

For the "no more than ten percent" pertaining to situations like those of Martin, clozapine had less ambiguously assisted in the ability to lead a socially and economically independent life. The large majority of clozapine-treated schizophrenia patients, however, were not in situations like Martin. In the Australian clinic, hopes for the 'optimal situation' did not constitute the same scenario as it did in the UK, but it nonetheless offered up a quality of life relative to pre-clozapine circumstances. For instance, Australian nurse Zoya reflected,

I know clozapine makes them sleep for long hours, but yet, they seem to do a few things – function at their best line – they remember they need to go for their blood tests, they know they need to function within the community. Some of them have jobs which they have not been able to do in the past. Like, one of my clients is now working in an op-shop as a volunteer. He said he has not been able to gain any

meaningful employment or relate properly with people until he started clozapine, which is fantastic.

As I explain throughout this thesis, different degrees of social participation did not preclude patients from everyday experiences of relatively ‘good outcomes’ and hope. As Georges Canguilhem posited, ‘to learn to heal is to learn the contradiction between today’s hope and the defeat that comes at the end – without saying no to today’s hope’ (cited in Meyers 2013:113). Past social and current clinical relations tended to play into one another for patients still experiencing chronic psychotic symptoms.

If we are to begin to understand the diverse range of treatment outcomes for people being treated for psychotic illnesses, we must acknowledge that ‘coping’ with symptoms involves ‘the experience of self as an active agent’ via a deployment of subjectively fashioned ‘strategies’ (Roe, Chopra & Rudnick 2004:127). These strategies, for both patients and clinical caregivers, cantered on hopefulness. Drawing on Lear’s (2006) concept of ‘radical hope,’ comprising of ‘an ability to imagine a future way of leading a good life even when a person or a society lacks the concepts with which to anticipate what this future will be’ Myers (2016:359) suggested that in the context of a peer group ‘recovery’ centre, ‘this radical hope ... can only continue to take root and blossom if people are willing to look beyond a person’s economic value and recognize another human life’ as ‘an ethical imperative’ (361). While it was not explored in detail, Myers (2016:372) noted that the ‘logic of care’ observed by AnneMarie Mol (2008) – concerning reciprocal relations between chronic illness patients and their clinical caregivers – may inspire the ‘radical hope that recovery [from schizophrenia] is possible for all.’

This thesis posits how, just as the condition of schizophrenia is both ‘ordinary’ and ‘extraordinary’ (Jenkins 2015), hope is and is not ‘radical’ in the clozapine clinic context, with no explicit peer group work and only biological monitoring. I suggest that Mol’s (2008) ‘logic of care’ can indeed be effectively applied to understanding how a more everyday hope for clozapine patients is made manifest. As Jenkins (2004:45), reflected, ‘[t]he occurrence and form in schizophrenia of positive emotions such as hope, contentment, joy, and humor, has received little attention.’ Clozapine treatment, as I came to understand it, was about choosing and hoping for life over death from moment-to-moment, but not in extreme ways

that denote overriding suffering. Experiences were, however, relative to what had come before clozapine: life with more ‘acute’ schizophrenia.

### On the axis of control between social and biological life

Conditions of schizophrenia speak to a threshold of control between social and biological life. While schizophrenia is now considered to be an ‘illness’ rather than a ‘disease,’<sup>5</sup> the legacy of Kraepelin’s model in psychiatry has been ‘a deeply biological vision of the subject and subjective experience – casting the mentally ill as a medicalized subject’ *with* ‘disorders of the will’ (Biehl, Good & Kleinman 2007:238). According to Foucault, nineteenth century asylums were premised on the ‘the imperative of labour’ and ‘a condemnation of idleness’ (1993:46). The notion of ‘madness,’ so long as it is institutionalised, ‘is imprisoned in a moral world’ (Foucault 1993:269). In the context of mental illness, the high moral value attached to self-sufficiency in Western culture now works in conjunction with an increasingly biological research agenda around the ‘somatic individual’ that can be improved upon (Novas & Rose 2000). Behaviours that do not affirm quests for self-progress may be enveloped under ideas of ‘uncontrollable’ biological symptoms, and/or social symptoms.

Biological and social potentials for control on the part of the schizophrenia patient have created an impasse for clinicians and policy makers. The de-institutionalisation of the last thirty years, intending to expose patients to greater opportunities for social independence, is met with incongruity insofar as Western ‘[i]ndividualism requires independence and competition, which are not conducive to recovery from schizophrenia’ (Lucas & Barrett 1995:307). In the United States, clinicians tend to be loyal to either only a biological or a psychoanalytic paradigm because bio-psycho-social models are harder to conceptually accommodate (Luhmann 2000). Reckoning with the term schizophrenia also threatens to undermine the discipline of psychiatry, wherein biology-orientated psychiatrists are the ‘custodians’ (Bentell, Jackson & Pilgrim 1988:331). As Corin (2007:275) noted, ‘one can easily get the impression that the gulf is widening between the uncertain, elusive psychotic experience and scientific knowledge, which is increasingly objective and objectifying and is

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<sup>5</sup> The term ‘illness’ is both socially contingent and ‘deeply individual, expressive, and intimate’ (Meyers 2013: 13), while the term ‘disease’ pertains to a locatable pathology in the organism. As Kleinman (in Myers 2013: 12) put it, ‘illness complaints are what patients and their families bring to the practitioner ... Disease, however, is what the practitioner creates in the recasting of illness in terms of theories of disorder.’ Further, ‘symptoms’ are ‘more than the incidental markers of disease’ insofar as they constitute ‘a fundamental part of people’s being and means of articulating a relationship to the world’ (Biehl & Moran-Thomas 2009:282).

rich with the flavor of certainty and the promise of control.’ Further, the biologically focused ‘broken brain’ paradigm of the 1990s had good intentions: to supersede the psychoanalytic and anti-psychiatry movements of the twentieth century that had hurtfully implicated families (particularly mothers) and medical culture (Luhrmann 2016). Attending to the role of socio-structural forces means to some extent shifting accountability back to the individual and their social worlds. This can come with undesirable consequences. Anthropologists such as Gregory Bateson and colleagues (1956) and Nancy Scheper-Hughes (2001[1979]) who posited, respectively, that a ‘double-bind’ of mixed communication styles between families and whole communities could explicate manifestations of schizophrenia, hit too many social nerves (see Scheper-Hughes 2000). Further, assigning clinical caregiver responsibility for outcomes is difficult to reconcile.

Currently, responsibilities between primary and specialist clinical caregivers have become clouded by health conditions that span ‘physical’ as much as ‘mental’ metonymical domains (RANZCP 2015). What is perhaps most uncomfortable for psychiatrists in terms of wider ‘health’ concerns is that intensive antipsychotic drug regimens appear to create the most marked neurobiological, ‘progressive changes,’ and are also likely exacerbated by ‘cannabis use, diabetes, and hypertension,’ while pharmaceuticals happen to generate the vast majority of State funding upon which psychiatry depends (Murray 2016:2; Murray et al. 2016). Further, antipsychotic treatments give primacy to the ‘psychotic’ symptoms that are not neatly ‘targetable’ as such.

Biomedical treatments for schizophrenia target observations of ‘positive’ and ‘negative’ symptoms, the latter of which are much harder to treat. ‘Positive’ or ‘psychotic’ symptoms are acquired through illness and appear to reflect an excess or distortion of normal functions, including hallucinations, delusions and racing thoughts (van Os & Kapur 2009). Positive symptoms also ‘imply the simultaneous *absence* of something normally *present* – the sense of ownership or intentional control’ (Sass & Parnas 2003:431). In the West, positive symptoms tend to be most acutely distressing for patient and caregivers and are thus the target of treatments (Jenkins & Barrett 2004).<sup>6</sup> Meanwhile, negative symptoms refer to functions and behaviours apparently lost due to illness that may particularly compromise

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<sup>6</sup> A quantitative study of a recently introduced clinical scale for ‘subjective well-being’ in the UK clozapine clinic where I conducted my fieldwork suggested that, across all clinical measurements, managing the ‘positive symptoms’ of schizophrenia correlates with higher scores of ‘eudemonic’ well-being (Brown, Mezquida & Fernandez-Egea 2016).

socio-economic participations (Mezquida et al. 2017). Negative symptoms include apathy and blunting of emotion, which may also coincide with cognitive impairment such as disorganized thoughts and speech, memory problems and difficulty concentrating and/or following instructions or completing tasks.<sup>7</sup> Negative symptoms, which tend to first develop pre-morbidly, often persist in the lives of people with schizophrenia during periods of low (or absent) positive symptoms (Sass 2004). From a philosophical perspective, negative symptoms prompt consideration for how patients' sense of self is impacted.

Philosophically, the condition of schizophrenia has been viewed in terms of inter-subjective dimensions. RD Laing's (1965:75) theory of schizophrenia suggested that, '[t]he individual has developed a microcosmos within himself; but, of course, this autistic, private, intra-individual 'world' is not a feasible substitute for the only world there really is, the shared world.' Further, '[i]f this were a feasible project then there would be no need for psychosis' (Laing 1965:75).<sup>8</sup> More recently, Sass and Parnas (2003) suggested that schizophrenia is a 'disorder of the self.'<sup>9</sup> Sass and Parnas narrow this self-disruption down to 'hyperreflexivity' and 'diminishment of self-affection ... the implicit sense of existing as a vital and self-possessed subject of awareness' (2003:428).<sup>10</sup> This thesis recognises how clozapine-treated schizophrenia patients can regain self-possessiveness. Further, it shows how experiences of biomedical treatments can help to reconstitute an individual's sense of self, building on the cultural influences on schizophrenia that anthropologists have observed.

Overwhelming cross-cultural ethnographic evidence suggests that, paradoxically, societies with less access to biomedical resources (drugs and tailored therapies) experience less 'severe' symptoms and greater 'recovery' rates of schizophrenia (Good 1997; Jenkins & Barrett 2004; Hopper 2008; Luhmann 2007; Marrow & Luhmann 2016). Signs of 'psychosis' invoke different clinical and cultural thresholds (Larøi et al. 2014). Within Europe and America, a recent meta-analysis estimates the prevalence of 'psychotic experiences' to be 17.5 per cent, wherein over three quarters of these experiences are merely

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<sup>7</sup> Further, '[a]sociality, the absence of socially orientated behavior – a key negative sign – is often accompanied by the presence of strange or socially inappropriate, self-directed behavior' (Sass & Parnas 2003:431).

<sup>8</sup> Laing (1965) observed patients who could only feel 'embodied' under conditions of being 'incognito' (128). He proposed this to be because '[t]he body clearly occupies an ambiguous position between 'me' and the world' insofar as it is the 'core and centre of my world' at the same time as being 'an object in the world of others' (131), and 'object-for-others' (130).

<sup>9</sup> 'Self-disorder' involves 'an ipseity disturbance,' whereby: 'Ipeity refers to the experiential sense of being a vital and self-coinciding *subject* of experience or *first person perspective on the world*' (Sass & Parnas 2003:428).

<sup>10</sup> Self-affection here is 'a matter of "mattering" – of constituting a lived point of orientation and the correlated pattern of meanings that make for a coherent and significant world' (Sass & Parnas 2003:436).

transient rather than accumulative; they do not become recognised as clinical symptoms or long-term disorder (van Os et al. 2009:185). Likewise, people who are diagnosed but no longer seeking clinical treatment are not accounted for in the statistics (Guloksuv & van Os (2018:230). At least part of the cross-cultural differences in schizophrenia manifestations and outcomes, however, can be explained by patients in Eastern contexts not being as socially defined by their illness. This includes differences *within* primarily Western cultures too. For instance, when comparing Anglo-American and Mexican-descent families in the US in terms of the interpersonal boundaries conceived of between a person with symptoms of schizophrenia and their family members without symptoms, Jenkins and Karno (1992:66) found that suffering was minimised amongst Mexican-descent families who regarded the condition as ‘*nervios*, a common condition that in its milder form afflicts nearly everyone.’ When people experience a ‘community expressed emotion’ comprised of ‘widespread criticism and intense experience of shame and anger’ (Eliacin 2016:89), the consequences for cultural emigrants can be grave. The ‘risk for [being diagnosed with] schizophrenia’ amongst African-Caribbean immigrants in Britain is fifteen times higher than for white British people (Eliacin 2016:86). This has been attributed to experiences of isolation when living in white neighbourhoods with insecure family support and significant unemployment rates (Eliacin 2016). People with schizophrenia cannot thrive in communities that do not accept them.

While cross-cultural or inter-cultural comparisons are well beyond the scope of this thesis as I was based in two predominantly Anglo-centric clozapine clinic populations, I preface with several anecdotal remarks made by clinical caregivers in these clinics that resonate with previous cross-cultural findings about inconsistent diagnostics and treatments (Good 1997). UK Clozapine Lead Nurse Clive confided that, despite growing up as a black South African during Apartheid, when he arrived in England he had never felt so “sad” and “lonely” in his life, which he soon related to the culture and unrelenting demands on the mental health system in the UK.<sup>11</sup> African-Australian nurse Zoya then told me that, in regard to documenting schizophrenia, “because Western governments are aware that in Third World countries people recover more than here, there is pressure to give schizoaffective disorder as

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<sup>11</sup> Until he had a family, Clive dreaded finishing work each day because he could not casually talk to strangers the way he could do in South Africa. He remarked how, despite the little financial wealth that people had in the area he grew up, “their ability to have ‘hot conversations’ with strangers, no matter where you were” – such as bus stops – meant that “people don’t have time to dwell on their own problems”; he observed that in England people demarcate their personal boundaries more. Indian-Australian clozapine assistant nurse Ramesh also told me that from what he had observed of mental illness rates in India compared to Australia, “if you take the ratio, there’s less” [mental illness in India]. I did not get a chance to discuss with Ramesh why he thought this might be the case.

a diagnosis instead of schizophrenia, where possible, to lower the statistics of people with schizophrenia.”<sup>12</sup> Another “loophole” in regard to disguising medication “outcomes,” she said, involved doctors skewing the recorded clozapine dosage. She showed me one patient’s record that listed ‘100 x 8 tabs’ instead of simply listing ‘800mg clozapine,’ to allude to a lower dose for the national database that draws statistics from milligrams of clozapine rather than number of tablets. When I asked her more about “cultural differences in terms of recovery” in Africa, Zoya reflected, “it’s still an individual journey,” and that the social receptivity of loved ones may be changing with Western influences in regard to stigma around mental illnesses.<sup>13</sup> Having spent no longer than a day in a clozapine clinic in a multi-cultural suburb of Sydney to gain experience before starting fieldwork, I had noted that every patient had attended with a parent or sibling. This was not what I observed in either clinic I was based in for fieldwork. When I mentioned this difference to Australian clozapine coordinator Kerry, she replied, plainly, “That.... [name of suburb] would be European, Greeks – that’s what they do.” People from migrant backgrounds did not make up a significant proportion of patients in the clinics included in this thesis. As I suggest, though, family involvement in the clinic contexts I observed did not necessarily translate to more desirable outcomes, perhaps due the culture of shame and fatalism around mental illness in which these families were operating.

A key issue that remains is the extent to which individuals with schizophrenia are impacted by their social circumstances as well as their biological predispositions. Tanya Luhrmann and Jocelyn Marrow (2016:197) conclude, ‘schizophrenia is not a genetic lightning bolt’; rather, ‘[s]chizophrenia is the story of the way that poverty, violence, and being on the wrong side of power drive us mad.’ As alluded to above, schizophrenia has been understood as a form of ‘social defeat,’ comprising an ‘outcome’ of unknown biological vulnerability that manifests when ‘the experience of defeat in a social context is felt ... so profoundly that it can make the body ill’ (Luhrmann & Marrow 2016:198). Although people like UK patient Martin (above) experienced ‘good outcomes’ while endorsing a ‘genetic’ framework for his schizophrenia, his socioeconomic securities cannot be disentangled from these good outcomes.

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<sup>12</sup> In Chapter One, I elaborate on how diagnostic politics impacted my fieldwork methodology, too.

<sup>13</sup> Zoya described one African woman she knew who had “done very well on medication *and* because she got married,” but this woman had strategically not told her partner about her diagnosis “until he already loved her.” She gave another example of an African man who “functioned very well when taking medication *and* going to church”, and would “relapse” if he went without either.

While ‘poor lifestyle’ behaviours are on the rise among general population groups, they are more prevalent amongst marginalised groups and those with serious mental illnesses. Kleinman (2012:182) observed that multi-morbidities exist as part of ‘the very terrain of social exclusion, health disparities, and social suffering.’<sup>14</sup> Whilst perceptions of social disconnect or isolation may result in multiple stressors on health and well-being (Wilkinson & Marmot 2003; Cacioppo & Hawkey 2009), such strains and suffering may not always be recognised as explicit social symptoms as much as they might reproduce broader social gradients in health. For people with schizophrenia in Western society, life expectancy is reduced by up to 32 years, largely attributable to cardiovascular disease (Lourey, Holland & Green 2012). Antipsychotic medication is thought to play a significant role, unhinging cardiovascular, metabolic and insulin regulation processes, and inducing sedation, with associated lifestyle factors exacerbating risks (Salzberg & Castle 2010). Diabetes is three times as likely to occur in those being treated for psychosis than the general population, while the prevalence of smoking is estimated to be up to three times higher than overall population estimates and tobacco has been singled out as key contributor to mortality (Murray et al. 2016).

This ‘preventable’ gap in life expectancy appears to be widening, despite efforts to assist targeted populations in improving health (Lawrence, Hancock & Kisely 2013; McGrath et al. 2008). An Australian study suggested that only a third of psychosis patients presenting to general physicians receive advice for ‘general health’ (Morgan et al. 2011), while a UK study suggested that ‘physical health’ screening assistance for people with serious mental illness can make a significant difference to patient engagement (Eldridge, Dawber & Gray 2011). Moreover, while anthropologists such as Scheper-Hughes (2001[1979]) suggested it to be paramount to consider the ‘every day social life’ of patients beyond biomedical settings, there is also a need to understand how it is that more contact with clinical caregivers via the clozapine clinic regimen does *not* appear to translate to greater uptake of ‘healthier lifestyle’ behaviours. Clozapine epitomises biomedical treatments for schizophrenia, because it is most associated with enhancing life at the same time as compromising life expectancy.

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<sup>14</sup> The concept of ‘social suffering’ denotes how psycho-somatic manifestations become socio-somatic experiences, orientating individuals toward shared meanings of their ‘body-self’ (Kleinman, Das & Lock 1997; Kleinman 1997:326).

## Clozapine: Life or death

In 1992, clozapine was promoted on the cover of *Time* magazine as the ‘magic bullet’ for treating schizophrenia that ‘Brings Patients Back to Life,’ while the *New York Times* presented ‘images of film star Robert De Niro taking a new medicine suddenly going from comatose to superstar’ (in Jenkins 2015:23). As Jenkins (2015:26) asserted, ‘the apparently promising image of healing is embedded in the brutal presumption that persons with schizophrenia had somehow previously been “dead”.’ Part of this ‘deadness’ may have been observed in relation to the ‘zombie’-like states induced by previous antipsychotic regimens, or it may have been the ‘flatness’ of emotion apparent in the form of negative symptoms. Questions of livelihood are interesting in the case of chronic schizophrenia, especially if people become at least stabilised, if not ‘invigorated,’ in the course of clozapine treatment.

The synthesis of clozapine in 1958 marked a transition to second-generation, ‘atypical’ antipsychotic drugs that dissociated antipsychotic efficacy and movement disorders, whereas the effectiveness of first generation antipsychotic drugs had been ascertained by the presence of motor symptoms effecting posture and muscle tone (Meltzer 2010).<sup>15</sup> Clozapine was first made available in Australia and Europe in 1971, albeit retracted from clinical use during the 1970s due to eight fatalities in Finland associated with blood and heart complications; a concern now addressed by frequent blood monitoring attached to clozapine’s reintroduction in the late 1980s (Amsler et al. 1977; Kane, Singer & Meltzer 1988). Clozapine prevails as the most effective antipsychotic drug at alleviating psychotic symptoms and suicidal ideation (Meltzer 2010). The extensive range of side effects associated with clozapine, which require ongoing medical attention, currently precludes its use in earlier stages of treatment. Clozapine is currently only prescribed in cases of medically defined ‘Treatment Refractory [or Resistant] Schizophrenia’ - when a person has not responded to at least two trials of antipsychotic medication (including both first and second-generation drugs) – between 20 and 40 percent of schizophrenia patients will meet these criteria (Lambert 2010).

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<sup>15</sup> Clinically referred to as Extrapyramidal tract symptoms (ETS), including dystonia (twitching or tremors), akinesia (difficulty in initiating movement) and parkinsonism (rigidity, slow movement, tremors). While these symptoms were previously associated with first-generation antipsychotic efficacy, the more severe cases of ETS – tardive dyskinesia (chronic involuntary movements) and the life-threatening neuroleptic malignant syndrome (neurological disorder marked by fever, visceral nervous system dysfunction and delirium) – have been consistently considered as adverse reactions to antipsychotic medication and also associated with non-compliance (see Meltzer 2010).

In Australia and the UK, clozapine is currently the ‘gold standard’ anti-psychotic treatment for chronic schizophrenia (Dold & Leucht 2014). Biologically speaking, clozapine is thought to work better than other drugs because it ‘produces lower and more transient’ dopamine ‘receptor occupancy’ (Murray et al. 2016:363). In other words, it regulates dopamine rather than directly ‘blocking’ dopamine (reward) receptors, which play an ambiguous role in schizophrenia. Alongside clozapine’s observed efficacy, however, are a plethora of physiological side effects that can exacerbate an inability to easily participate in public life. Imminent physiological risks include agranulocytosis (disruptions to the bone marrow production of white blood cells), myocarditis (inflammation of the heart muscle), pulmonary embolism (a blood clot moving to the lung), metabolic syndromes (often culminating in obesity), insulin resistance, seizures, excessive salivation, chronic sedation and constipation (Fitzsimons et al. 2005; Salzberg & Castle 2010). In terms of chronic ‘lifestyle’ morbidities, clozapine is associated with significant weight gain in around 7 in 10 patients, impaired glucose tolerance in 1 in 10, and Type II diabetes mellitus in approximately 1 in 10, along with hyperlipidaemia (raised lipid levels) in 6 in 10 patients (Lambert 2007; Hägg et al. 2003; Henderson et al. 2000; Meyer & Koro 2004). Also of note is that clozapine, in binding to dopamine receptors, however ambiguously, is metabolized by the same catalytic enzyme induced by nicotine (Prior & Baker 2003). Smokers treated with clozapine may thus require twice the dose, when compared to non-smokers, to achieve similar blood levels of clozapine – and abrupt smoking cessation may result in ‘clozapine toxicity,’ which can be fatal (Prior & Baker 2003; ACSQH 2012:4). However, insofar as cognitive function restored by clozapine may also enhance social function, and the monitoring of physiological risks attends to imminent concerns, an overriding positive benefit-to-risk ratio for clozapine has been deduced (Meltzer, 2010). This benefit-to-risk ratio also speaks to the heavier issue at stake: suicide.

For reasons that might become clearer if we attend to the social structures at play with clozapine treatment as well as apparent biochemical influences, clozapine’s benefit-to-risk ratio becomes easier to comprehend when we think about it in terms of life *preservation*. Regardless of the factors that threaten life while taking clozapine, clozapine is the only FDA approved antipsychotic drug to treat suicidal ideation (Patchan et al. 2015). For people who have experienced acute psychosis, suicide – attempted by approximately fifty percent of people with schizophrenia (Patchan et al. 2015) – comes from a place of perceivably

irredeemable and interpersonal anguish. It is important to acknowledge the anguish and lack of hope that most patients in this thesis felt prior to taking clozapine.

Many representations of acute psychosis provoke the theme of fear of death tied closely to whether adequate ‘interventions’ or understandings from others are available. The experiences of people with clozapine-treated, chronic schizophrenia concern a kind of after-life that follows acute suffering; experiences of suffering while undertaking clozapine treatment become more manageable. While the narrations by patients in my research often peeled back to recalling states of severe ‘psychosis’ precipitating their clozapine treatment, memories and descriptions were mostly distant. A number of people politely declined to participate in my research in case talking with me about schizophrenia conjured up too many past experiences; “I would like to help you, but I just can’t look back,” was an understandable response I received a number of times. Moreover, previous ethnographic accounts have emphasised how ‘symptoms of mental illness are manifestations of a type of affliction shared by virtually all mankind’ (Murphy in Luhrmann 2016:16), and that experiences of ‘sanity’ and ‘madness’ are not mutually exclusive (Martin 2009).

When participants did describe their experiences of acute psychosis and/or the meaning of schizophrenia, explanations were simultaneously accessible and wayward. For instance, UK patient Bradley, 28, said, “schizophrenia, to me, is someone who can’t talk – or who *can* talk, but they’re always in thought and they don’t... They don’t feel like they can communicate with any others.” Bradley quickly added that when he had searched for an “Oxford Dictionary” definition, however, he had found: “‘banana skins in a microwave’ – something like that, but it’s not in the dictionary anymore, it’s more medical.” Of course, ‘subjectivity ... is as much about swerves and escapes as about determinations’ (Biehl 2010:72). By the end of fieldwork, I felt that in some ways Bradley’s recollected dictionary definition aptly captured the absurd, arbitrariness that he was trying to grapple with more than medical terminology allowed. One Australian patient participant had gone so far as to publish several books to make sense of his experiences of psychosis, and attempting suicide.<sup>16</sup> UK patient and rap music fan Steve, 21, articulated the “poetic justice” for “police brutality” he had experienced while being admitted to hospital by quietly rapping to me one day: “police should treat everyone equal/ going mad bring on a non-lyrical sequel/ hand cut open for

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<sup>16</sup> To quote from this book or to specify what he said about it would be to compromise this participant’s anonymity.

disease/ I just told them to leave/ but my mum they did deceive/ no lift back from hospital/ I could not believe.”

The tussle of negotiating the giving and receiving of care is perhaps the most difficult matter to reconcile for individuals experiencing clinical attention for psychotic illness. In her screenplay *4.48 Psychosis*, London playwright Sarah Kane wrote, ‘[s]anity is found at the centre of convulsion, where madness is scorched from the bisected soul’ (2000:31). Kane, who had drawn on her experiences as a hospital inpatient, positioned the psychotic patient as a doctor’s ‘proselete to sanity’ (2000:31;33): ‘to feed, help protect, comfort, console, support, nurse or heal[;] to be fed, helped, protected, comforted, consoled, supported, nursed or healed[;] to form mutually enjoyable, enduring, cooperating and reciprocating relationship with Other, with an equal.’ Kane left a note for her agent on the play manuscript: “Do with it what you will, just remember – writing it killed me.” Kane committed suicide shortly afterwards.

There was something about being on clozapine treatment that alleviated the acute taunting of death and inadequate clinical care pre-clozapine. Most patients participating in my research had previously attempted to take their lives, having not yet found the socio-therapeutic connections Kane (2000) so expressed a longing for. Once on a clozapine regimen, however, patients then entered an ongoing social contract with clozapine clinical caregivers. In the clozapine clinics where I was based, it was unheard of for patients taking their recommended dose to ever again lose their appetite for living, even if interpersonal relationships were, as for all of us, ongoing projects.

Life beyond suicide brings alternative future imaginaries. Stevenson (2014:147) posited in regard to the normalisation of Inuit youth suicide in the Canadian Arctic, ‘suicide answers in one temporality a question that cannot be posed in another: What if the future cannot redeem the present?’ Drawing on Foucault’s attention to suicide as ‘the ultimate mode of imagining,’ Stevenson reflects that, ‘suicide is sometimes invested with the desire to live differently’ (2014:172). Further, Jenkins (2004:45) noted in regard to people with schizophrenia who do *not* kill themselves, ‘the deep well-spring of human endurance and resilience when confronted with arguably the most painful and horrifying of human experience imaginable’ also illuminates a powerful inclination *toward* life beyond what suicide might have offered – as indeed most of my research participants were doing. This does not mean people were not

sometimes, unwittingly, thrown back into their past inclinations when time passages were conflated during dreaming states.

Several clozapine patients in my study were reminded of death through their dreams. As Stevenson (2014) observed of what it means to live and care in a community with a suicide ‘epidemic’, dreams could also have constituted a focus point for this thesis. Patients often spoke of dreams that would sometimes throw them back into their past as a marker for change and what could not be completely overwritten by clozapine. For instance, UK patient Joanne, 53, told me that “my dreams sort of sort me out sometimes.” They often tormented her with particular experiences from her time at university when she first became unwell. Joanne, who had attempted suicide prior to taking clozapine, described how one day recently she had a dream where, “it ended by me thinking ‘the only thing I can do is kill myself,’ I’ve got to... no-no-no I don’t want to!” Joanne mimicked herself panicking, palms to face, “and I woke up, and it was like, *yeah*, I didn’t, and I *survived* and I’m here, *I’m here* ... the dream was telling me, no you *didn’t* want to do that, and you’re okay, you haven’t done it.” Stevenson’s ethnographic participants affected by the suicide of loved ones dreamt of those loved ones such that, she concluded, ‘images (reckoned as visual, sonic, or linguistic) are what keeps us alive’ (2014:174). For patients in my study, images – both in the form of dreams or even residual ‘psychotic symptoms’ but involving themselves – also seemed to keep them alive, in conjunction with being able to exert at least some agency and hope through the clozapine care regimen.

The expectations that come with different ‘categories’ of illness are critical to both treatment decisions and hope. Another paradox of antipsychotic treatment in the specific case of clozapine is that, although the term schizophrenia may be unhelpful because the stigma does not imbue hope (Guloksuv & van Os 2018:236), clozapine treatment is associated with both a label of ‘treatment-resistant schizophrenia’ *and* greater hope for alleviation of psychiatric symptoms than any other drug. ‘Clozapine patients,’ as I refer to them throughout this thesis, perhaps reclaim something by not identifying as ‘*consumers/survivors/ex-patients*’ of the Recovery Movement (Estroff 2004), but rather simply ‘patients’ of clozapine over and above ‘treatment-resistant schizophrenia’.

The clozapine clinic as an ethnographic focus

*The tension between healing and cure ... is found in the lifeworlds of individuals and the moral-social world of the clinic.* – Meyers (2013:14, original emphasis)

Previous ethnographic evidence on clozapine treatment and associated subjectivities focused on everyday worlds beyond a privately funded clozapine clinic in America. Jenkins' 2015 volume *Extraordinary Conditions* begins with a chapter titled, 'Cultural Chemistry in the Clozapine Clinic.' Expanding her earlier ethnographic work on subjectivity and psychopharmaceuticals (Jenkins 2010), she mapped out a wider 'cultural chemistry' of recovery-orientated atypical antipsychotic drugs, whereby the 'culture' in question involves an "assemblage" (Deleuze & Guattari 1988) of 'the cultivation of biology, desire, meaning, social practices and institutions' (Jenkins 2015:30). In so far as attending closely to patient experiences of taking clozapine as the first exemplar atypical anti-psychotic, Jenkins' analysis is not specific to clozapine treatment nor does it specifically concern the clozapine treatment setting itself. Her analysis was directed outwards, to 'the clinical prescribing patterns expanded beyond clozapine' (Jenkins 2015:31), rather than examining experiences 'in' the clozapine clinic per se.

I soon learned that the publically funded clozapine clinic settings in Australia and the UK where I conducted fieldwork had become everyday social worlds for clozapine-treated schizophrenia patients. As Todd Meyers (2013:11) suggested in his ethnography with adolescents being treated for opioid addiction, 'the moral-social world of the clinic' plays a significant role when understanding 'the discursive registers that hold "what is done" apart from "what is hoped for".' It is critical to understand the differences between clozapine imaginaries and practices in the spaces where clozapine treatment was the most intensified: at the clozapine clinic.

In entering the clozapine treatment monitoring regimen, patients at first have their blood tested three times a day, tapering out to a minimum monthly clozapine clinic visit thereafter. Patients can be said to enter a formal social contract insofar as they put forward their blood and bodies for monitoring, in exchange for clozapine tablets and social interactions and routines to express their agency through. While the alleviation of psychotic symptoms is critical in biomedical cultures, the question of what well-being, wellness, health or quality of life continuums *mean* as per the lived experiences of self and social functioning and control in the highly structured context of clozapine treatment and 'physiological' morbidities, was

unclear to me prior to undertaking fieldwork. The purpose of my ethnographic research was therefore to investigate what clozapine-treated schizophrenia patients and their clinical caregivers do with the social structures and expectations that they are given.

I argue that the clozapine-treated schizophrenia patients participating in my study predominantly worked actively with and alongside their clinical treatment regimen to experience ‘health agency.’ That is, patients experienced a sense of personal power in and through their health and clozapine treatment trajectories. The clozapine clinic treatment regimen, while ostensibly surveilling and exerting power over patient bodies equally invited patient quiet manipulations – even of things like blood tests. The resultant self-command in an environment of apparent control contributed very significantly to patient experiences of well-being in modest rather than remarkable ways. Patients and clinical caregivers in my study were also not polarised and disconnected in the way that Estroff (2004) described of the inability of her American schizophrenia and clinician participants to productively understand each other. Rather, during their treatment monitoring patients were able to partake in predictable, reciprocal relations with clinical caregivers despite the seemingly reductionist therapies offered up by the biologically focused monitoring regimen.

This thesis contributes to inter-disciplinary knowledge about how clozapine-treated schizophrenia patients experience their ‘health,’ and how it is that they choose life over death. Every patient in my study engaged in everyday behaviours, no matter how seemingly trivial, that they perceived to be ‘healthy’ and future-orientated. My analysis thus partly critiques biomedicine and partly critiques the politics of anthropology in its tendency to reveal the atypical conditions of the oppressed to avoid the danger of the agent with schizophrenia being cast as too much of an ordinary subject, lest it be seen to dial down the spectacular qualities or oppressive conditions under which people suffer institutional force. As Warin (2010) observed with anorexia patients, it can be just as fruitful to de-spectacularise psychiatric conditions. Warin’s (2010:90) ethnographic participants situated themselves as ‘extraordinary,’ so as to still set themselves *apart* from the ‘ordinary’. Similarly, Jenkins (2015) suggested schizophrenia patients to exhibit expounded human qualities to be better appreciated. Here, I show how we can go even further in humanising people with schizophrenia by attending to more mundane ways in which clozapine patients go about making their health and their lives their own.

## Chapter outlines

I prosecute my argument through four chapters. Chapter One discloses my ethnographic methods and partial positioning throughout the process of fieldwork and analysis. It is a chapter about how it was that I, personally, came to make the claims that I do about my participants' experiences. Drawing primarily on Lucas (2004) and Strathern (2005), I explain that, despite the bounded nature of my clinic-based fieldwork and my reflexive accounts of it, the experiences of containing and connecting my experiences within and beyond the clinic became a useful analytical tool. I set out more specifically how 'health agency' operated as a 'will-to-power' (Nietzsche in Rapport 2003); a personal force that superseded expectations about what 'health' looks like when only certain 'parts' are seemingly accounted for. I suggest how patients reconnect 'social' aspects of health themselves, and in doing so live with hope for greater understanding and resolve. Having suggested how socially orientated health agency overpowers what first appear to be conditions of social disempowerment, I can then focus in on how the particular aspects of clozapine treatment inform health agency.

Chapter Two attends to how patients express their health agency through manipulating even the most 'objective' aspect of the clozapine treatment regimen: the blood work. I explore how the clinical circuitries and rhythms of blood monitoring are harnessed by patients in subtle but productive ways to complement the 'logic of care' (Mol 2008) embedded in clozapine blood work. Patients engaged in practices that informed their blood results, and also worked to make up for clinical disconnections. Patients were thus found to be active contributors to even the flows of biologically reductionist regimens. Herein, I develop Jenkins' (2015:63) brief observation that the 'interiorization of the clinic' was a 'final relational quality of medication,' by attending closely to the processes of blood work to show how patient experiences of control and social participations reflect metaphors for health while on clozapine.

Chapter Three demonstrates how patients express health agency during clozapine treatment by utilising clinical ambiguities and reworking ostensible mind-body compartmentalisations of health. I highlight ways in which imaginaries of health are continually negotiable, along with ways in which apparently 'unhealthy' consumption choices, that contribute to clozapine-associated weight gain and mortality risks, can also serve as experientially 'healthy' choices, too. Clinical unknowns about clozapine allowed for greater flexibility in clinical and patient

interpretations of how it impacts individuals. Patients and clinical caregiver openness to new explanations bring to the surface tensions between agency and structural determinants, in the neoliberal context, along with making way for new possibilities for change. I suggest how health can be considered as a verb, and how patients proactively move or discharge energies imagined in their bodies and minds in making their health as they experience challenges to it. Chapter Four explicates how health agency is made through the temporality of clozapine treatment, wherein agents utilise the clinical focusing on time in the present. I argue that patients compliment their clozapine regimen by formulating their own present-centred rituals to deal with stress and uncertainty. Whereas previous phenomenological explications of schizophrenia emphasise how patients suffer from fragmentations of the self, I suggest that clozapine-treated patients can, in spite of persistent clinical symptoms, experience embodied or ‘enminded’ subjectivity that anchors them in the world among others. My ethnographic findings contextualise experiences to align them with more general existential anxieties in Western culture. I explore how achieving present-state awareness translates to optimal states of well-being comparable to meditative pursuits, and suggest that symptoms of schizophrenia and side effects of clozapine are highly contextual and can be temporally evaded.

In my conclusion, I decipher what my ethnographic findings mean in terms of previous literature on schizophrenia and its treatment as overviewed in this Introduction. Clozapine-treated schizophrenia presents some particular cross-roads for theoreticians who underscore the differences rather than un-spectacular similarities between schizophrenia patients and those of us without schizophrenia. I iterate how personal power, a will to engage in *labour* of some sorts and everyday efficacy were evident in the lives of patients discussed in this thesis. My findings thus both support and diverge from previous anthropological and philosophical approaches to schizophrenia in Western society, and I call for future research to examine ordinary forms of agency and power within extraordinary and extreme, highly structured conditions.

## Chapter One: Ethnographic Partialities and Locating Health Agency

*Ethnographic studies of mental illness not only take us deeply into the lives of individuals, families, and communities but constantly lead us outward, toward broader forms of social rupture, resisting closure and our efforts to control our data.*  
- Good, Subandi & DeVecchio Good (2007:247).

*There are always contradictions ... the only way I've been able to deal with these things is that they're a real entity ... We're all searching for something ... my ideal place is if we were all kind of realised ... We should all be connected. But for me, this schizophrenia is that we've all been separated from each other ... the residue of what happens when you're opening up this connection with other people but you don't have the right words, you know, to explain what's going on, so it's about getting back together ... I'm striving for everyone to be on the same page.*  
- Christopher, 39, UK clozapine patient

Learning what I have from my ethnographic terrain involved ongoing efforts to contain or connect experiences, and to appreciate the ephemeral and contradictory nature of doing so. When I was with my participants, my 'ethnographic engagement' aligned with what Lucas (2004:161) described as 'the task of building intersubjectivity and having patients' difficult experiences mean something to me as well as to them.' I, too, moved between "searching for something," as UK patient Christopher described, and finding meanings – in the field and also beyond it. This chapter explains how I wound up with the term 'health agency' to describe my participants' experiences. As Rapport (2003:114), drawing on Nietzsche, said, 'to recognize complexity and contradiction, to interpret (and keep reinterpreting) these into manageable environments calls for strong will-to-power.' In the clozapine clinic, there was an abundance of will-to-power to keep making meaning.

The first part of my argument makes the case for an ethnographic enterprise of partial truth-making, which paved the way for deeper insights into my participants' experiences. The second part of my argument posits the concept of health agency as the personal persistence and hope for holistic health – in spite of the 'physical,' 'mental,' 'social' compartments not always being experientially available at once. In relating to all my participants by way of learning to work within 'compartments' of experiences, there was a delicate line between empathy and the need for 'clinical' professionalism – an epistemological limitation embedded in the conditions of entry into my particular field sites. As Lucas and Barrett (1995:318) suggested about how our thoughts about someone translate to how we are in that person's presence, '[w]hen this thinking concerns the 'radical otherness' of psychiatric illness, it also has consequences for how we treat people, socially, custodially and

therapeutically.’ The overarching incongruence between patients and clinical caregivers that I consciously suspended as far as possible was the notion of patients’ “lacking insight” into their conditions when their views did not align with those of the clinic. I instead privileged the insights of the company I was in from interaction-to-interaction.

More than most anthropologists, those working in a field increasingly governed by clinical paradigms need to assert anthropology’s merit, while making practical compromises. In considering the future of anthropology in the ‘cognitive’ terrain, Bloch (2012) asserted that participant observation would only count if we fulfil the reflexive endeavour to find the other’s perspective through our own selves. Herein, ‘what lies behind concepts and schemas gets known by a process of minute, very rapid and continual mind reading’ such that ‘understanding occurs’ (Bloch 2012:183;184). Bloch (2012:184) posited, ‘[t]he way to know the implicit in those one is studying is through the ethnographer’s own introspection ... the ethnographer can claim that because interaction causes mutual colonisation a reflection on oneself after having been colonised is a discovery of others.’ While an intimate ‘mutual colonisation’ of my mind and a patient’s mind or clinician’s mind was not entirely feasible, I was careful to be reflexive about what I came ‘to know.’ My ethnographic experiences uncovered for me the ‘implicit’ importance of compartmentalising irreconcilable meanings in ways that my participants did. Further, what I learned could not be contained to clinical space – it was just more (usefully) concentrated there.

From the beginning, I immersed myself in the deeply cultural and inter-subjective manifestations of schizophrenia (Jenkins & Barrett 2004; Jenkins 2015; Sass 2004). As Foucault once said, ‘only the real conflict of the conditions of existence may serve as a structural model for the paradoxes of the schizophrenic world’ (cited in Woods 2011:162). Like most anthropological enquiries into mental illnesses and subjectivity, the constant openings ‘toward broader forms of social rupture’ (Good, Subandi & DeVecchio Good 2007:247) transcended for me the confines of what were, at first, ethnographically bounded field sites. There were multiple ‘external reference points’ (Strathern 2005:16) to sort through. Marilyn Strathern (2005:119) suggested that, ‘present formations are only fleeting concepts and present exercises but partial studies,’ whereby anthropological accounts ‘produce infinite complexity out of complexity’ as ‘[w]e become aware of more and more gaps.’ For me, some of these gaps pertained to doing fieldwork in two ‘spaces’ that were simultaneously inside and outside of my own cultural experience.

One field site was in an Australian city and the other was abroad in the UK. I practiced ‘episodic fieldwork’ (Dalsgaard & Nielsen 2013) between these two clozapine clinics over 18 months (2015-2016). I had a total of 59 official participants: 43 patients diagnosed with ‘treatment-resistant schizophrenia’<sup>17</sup> and 16 clinical caregivers. Informal caregivers were not included in this research, which I explain below. I conducted 130 audio-recorded interviews and observed and participated in clinical activities when it was appropriate for me to do so. I got to know many verbally consenting patients in this process, who allowed me to observe them during clinical activities, who could not be referred to in this thesis. Likewise, information obtained from formal consenting participants ‘off record’ cannot go ‘on record.’ While such insights are not specifically presented, they contributed significantly to my overall understanding and analysis. Because working in the area of mental health invites a particular intimacy and lens for wider social life, my experiences beyond the clinic during fieldwork time but not ‘clinic time’ also added another permeable layer of consideration, resonances and critical reflexivity. I had three perspectives to account for: clozapine-treated schizophrenia patients, those of clinical caregivers, and those of myself as the participant observer in particularly sensitive and sanctioned spaces.

Doing interdisciplinary fieldwork in Australia and the UK meant my position required constant self-attuning toward a safeguarded kind of openness, shaping my ethnographic receptivity and analysis. As Abu-Lughod (1986:10) purported,

The nature and quality of what anthropologists learn is profoundly affected by the unique shape of their fieldwork; this should be spelled out ... to ignore the encounter not only denies power of such factors as personality, social location in the community, intimacy of contact, and luck (not to mention theoretical orientation and self conscious methodology) to shape fieldwork and its product but also perpetuates the conventional fictions of objectivity and omniscience that mark the ethnographic genre.

To minimise the ‘conventional fictions of objectivity’ around my analytical claims, I first disclose the compromising dimensions of me pursuing this particular fieldwork. The process of me genuinely accounting for my position amidst those of my participants was indeed how my ethnographic data could be processed at all. There is ‘the indivisible experience’ between

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<sup>17</sup> Footnote 26 discloses diagnostic details and patient participant inclusion criteria, and I expand on patient participant demographics shortly.

the ethnographer and their fieldwork (Geertz 1995:135), and I hold myself answerable to all ethnographic conduct, observations and interpretations that I have made.

### Entry points

The conditions of entry into my ethnographic fields shaped the processes of ethnography that followed. While my formal ethnographic enquiry spanned 18 months, consisting of four phases of interviews and observations during ‘clinic time’ between the two clozapine clinics, my experiences are not this neatly bounded. My position upon entering the field was first coloured by the interdisciplinary collaborations and my own partialities that had hitherto been dormant to me.

My anthropological approach was necessarily influenced by inter-disciplinary collaborations, set up over an 11-month consultation and ethics clearance process. My professional networking efforts (with psychiatrists, nurses, academics and administrators), leading to informal introductions to clozapine-treated schizophrenia patients and clozapine clinics (not included in my fieldwork), only came into formal fruition in Australia after the lead clinician of the UK clozapine clinic agreed to accommodate my research. It was not until I had completed my first phase of fieldwork in the UK that final ethics approval could be granted for the Australian field site. I entered the field indebted to the lead clinician in the UK, a neuropsychiatrist who provided necessary co-supervision, legal sponsorship of my study through the UK National Health Service (NHS), and allowed a junior anthropologist into a research field otherwise reserved for medical researchers.

Interdisciplinary collaboration meant that my fieldwork occasioned both clinical and anthropological values and provisioning. My position as an independent researcher was scripted by clinical safeguarding as well as being openly experimental in terms of my ethnographic conduct. In regard to ethical requirements, recruitment of patient participants and their signing of consent forms were done via clinical caregivers; I was introduced to potential patient participants to explain my study only after initial patient interest had been verified by a third party. I recruited double the amount of patient participants in the UK than I

did in Australia.<sup>18</sup> This reflected greater accommodation of my research in the UK. It also meant that I felt further indebted to the clinical staff who were willing to help me.

I was necessarily more associated with clinical caregivers rather than patients. As an NHS ethics requirement, I undertook a number of staff training modules (online and in person), a blood test and a police check – my ‘rites of passage’ into the clinical environment. In the UK clinic, I was often referred to as a ‘colleague’ by clinical caregivers. In both clinics, I was assigned a secure workspace with other staff, separate from patients’ clinic space. I worked most closely with UK lead nurse Clive and Australian psychiatrist Adam, who both took me on as their ‘student,’ teaching me about the pharmacology of clozapine and often giving me ‘homework.’ In the UK clinic, I was soon called upon to explain the entailments of clozapine treatment to newcomer clinical trainees. While continually pointing out my non-clinical position to the newcomers I seemed to be inducting, it was a way for me to reciprocate Clive’s assistance to me in recruiting participants. To UK patients, I became “the clozapine lady.” Although the nature of my field sites and my place in them quickly provoked Foucauldian considerations of social power reproductions via professional and therapeutic relationships (Taussig 1980), my anthropological pursuit to illuminate any incongruence between patient and clinical rationales of illness and treatment (Kleinman 1980) was inherently respectful of the clinical and authoritative filters granting me access. This meant a constant resetting of my position as a critical ethnographer studying both receivers and givers of clozapine treatment. My liminal position between clinic ‘colleague’ and independent anthropologist was also exacerbated by my previous exposures to the medical field.

Although I had limited previous experience with mental health related clinics, medical treatment contexts and practices were not entirely new to me, which was both useful and another bias to manage. I was, beyond ethical requirements, situated in an ethnographic ‘*standpoint purgatorio*’ (Contreras 2015:250). I was a “‘halfie’ anthropologist’ (Abu-Lughod 1991) who had grown up privy to medical discourse in a family of medical doctors. I had previously worked at a pharmacy, at a General Practice, in a public health policy department and had obtained a Bachelor’s degree in psychology. I did not, however, have any clinical experience in authoritative roles within the medical field, nor had I worked specifically among mental health patients. This was a disadvantage in terms of accessing my field sites

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<sup>18</sup> I had 29 UK patient participants, 14 Australian patient participants, 8 UK clinical caregiver participants, and 8 Australian clinical caregiver participants.

but an advantage in terms of investigating matters afresh in the field, where I had to simultaneously gain trust and maximise my impartiality. The process of field access and professional scrutiny meant I was in a provisional ‘in-group’ position with clinical caregivers. I only disclosed parts of my “halfie” background if asked, however it helped to minimise any potential ‘othering’ felt by staff when engaging in biomedical models (see Pope, Cubellis & Hopper 2016:518). Having half-baked medical knowledge also helped me to blend into the ‘safety’ of the clinical world from the point of view of some patients who might not have trusted me otherwise.

Clinical affiliations were most prominent when ‘recruiting’ patient participants and when discussing medical matters that prompted reproductions of clinical language and information. I had to discern the boundaries of confidentiality when discussing medical matters of potential clinical concern, especially when these concerns were otherwise deemed by staff to be ‘delusional.’ My reluctance to suspend seeing things clinically and detach from the people whose lives I came to care for, as an anthropologist, sometimes affected my relationships with clinical staff participants, as I later suggest in regard to time spent with Clive. I found myself trying to compensate for my “halfie” bias by relating to experiences of patient participants wherever possible.

As I had to be clear about my anthropological interest in health experiences, my own ‘healthy’ status, age, life stage and gender simultaneously facilitated and inhibited my ability to connect with participants. I was a young woman with no chronic health conditions. I was not ‘overweight’ and this put me in contrast to most patients and some clinical caregivers who were. I was not a smoker, excluding me from opportunities to partake more naturally in staff and patient smoking breaks and conversations that took place just outside the clinics (safeguarded enough to count as ‘clinical public space’). Having smoked occasionally as a teenager, however, I was glad to be able to admit this when some patients paused to ask me whether I could relate to their experiences at all before elaborating on why they enjoyed smoking. Upon entering the field, I also happened to be the average age of females who receive a diagnosis of schizophrenia (age 27). I had never received a diagnosis of a psychotic disorder, although some of my extended family had.<sup>19</sup>

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<sup>19</sup> Much of this was brought to my attention in doing this project. Of note is that, a few months prior to commencing fieldwork, my second cousin in the UK who had been diagnosed with schizophrenia some years previously, killed his mother (a psychiatrist and his only caregiver) during a psychotic episode whilst he was refusing medication. This gave me

While I could make no claims to being a fellow patient in, say, the vein that Martin (2009) dynamically utilised in her ethnographic enquiry into bipolar disorder, my continual reflexivity allowed me to become aware and humble about how porous *all* categories of health and illness are. Ways in which I found myself relating to patients' various 'mental health' difficulties fed into my sense that schizophrenia does indeed exist along a continuum of human conditions. Moreover, the majority of clinical caregivers revealed to me their otherwise unspoken abilities to relate to patients in this way, too. As far as being able 'to see things from both perspectives [that of the ethnographer and that of the participant] at once' (Myerhoff 1994:41), these perspectives shifted as I interviewed and observed my participants at different points in time. Building understanding in the first instance was enabled by my liminal position – professionally and personally.

I felt closer in liminal life stage to patient participants than to clinical caregivers because I was neither established in a career nor investing in a family of my own. The subject of having a family of one's own came up more explicitly in conversation with female patients, and I felt relieved to not have something that some desired for themselves. Admitting that I had a partner sometimes made me feel guilty. Nonetheless, two UK patient participants (one male and one female) in my study had current long-term partners, and four UK male patient participants and one Australian male patient participants were fathers, albeit mostly estranged from their children (and grandchildren). A handful of other patients across both clinics had intimate and/or familial relationships with their hallucinatory presences.<sup>20</sup> I felt comfortable in my ability to bond with both genders, perhaps because of my younger unestablished status. This was critical because the majority of patients were male.<sup>21</sup>

While gendered experiences emerge throughout – especially in Chapter Three, in which I discuss gendered differences in respect of weight concerns, and Chapter Four, in which I

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great insight into the possible ramifications of untreated psychosis. My second cousin was subsequently put on clozapine. I have undertaken ongoing counselling throughout my PhD to ensure that this incident had minimal impact on my research.

<sup>20</sup> For instance, one man felt himself to be married to a particular female celebrity with whom he would console every morning and night; another man considered himself a step-father to the children of a celebrity with whom he had a relationship that had evolved from being sexually intimate to a non-intimate companionship involving much "laughter" over the last twenty years. Another example was Australian patient Daisy who I describe later in this Chapter.

<sup>21</sup> Across patient participants there was a male: female ratio of 35: 8. The male: female ratio for people with schizophrenia, generally, is estimated to be 1.4: 1 (McGrath et al. 2008). While I do not have statistics for gender differences in clozapine-treated schizophrenia, females with schizophrenia across cultures are suggested to have slightly higher 'recovery rates' (Hopper 2004:75), which may suggest that less females are put on clozapine. The male: female ratio for staff participants was 7:9.

explore gendered differences in patients' willingness to seek extra psychotherapeutic supports to confront the past – I have not taken a focus specifically on gender in this thesis. I have favoured instead Rapport's (2003:16) position, that individuals possess 'capacities [that] can stand for the potentialities of Everyperson.' Alongside a multiply of other factors, gender shapes and bends those potentialities, but I have not privileged it less it overwrite the attention I pay to how individuality emerged for each patient. In doing so, I have attended to the experiential '*truths*' of people's own presents and pasts, as they have privileged them (Weiss 2002:198, original emphasis). This is a position the feminist philosopher Gail Weiss regards as crucial when making analyses of people who have been socially disenfranchised, 'rather than reserving the ascription of truth only for those experiences that will lead to their emancipation in the future' (2002:198). Weiss (2002) was writing in response to feminist critiques of Merleau-Ponty's observation about how the body is formed up in experiences that are not wholly determinable (by gender, or indeed any other singular factor). She remarked, 'people continually engage in a series of intercorporeal exchanges with their environments that are grounded in bodily activity, activity that is always directed toward environments themselves, transforming them in the process' (Weiss 2002:196). I found that gender fashioned patients' experiences of previous social influence and present understandings, as did experiences of sexual/physical/emotional abuse. But in the clozapine clinic, neither of these determined the entirety of experience, and each played an inconsistent and indeterminable role. Patients in the clinic hailed from all walks of life; a diversity of socioeconomic backgrounds was represented, as were different ethnicities and generations. I have noted these where they became pertinent to individual expression of health agency.

I found myself drawing on both my 'pre-academic' and 'academic' backgrounds to build rapport with participants. While most patients were now reliant on welfare support, included in my study were, for instance, musicians, shop assistants, several political science students, a public servant, a librarian, a Doctor of biochemistry, a delivery truck driver, and martial arts instructors. I was thankfully able to follow conversations with vernacular references about street culture, drugs, music and celebrity culture, school difficulties, or else relate to experiences around pressures of parents, school and work, as well as share various intellectual, political and philosophical interests. With clinical caregivers, I also drew on aspects of previous social exposures, varying my language styles and the extents to which I concealed or highlighted my personal or professional interests. In the UK clinic where I was able to blend in more easily with a more cohesive 'team' of staff, my younger life stage and

childlessness nonetheless created as much difference between my personal position and that of clinical caregivers as my anthropological agenda did.

In an effort to blend into and respect both clinical environments as much as possible, I wore similar clothing to the staff and students (nurses, medical and research-based): loose fitting, smart, neutral colours, with minimal make-up or accessories. An unspoken dress code for patients clinically deemed ‘less well’ were more colourful, mismatching, multiple layered materials. I learnt that this was a strategy to conceal or protect oneself, utilising pockets, wearing bold makeup or sunglasses, or else to embody a more innocent status by dressing in ill-fitting children’s or teenager’s attire.<sup>22</sup> Although the clinical dress code seemed more fluid in the Australian clinic, I tried to be consistent with my appearance throughout the duration of fieldwork, mainly in respect for the clinical authorities that had granted me access and for the potential safety assurance this may have given patients. My attempts to blend in enough with my clothing, as form of ‘cultural transvestism’ (Keane 2005:6), were of course easier than in other ethnographic contexts. Yet, in the process of considering how, say, I should not wear particular nail polish shade because it might ignite fear in patients, I became somewhat ‘hyperreflexive’ in ways that patients can be (Sass 2004).<sup>23</sup> Moreover, as Keane (2005) would contend, my clothing was not only a symbol because it allowed me to be differently orientated to and in different worlds.

While the role crafted for me was as a clinical staff member, I had to work to convince patients of my anthropological position. First, I reiterated to nearly every patient participant that, “I am primarily interested in what is important to you, not your clinician.” I told patients that despite my access to their medical records, there was no two-way exchange of information. Medical records were seldom consulted when going through my ‘data,’ and all data drawn on in this thesis comes directly from participants. Getting this message across either facilitated longer-term participation in my research or triggered further confusion about my role in the clinic for those who could not trust me enough to participate. My role became clearer once patients spoke with me and could place me as both an outsider and an insider, depending on their needs. Some patients were willing to talk with me straight away, while

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<sup>22</sup> Further, as UK patient Luke, 45, explained to me of why he wore his dark sunglasses all the time: “I just feel kind of more well with them on” – although he had begun to wonder, a few months into clozapine treatment, if he might take them off while inside the clinic. When I last interviewed him, Luke briefly took off his sunglasses to show me how he had recently glued them back together. He reiterated, “they make me feel better”.

<sup>23</sup> ‘Hyperreflexivity’ has been described as a negative symptom referring to intensified self-awareness and fixations on phenomena such that aspects of the ‘self’ become objectified (Sass 2004:306).

others expressed how “busy” they were and would come in on their non-clinic days to talk with me instead. This also provided freedom and flexibility for patients who decided not to show up at agreed times, which was more common in the Australian clinic.

Participating was by no means easy, but it became predictable and we learned together because I was open about never having done fieldwork before. Before our second interview UK patient Joanne, 53, said that talking with me meant: “Straight on communication, I know I’ll feel very tired, sort of suffering this evening, but I’ll just keep myself quiet, and be quiet, and it’ll be fine.” However, Joanne insisted that talking with me was her “choice” and that, “it gives me a lot of good feedback, talking to you.” We established that this “feedback” was different from psychotherapeutic treatment, which Joanne had had in the past, because it was research orientated. What was more, clozapine clinic appointments otherwise did not comprise open-ended conversations. UK patient Gordon, 39, who was initially painfully shy albeit adamant to participate, told me during our last conversation when we were both more at ease: “You have, have... the same idea - the same ideas about, life and its meaning.” I tried to contain and balance the processes of gaining trust with patients by making ongoing efforts to distinguish myself as an anthropologist who could ‘safely’ relate by virtue of me being in clinical space.

### Porous parameters

My fieldwork settings were not as demarcated as they first seemed. Contrary to anthropological expectations to attend to far-reaching everyday worlds, it was not ethically feasible for me to conduct ethnography beyond the walls of the clozapine clinic nor was it practical to include informal caregivers as another participant group. Further, while the medical environment was likely to incline participants toward expressing more medical complaints than they might in a home environment, I was also exploring how agency operates *in extremis* (Rapport 2003). The benefits of minimising risk and confusion for patients also far outweighed the limitations of biases and field boundaries.

By way of the people I was working with, any additional ‘data’ may have been *too much* for me to contain, especially if I had included informal caregivers as a third participant group. While Corin (2007:276) has suggested a need to disentangle the elusive ‘cultural signifiers’ of communication used by both patients and their families in order to ‘question psychosis

from the perspective of people who experience it,' it was not common for family members to accompany patients to the clinics. This was partly because in Western society family members are unlikely to be directly involved in the caregiving for people with schizophrenia (Luhmann & Marrow 2016). I observed this to especially be the case for clozapine-treated schizophrenia patients. After interacting with some of the few parents who were occasionally involved in clozapine clinic visits, the high sensitivities and emotion expressed by these parents only affirmed the decision to exclude them from formally participating in my study. As a non-parent myself, I also could not have as easily related to their experiences as I could to their children. Further, given the frequent contact clozapine patients have with the healthcare system (minimum monthly check ups), it is critical to understand ways in which people on the 'treating' side of treatment registers understand their regular transactions with patients that uphold the biomedical imaginaries at play.

The clozapine clinic spaces were compartmentalised into different treatment rooms, facilitating what Kleinman (2012) has ethnographically critiqued as a wider therapeutic discourse of focusing on one thing in isolation at any one time. Clozapine clinics in Australia and the UK involve treatment registers dividing 'mental' and 'physical' health provisions, via an administrative circuit that the patient must pass through with pathologists/ phlebotomists, clozapine nurse coordinators and psychiatrists comprising the minimum number of direct clinical contacts. In the UK clinic, blood monitoring (Chapter Two) occurred on site and so clinical caregivers partaking in my study included phlebotomists, pharmacists, a pharmacy technician serving as 'clozapine coordinator,' as well as a 'physical health' nurse, in addition to 'mental health' nurses and psychiatrists. Clive was the lead nurse with prescribing rights and he and George, the lead psychiatrist, shared most of the authoritative responsibilities in regard to clozapine treatment.

Clinical caregiver roles, like my own, were simultaneously compartmentalised and blended. I had similar privileges that general staff did, and was witness to clinical activities, but I could not participate to the extent of being a clinical caregiver; I was both provided with and restricted from access to things and persons. The altering of clinical roles and spaces was particularly prominent in the Australian clozapine clinic. The Australian clinic space was situated within a mixed public mental health service facility, and patients were required to attend pathology services earlier in the week of attending the clinic. Both clinics were open twice per week. Compared to the UK clinic, clinical caregiver roles were more fluid, with

two ‘mental health’ nurses assigned as clozapine coordinator and clozapine assistant, covering ‘physical health’ checks too. The boundaries around clinical space were markedly different between the two clinics.

The UK clinic was situated in a refurbished three-story Victorian-style building that blended into the row of houses on its street. The only times I was alone with patients for extended periods was during interviews, which were conducted in one of three rooms: a rarely occupied ground level front room; Clive’s recently acquired office next door to the front room, or George’s office on the first floor and main clinic level. The ground floor of the clinic included a front reception, patient toilets and various types of usually vacant rooms (the building had been used by the local NHS Trust for various day service activities over the last thirty years). George had assigned the front room on the ground level to me to use for interviews when not occupied by a separate community-run mental health group that ran on one morning of the clozapine clinic days. It was a large room with bay windows, a mantel fireplace ornamented with a non-working antique clock and two porcelain vases. The room had minimal items in it: several desks, crookedly fitted together, one supporting a second non-working clock balanced against a wall with an empty notice board of faded crepe paper. Here I would sit with patients on two modern fabric armchairs around a coffee table. Patients were not otherwise familiar with this room, like they were with George’s room. This did not seem to make a noticeable difference, however, in our interactions. Some patients were familiar with Clive’s room.

Whereas the front room seemed to hold a disjointed but not discomfiting history, Clive’s room next door had a more temporary feel. It was new to him, too, and his time was mostly spent elsewhere in the clinic or doing home visits. The room contained a desk, computer, phone, a coffee table with a few fabric armchairs, surrounded by empty walls, four empty bookshelves, but with plenty of daylight flooding in through a set of French doors. It could open right out to an overgrown garden with the hum of insects and a loud air-conditioning generator that was switched on at times when Clive felt that various patient body odours had excessively penetrated the indoor air. Other ‘clinic rooms’ toward the back of the building were, in contrast to the front room and Clive’s room, uncarpeted and equipped with clinical apparatuses, including the echocardiogram (ECG) machine and spare equipment.

Activities in the UK clozapine clinic mainly took place on the middle level, with two ‘blood rooms’ distinguished by linoleum flooring, hazardous material bins, pathology chairs, sinks, clinical trolleys with blood drawing utensils. The larger blood room contained the blood mixing machine and analyser, concealed medical supply cupboards, and a large safety box with the week’s clozapine supply from the hospital pharmacy. George’s consultation room, next door to the larger blood room, contained a desk, computer, mostly full bookshelves, filing cabinets, a whiteboard for teaching students, and several personalised items like a contemporary painting and a stylish lamp (making it feel more lived in than Clive’s). Further up the corridor was the ‘physical health’ room occupied by nurse participant Narelle. It too had linoleum flooring, a sink, several consultation chairs, multiple bodily measurement machines, informative posters regarding patient nutrition and bodily measurements, as well as a number of Narelle’s personal paintings by local artists and pot plants that she had brought in. Her window was often open, to the sight of what phlebotomist Sam told me was a “butterfly tree,” emitting sounds and smells of pollenated summer air. The clozapine clinic waiting room was also on this floor, with many armchairs, coffee tables with various books, magazines and leaflets, and pot plants. The walls were pinned with ‘health’ posters. Narelle was in the process of collecting items to refurbish the waiting room and corridors with non-clinical ‘well-being’ images instead, and I contributed an Australian Indigenous art poster when I returned to the clinic.

The waiting room was, nonetheless, a disordered space when in use. During clinic days, the waiting room contents (chairs, tables, reading material, plastic water cups) shifted around, while activity ‘inside’ it leaked elsewhere in the clinic, as different patients moved through. An excerpt from my field notes after clinic hours one day summed up the atmosphere that I sometimes found disquieting:

*Waiting room empty. Loud pop music playing from the radio, windows flung open, curtains loudly flapping. Seems chaotic. Asked [receptionist] and [phlebotomist] downstairs about the music and they said, “yeah, one of them must have put it on.” But no one seems fazed or bothered to turn it off even though it’s echoing throughout the 3 story-building. It’s been playing for at least 30 mins.*

I never tried to contain what I perceived to be ‘chaotic’ happenings in the waiting room space. I nonetheless found myself feeling very relieved one day when, while chatting to UK patient Joanne in the waiting room, Joanne found the curtain flapping intrusive enough to get

up and close the windows before we could continue our conversation. Doing what they pleased to make the waiting room suit their preferences, UK patients suggested some ownership over this particular clinical space.

I often sat in the UK clinic waiting room with patients during spare moments, observing and chatting to them. I always had at least a notepad with me, as another way of suggesting my position as a researcher. Being in a medical setting, my taking of notes during patients' clinical appointments was not an unfamiliar practice. I tried to adapt my position to the activities happening in each room, and my role was of course more formalised when in clinical consultation rooms. My participation in clinical space involved moving between the waiting room where I chatted to patient participants and clinical rooms where I sometimes assisted with basic clinical tasks (such as preparing equipment, holding blood tubes and placing ECG pads on patient's bodies). Patients doing 'follow up' interviews with me often waited for me in the waiting room. I was wary of this routine fitting into the clinical one, but tried to balance out formalities when I could by, for instance, joking about it and then ensuring patients could choose where to sit when we entered the interview room (and I avoided sitting on the formal 'clinician' chairs when in clinic rooms).

On the top level of the clinic was a computer/researcher room and the staff toilets. I interacted with various other research students doing placements at different times I was there, but I also valued this space to take quiet moments for myself and to catch up on field notes. There were plenty of opportunities for interactions with clinic staff. I usually joined the clinic team for lunch at a cafe over the road and I had many fruitful conversations while walking and driving around town with Clive in between clinic hours. Opportunities for non-clinic time interactions were also helped by the fact that I conducted all fieldwork over four summer periods between the UK and Australia.

The Australian clozapine clinic was quite different from the UK clinic. It was, in line with its operative circuit to be described in Chapter Two, unstructured and inconsistent, with little emphasis on clozapine patients as people per se. It ran out of a central mental health outpatient centre within a multi-story government health building, where psychiatrists, psychologists, nurses and social workers were based but few formally involved in the clozapine clinic. Clozapine consultations took place in whichever rooms were available, often delegated at the last-minute, and there was a strict divide via a security door between

the general waiting room (not specific to clozapine) and the clinic itself. To improve room availability, the clinic was under renovation processes. By the time I finished there, the waiting room had been expanded and additional consultation rooms constructed, albeit not all fitting within the initial parameters of the clinic – the doors of rooms outside of the main secure area were fitted with security codes and small ‘security’ windows. The interviews I conducted in the Australian clinic took place both inside and outside of officially ‘secure’ areas, depending on room availability.<sup>24</sup> It was hard enough for clozapine nurses to secure rooms to conduct clinical checks in; having me around was a further stretch to the resources.

While the doctors had their own rooms, to be utilised by the other staff when vacant, most of the secure area was taken up by a large communal office with multiple desks, one of which I was initially assigned to work at. I was granted password-access to a desktop computer, and, despite repeatedly explaining my ‘student researcher’ status, my security clearance tag that I wore read ‘Consultant’ (this was arbitrary, however, with small font and the tag worn face down). There was little privacy either side of the security door, and overhearing very private conversations between case workers and their clients took some getting used to on my part. Staff would talk openly with each other about their clients/patients, and these conversations sometimes carried over into more informal discussions in the staff room. Discussions about clients in the UK clinic were more discrete.

There was less camaraderie between clinical caregivers in the Australian clinic than in the UK clinic. I sometimes joined the general team for lunch, but often felt aloof and unable to engage easily with them. In my field notes, I wrote things like, ‘I feel like a fly on the wall’ (sometimes helpfully so); ‘it’s never clear what is going on but from what I can gather...’ or, ‘feeling directionless again.’ In the Australian clinic, my seldom involvement with clinical activities or opportunities for fluid movement between ‘staff’ and ‘patient’ areas meant that I spent more time merely observing the operations around me. This, of course, was important within the context of a medical clinic where nonverbal and embodied articulations are often just as critical as information given verbally (Csordas 1994; Desjarlais 1992; Jackson 1983).

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<sup>24</sup> It was never possible to reserve a room for the day in the Australian clinic, as I had been able to in the UK clinic, partly because the security protocol was highly pervious. I did not want to turn away patient participants who had often come in specially to talk with me, so I utilised whichever room I could.

I experienced, however, some disenchantment that paralleled with some of the Australian clinical caregivers' experiences. There was a high staff turnover and staff often took time off, sometimes without notifying any of the other staff, and their colleagues did not always notice. For instance, when I explained to Zoya one day that Australian nurse Kerry, with chronic health conditions of her own, was not here because she had been admitted to hospital, Zoya remarked to me how absurd it was that “no-one checks in on one another around here”; compared to what she had experienced in Africa where “everyone wants to know how each other are, but here - *nothing*.” Zoya was passionate about her work, but this quality did not seem to be appreciated in this particular clinical environment. During my fieldwork, Zoya was hospitalised following an assault by a (non-clozapine) client during a home visit. No one was surprised, because she was called upon last-minute, with only a trainee nurse to assist, and was seen by other staff, in any case, to be “too trusting”; “too warm” with clients with whom she might only see short-term. Australian nurse Callum, saddened by this incident, told me with full conviction – leg tapping, stern expression on his face and maybe even a tear in his eye – that he understands why clients get angry because “they all get let down”; because as soon as trust is built, the staff member has had to move on due to burn-out or getting relocated.

Participant observation with clinical caregivers varied within the Australian clinic. Zoya, Callum, Kerry and social worker Jill were kind and receptive to my presence when they were around, while psychiatrist Adam took an active interest in my project. We often exchanged reading material. Getting to know Adam allowed me take up a degree of genuine collegial positionality. The support I received otherwise was patchy at best. Compared to the UK clinic where there were more provisions and predictability, my interview scheduling was fraught and unwelcomed, as the below field note suggests:

*Came in at 10am - earlier than clozapine clinic starting time, to interview Myles, who didn't show. Left voicemail message for him to call me back. [Receptionist] once again said as soon as I arrived, before I had a chance to say anything, “there's no room for you.” I explained that I planned to use Ramesh's [clozapine assistant] room as the cloz [sic] clinic doesn't start for another hour. She didn't respond. Went and spoke to Ramesh who said he has to use meeting room today, rather than clinic room, so I queried him about Sandra's [psychiatrist] room as she's away this week (she'd mentioned this to me while eating lunch in the presence of everyone else last week), and he looked surprised. Chances are [the receptionist] doesn't know this either/didn't remember, because it wasn't written on the whiteboard [with daily*

*room delegations]. As Myles hadn't showed, Adam [psychiatrist], nice as ever, invited me to sit in on other consults to observe "the other stuff that is important."*

Generally, Adam's consultation room was the only room I did not feel like an imposition walking into in the Australian clinic, and we often ate our packed lunches together in there while debating the intersections between philosophy and psychiatry. Adam was the only doctor who had personalised his room, having pinned up several deconstructed Beagle dog calendars to cover the large noticeboard otherwise displaying dated 'health message' posters. We often ventured outside the building for coffees. Spending time with Adam, however, sometimes meant I missed opportunities to catch up with patients. This was largely due to the unpredictability of appointment timing and interview room availability – and me not being able to set up the same relationships with the receptionist nor lead nurse as I had benefited from doing in the UK clinic.

Unlike in the UK clinic, appointments in the Australian clinic were not scheduled aside from the general day, and the receptionist and main clozapine assistant were highly irritable and unreceptive. I felt myself to be constantly getting in the way of their operations – exemplified by the receptionists' frequent and coldly delivered remark, "there's no room [available] for you." Perhaps I was particularly sensitive to this because the UK receptionists had included me in all staff matters (social and clinical) and notified me of patient arrivals via text messages if I was elsewhere in the clinic. I did not interview receptionists in either clinic because finding the time to do so outside of clinic hours, within the clinic itself, would have been a big ask.

In the Australian clinic, if no rooms were available I used the staff 'meeting room'. Although very large, it had the distinct feel of a storeroom due to the dim light, no windows, an array of scattered furniture, dated equipment and faded posters. Aside from the lighting, this room sometimes felt like the waiting room in the UK clinic, insofar as I had to hold myself back from restoring the order of the contents. For instance, following a clozapine appointment in the meeting room with my recently recruited patient participant Keith, who had just commenced clozapine, and his caseworker, I wrote the following field note. Zoya, covering for Ramesh for a few months, had asked me to escort Keith and his caseworker into the room while she fetched something:

*The three of us were all seated waiting for Zoya, then case worker commented that this was all new – they weren't sure what was going to happen in appt [sic]. Wanting to be of some use, I explained the routine checks ... The cotton wool with blood and finger prick lancing device from previous patient was still on table in front of us and I wanted to move it but wasn't sure what my place was, or whether to draw attention to it. Keith didn't seem to mind, however. I wonder if the slightly chaotic and run-down nature of this room actually makes patients more comfortable. Zoya asked me to get Adam to write pathology request for "level 3, [pathology company]" but I couldn't find him, and I missed some of the questions Zoya was asking Keith in meantime.*

Unlike Ramesh, who went so far as to stop me from helping him to plug in the blood pressure machine one day, Zoya welcomed any small help I could provide. Yet, to participate in clinic space with Zoya meant more compromise in regard to clinic time with patients. With Ramesh, I had to make sure I was 'ready' with my field folder (containing consent forms, notebook and recording device) each time I noticed him get up from his desk, as he rarely included me otherwise. He, unlike Zoya, told me that he did not like being a nurse. Ramesh took lunch breaks regardless of whether patients were waiting, meaning it was often a rush of back-to-back check-ups in the afternoon. As well as keeping patients waiting, this truncated the opportunities for me to interview people in between check-ups because the patients who were seen first were the ones I mostly interviewed. I had more opportunities with Zoya and in the UK clinic due to more flexible and scheduled appointment times, respectively, meaning a steadier flow of patients and interview times.

### Permeable protocols

In both clinics, an ethical provision that I closely adhered to in spite of clinical shortcomings was the inclusion/exclusion criteria of patient participants.<sup>25</sup> To rule out additional participant vulnerabilities that come with younger and older age groups, all patient participants included in my study were aged 18-55 years at the time of formal consent. I also only included patients with a diagnosis of schizophrenia not schizoaffective disorder.<sup>26</sup> Distinguishing between

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<sup>25</sup> Inclusion/Exclusion criteria was contained according to all three ethics protocols approved by the Australian National University HREC (2014/420), the NHS Health Research Authority (15/WA/0151) and ACT Health HREC (ETH.9.15.166).

<sup>26</sup> To be put on clozapine, patients needed to meet the criteria for 'treatment resistant schizophrenia' whereby they had not responded to at least two alternative antipsychotics (including at least one first generation and one second-generation drug) (Lambert 2010). All diagnoses for participation in this study met the F20 criteria for schizophrenia in the ICD-10 classification manual (WHO 1993). I could have potentially applied for an amendment, to allow for inclusion of schizoaffective disorder, however by the time I realised the fluidity in diagnostics my study was already underway and, given adequate interest in the study already, I decided to utilise this diagnostic form of containment given to me, however arbitrary.

these diagnoses was mostly unfamiliar to nurse participants because clozapine monitoring did not concern diagnosis per se, and one psychiatrist even offered to change the diagnoses of some participants so that I could talk with them (I declined). Zoya shook her head in sadness one day upon checking a potential patient participants' diagnosis: "He'd be a good participant for you, he definitely has schizophrenia – it's just in this country they say schizoaffective because of stigma."<sup>27</sup> Despite my efforts to confine my research focus to that of chronic schizophrenia patients because this 'group' today receives far less attention by way of research enquiry, this issue elucidated for me the highly subjective and potentially negotiable process of psychiatric diagnostics. I later learned that, stigma aside, 'diagnostic switches are common' due to apparent symptoms providing a mere 'snapshot', which is subjectively assessed (Guloksuz & van Os 2018:237). The social influence on diagnosis is, of course, also a key impetus for dissolving the term schizophrenia into a 'psychosis continuum' (van Os et al. 2009). For the sake of making the most of the time I had in the clozapine clinics, however, I did not concern myself with the politics of diagnosis, even though such politics directly shaped who could participate in my research.

Unfortunately, there were a number of people who wished to participate but could not due to these ethical and clinical filters. It was particularly frustrating to have to exclude seven valued participants from my formal 'data' set *after* interviewing them, upon checking patient records later to discover their diagnosis was listed as schizoaffective disorder or that they were over the age of 55. To minimise this happening after these retrospective participant exclusions, the nurses involved in recruitment then had to take extra time to check through patient records for me – another source of my indebtedness to them.

Another unruly aspect of the clinical filter for recruitment was the variation in clinical judgements about how suitable patients were for participation in my research, and the extent to which staff felt a need to safeguard me as an ethnographer. I ended up with a fairly wide range of patient dispositions, albeit my audio-recording device likely dissuaded patients who felt more 'paranoid' (Martin 2009). Clinical caregivers in the UK clinic made a more concerted effort to be selective about who might be 'appropriate' patient participants, and

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<sup>27</sup> I asked how she knew this patient was not 'schizoaffective' and she said it was because he was on a high dose of clozapine and not taking mood stabilisers. Further, UK lead nurse Clive suggested that I not include the word 'schizophrenia' when explaining my study to participants, because it was "too off-putting for most patients." I contended that this would be evasive (as indeed Scheper-Hughes' (2001[1979]) ethnography had been), but perhaps given the field site it would have been less so. In any case, I found that most patients spoke to me directly about having a diagnosis of 'schizophrenia.'

were careful to ensure I knew the safety protocols and that I was never left alone in the clinic. Clinical caregivers at the Australian clinic were not as obliging, and the more chaotic, time-pressured environment made it difficult for me to clarify safety protocols. I was once forgotten about and left entirely alone in the Australian clinic while interviewing a patient in the ‘meeting room’ because staff left the premises by 5pm sharp. I finished the interview at 5.10pm. This patient, it turned out, was on parole having committed a violent crime, which he himself disclosed to me in great detail during the interview. This incident prompted awkward apologies from staff members the next day, particularly because it had occurred within 24 hours of Zoya being assaulted. I was then given a more specific explanation of security protocols and felt less burdensome asking questions to maximise my own sense of safety in the clinic.

The process of ‘handover’ from the clinical caregiver ‘recruiting’ and obtaining written consent also varied between clinics, and the limited time frames I had to work with often made the beginnings of interviews quite haphazard. In the UK, each consent form had to be signed by a clinical caregiver as well as the patient participant, to verify the appropriateness of recruitment.<sup>28</sup> While this was not necessary in the Australian clinic, marking the point at which the interview started proved challenging when patients wanted to converse with me immediately. In the Australian clinic in particular, patients would divulge information more hastily and in minutes of starting the first interview. For instance, 55-year-old Australian patient Daisy, immediately after signing the consent form, started in a defiant tone, “I don’t think I have schizophrenia though... because I got raped you see, and I lived a hard life.”<sup>29</sup> I started to ask her how old she was when- [this happened], but she intercepted quickly, “I was 14, Mum used to lick and suck us as babies but I never worried about that, because I knew how much she loved us, like such a strong mother, she brought us all the way from Africa, moved from Africa, to England and to Australia, with my family.” Daisy’s eyes became dazed; she was flustered: “*Can’t talk too fast,*” she warned me, breathing in deeply and

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<sup>28</sup> Signing consent forms was only needed for the initial interview. Ramesh (the Australian clozapine assistant nurse) remarked to me several times, however, that “patients won’t remember you.” Upon returning to the clinic after completing follow-up fieldwork in the UK where all participants had remembered me, I said to Ramesh that I thought that patients in the Australian clinic would remember me, too, to which he responded again, “no, you’ll have to remind them of your research as they won’t remember talking with you.” When Ramesh was about to begin a new job during my second field visit in the Australian clinic, I asked if he had told the patients he was leaving and he said, “some of them but they won’t know anyway.” Given the subsequent unflinching recollection of all of my participants, including those who Ramesh thought were “not worth” approaching (other staff members suggested them and recruited them for me instead), I was sceptical of Ramesh’s clinical judgement around participant ‘appropriateness’ and memory capacities.

<sup>29</sup> The differing perceptions around diagnosis itself, while noted as a barrier in other ethnographic studies on mental illness (e.g. Estroff 1991) was rarely an issue in my study, perhaps due to patients having been ‘in the system’ longer and clozapine treatment taking away the focus of their ‘mental’ illness.

quickly and then loudly exhaling. But she kept talking, bursting with words. Given my anthropological position, I wanted to give patients as much chance as possible to express what they wanted to. Daisy was a surprise participant, whom the recruiting nurse (Ramesh) approached with doubt that she would be willing to talk with me. Patients like Daisy became much easier to talk to and to be with given some time and openness on my part.

Just as I learnt to embrace the lack of structure and confronting content in conversations, where time also limited the amount of questions I could ask, I learnt that a sense of containment would always follow if I allowed patients to steer conversation. Given the dearth of conclusions about schizophrenia and the ongoing efforts of all people brought into the conversation about it, including patients' active making of 'sense' as much as their making of 'health,' it was valuable to concentrate my fieldwork in two particular spaces. Contrary to traditional ethnographic methods that aimed to lessen the subjectivity and bias of the ethnographer through psychoanalytic 'hygienics' that might 'privilege a norm of objectivity' in the ethnographer's gaze (Rabinow 2007:99), I attempted to elicit 'a mode through which interviewees [in a set place and time] could speak for themselves' (Rabinow 2007:111). This 'ethnographic present' taps into Hegel's attention to 'representation,' wherein the eminence of what was spoken in this space and time 'remains open' (Rabinow 2007:113). As I discuss throughout this thesis, different contexts and inter-subjective dynamics brought out different 'sides' to people, as would indeed be the case for anyone. Exhibiting of 'symptoms' seemed to be connected to clinical monitoring and the extent of clinical receptivity. My interpretations, like my positionality, involved careful scrutiny of what was revealed within the 'clinical present.'

### Being with participants

Given my provisional positionalities described above, my ethnographic receptivity during fieldwork is important to unpack. As Strathern (2005:10) has noted, prior to the reflexive turn in anthropology, 'The fieldworker' was a powerful portrayal of the single consumer or receptor of experience.' The postmodern ethnographer, accountable to her own multiple positionality, must grapple with how, 'the consumer's gut, alas, in the long run turns everything into flesh ... the image returns to the act of consumption which submits everything to consumerability, each event or observation being equally absorbed in that unifying pastiche, the capacity to experience' (Strathern 2005:15-16). In this way, an

ethnographer's receptiveness to participants can feed into their own experiences such that field and non-field become ultimately indistinguishable.

Anthropological receptivity, unlike clinical detachment, strives to be amenable to alternative ways of seeing and doing, open and antithetical to power relations – albeit simultaneously 'absorbing' these, too. It was entirely possible that I, limited in my inter-subjective access, was narcissistically only connecting with participant experiences that were already 'open' to exchanges of ideas with me. Inter-subjective projects of understanding between myself and my participants could not be extricated into field and non-field experiences.

UK lead nurse Clive and Australian psychiatrist Adam held me accountable to my position and helped me to find the balance between clinical detachment and personal affect. One afternoon Clive announced to me, albeit somewhat fancifully, that he was "thinking about doing something different" from working in mental health (his career of 22 years). He added, "what you're doing is very different from everyone here." I felt assured that he understood my "different" position. But I received more mixed feedback from Adam. Early in my fieldwork I wanted to know what Adam would make of how a patient participant had seemingly *changed* before my eyes – from speaking tangentially about distressing phenomena to then, after me merely 'humouring' him for some time, becoming completely coherent and calm. Adam responded that I was "inevitably becoming part of the treatment experience," whereby the "social contact people receive when they come in here is of course part of their recovery path." I thus grew cautious that I was not distinguishing my position enough. I soon learned, though, that, regardless of whether I was contributing to a "recovery path," not many clinicians were contributing to a *unified* "recovery path." Later in my fieldwork, Adam expressed exasperation about the lack of attention to therapeutic relationships in clinical practice. He said he was tired of staff "not seeing patients as humans." While I could never be entirely sure that my part in peoples' clozapine treatment experiences evoked sensitivity that was markedly 'different' from clinical interactions, I certainly took care to treat patients like I would anybody. My liminal position may have been, however, sometimes 'pathological' for being so 'open,' and ultimately inexperienced compared with the clinical company I was in.

As well as spending time with Clive in the UK clinic, I also spent time with UK nurse Narelle, who had received additional psychoanalytic training. Psychoanalytic approaches

crossed over nicely with some of my anthropological thinking. I spent many hours, either side of clinic time, talking with Narelle, sometimes extending into email conversations. She provided me with emotional support at times, and we ran different ideas past one another. I felt that we reinforced for one another that our professional ‘meaning-making’ was critical to supporting patients to find meaning – beyond clinical concerns.

I also became aware of the ways in which some of my thinking style coincided with patients. There were more explicit things, such as scrutinising clinical information. One day when I queried Clive about the ‘symptomatic’ aspect of clozapine, he quipped, “ah, this is what the patients say!” Then there was the more complex matter of me embracing the contradictions and potentialities expressed by patients during interviews, even though they did not, later, upon deeper reflection, make sense to me. As Rapport (2003:30) pointed out, however, ‘the closure of world views and the sequentiality of narratives do not necessarily translate to singularity or consistency regarding the order that is construed or conveyed either within or between such forms.’

Arguably, there is exciting potential for anthropologists to explore experiential revelations together with their participants, although the multiple, clinical considerations in the clozapine clinics came with vulnerability when venturing outside of medical frames. Enquiries into other bodily sensations and personal health beliefs and behaviours were sometimes very confusing for patient participants as they were not used to communicating these things. When I sensed we were on sensitively uncommon ground, I did try to bring conversations back to what participants had mentioned of their experiences that could be connected with previously established mutual understanding. As Lucas (2004:158) said of the workshopping of ideas between himself as an ethnographer and his participants with schizophrenia, conversational exchanges ‘drew on common, orchestrated understandings that were shared between participant and researchers because we each had a practical, working knowledge of our culture in some of its aspects.’ There was always an inroad, but the path ‘out’ was less clear.

Part of drawing boundaries was about knowing that I already had enough data to focus on, in spite of many other possible themes of interest. There were vast, macro level topics that were continually connected but beyond the limits of my enquiry. These ‘external reference points’ (Strathern 2005:16), stretching far beyond what occurred in clinical space into deep socio-political matters prompted a constant effort to ‘control’ my data (Good, Subandi &

DelVecchio Good 2007). For instance, the UK Referendum and the lead up to the 2017 USA election was far from lost on patient experiences. These happenings intensified the social fractures and inequities that patients sometimes spoke to me about, as integral parts of their delusions or else in terms of entirely warranted matters of housing security and mental health funding cuts. I thus sympathise with the many anthropologists who consider schizophrenia and its treatment by attending to social chemistries well beyond the clinic walls.

My simultaneously safeguarded and open ethnographic receptivity ultimately provoked continual self-questioning and an experiential irreconcilability. There were ‘multiple domains from which understanding could equally emerge, or recede again, into “ununderstanding”’ (Lucas 2004:160). I found that my experience of doing ethnography aligned somewhat with Stevenson’s (2014) reflexive gaze of ‘uncertainty,’ when she explored the ‘ethics of care’ among an Inuit community in the Canadian arctic. Stevenson noted her affinity with her participants in accepting circumstances where, ‘the facts falter and when things (and selves) become, even just slightly, unhinged’; where her own ‘life’ often felt ‘beside itself’ (Stevenson 2014:2). Upon starting this thesis and addressing my official ‘data,’ I conceded of how much would still be suspended and leftover somewhere, ‘unhinged,’ or in incommunicable resonances that cannot be contained beyond the implicit coming together of certain moments. This, however, became less remarkable over time, as I learnt to embrace the silent applications to wider realms of social life – but once more comfortably attuned rather than overwhelmed or protectively detached from the experiences.

### Being with data

The temporal-spatial underpinnings of my fieldwork were not only necessary for ethical safeguarding, they became instrumental to my personal and analytical boundary making. As Dalsgaard and Nielsen (2013:8;14) assert in regard to ‘episodic fieldwork,’ ethnographic insights evolve over periods of ‘being present’ long enough to become part of the field, but also being absent in order to account for the ‘event’ of being inside or outside the formal field site. Despite most of my time being spent outside the clinical setting, I of course felt continually immersed in my data.

First, doing my fieldwork in an Australian city familiar to me meant that the boundaries between field and non-field felt ironically tidier due to unfamiliar versus familiar spaces and

experiences. While in the UK, I was living in a city I had not previously visited, and where I was trying to study one aspect of unfamiliarity, while attuning my 'self' to new and separate relations between and outside the one building pertaining to my field site. In both field sites, stories concerning particular spaces outside the clinic meant that when I walked through these spaces during time that was my 'own,' I would experience these spaces in intense contrast to what I had previously. This was sometimes disturbing, if physical assaults or police arrests had occurred in places where I was otherwise going for a peaceful walk or having a picnic with friends. However, the new associations became something beyond the clinic that I could quietly and 'safely' share with patients without the physical intrusion of being there with them.

I also found that spending time with old friends and new friends outside of clinic time meant that I was more sensitive to unspoken crossovers into what would be clinically classified as 'mental illness' or 'lifestyle risk factors' for metonymical 'mental,' 'physical' and 'social' manifestations of illness. Intimate disclosures from friends and family about their own experiences became much more common, perhaps as I became more receptive or comfortable with this subject matter. It was principally useful for me to consider the striking similarities between my research participants and people who do not carry any such diagnoses. Nearly all of my social experiences during fieldwork informed my ethnographic understanding in some way, along with my own 'self' understanding (Strathern 2005). This became both enriching and personally affecting. As Strathern (2005:27) noted,

What happens 'takes place' because it happens somewhere, in the presence of others, because events become interventions, the subjectivity of different persons the issue. However, these interruptions to the self do not guarantee a return to the familiar. Rather, there is a sense of holding in one's grasp what cannot be held – of trying to make the body do more than it can do – of making a connection with others in a partial manner.

With interruptions and vague resonances everywhere, 'partial connections' emerged. Critically, my relationships with clinical staff outside of clinical operations and clinical time allowed me to think through my ideas in clinically relevant ways, and to eventually accept the practical limits of my ethnographic position and personal containment of 'data.'

About 15 months into fieldwork, the accumulative impacts of taking in others' lives into my own began to take a toll. I was noticing myself becoming more superstitious and fearful in

situations I had not otherwise been. I also became more emotional than I had felt in a long time, in spite of patients' own apparent disconnection from hardships and the feeling of hope that persisted everywhere else. I found it difficult to separate 'clinic time' from my personal life outside of it, because I was largely processing my field experiences in non-clinic hours when it was more appropriate for me to do so. Of the conversations Clive and I would have during *non-clinic* hours, Clive commented, "the areas we visit when we talk leave me feeling like we have gone into the deeper context, but we clinicians can't afford to go there because symptom management and looking after ourselves must be a priority." I did not have such priorities, yet Clive was adamant that I should still reach out to him. I wrote this field note one evening having returned from an informal meeting with him, on a non-clinic day:

*I met Clive for a drink. Let myself cry as we spoke. Explained that I find it conflicting to reach out because he is ultimately a participant in my study too. He said this was "crazy" because, "it's like saying 'go into a war zone and you're not allowed to join anyone in a team.'" He reiterated that I was like his sister now and that I must call him to debrief about anything, any time. Very grateful.*

Perhaps like patients who spoke to me of their troubles only occurring outside of the clozapine clinic – how, for instance, their (hallucinatory) 'voices' would be waiting outside, talking or tormenting them and causing panic attacks on the walk home, while 'chest pains' would be felt in quiet moments when one was on their own – it was mainly *outside* clinical spaces that I *felt* myself to be personally affected.

Doing anthropology, Ingold (2014:288;389) suggested, is making an 'ontological commitment' no matter the 'considerable existential risk' to the anthropologist. Participant observation, Ingold posited, 'is to join in correspondence with those with whom we learn or among whom we study, in a movement that goes forward rather than back in time' (2014:390). I was, vicariously or inherently (through my methodology), exposed to some 'trauma' that patient participants embodied, as well as their own attitudes that were in line with the 'forward' moving nature of ethnographic practice. I kept looking ahead, until it was no longer sustainable for me to do so. In leaving the field, I had to focus on what *had been*. At an academic conference around this time, a UK journalist had a word to my senior colleague that he should "check in" with me because I seemed "emotionally stretched." He said that this was something he recognised from his journalist colleagues suffering from "PTSD" [post-traumatic stress disorder] who "cannot find their feet after returning from areas

of conflict.” I initially thought such a comparison was highly distasteful – I had *not* been working in a war zone, and I had begun to feel indulgent when any focus was taken away from the experiences of patients who were all surviving (and not complaining about) substantiated and often ill-recognised traumas of their own. But this was how many of my patient participants’ much more significant traumas had also been dismissed – continual dismissals, and guilt, over many years. I subsequently allowed myself to feel flooded in what I can only describe as a displaced grief. It took me many months to feel ‘in control’ of my ‘data’ again, without the overwhelming conflict of deeply personal connections and a protective estrangement from it all. These experiences, however, inadvertently helped me to relate even further with many of my participants.

Of course, the act of comparing experiences that deciphered yet blended ‘fieldwork’ and my respective positions before, within and beyond my being there, pertained simply to ‘one of the ways anthropologists create complexities for themselves, and thus their sense of having to get things into proportion’ (Strathern 2005:108). Although ostensibly practicing multi-sited ethnography situated in two specific field sites, in the end my ‘data’ was drawn from what Dalsgaard & Nielsen (2013:6) term ‘temporal sites’: ‘a confluence of different times and temporalities, [which] emerges rather as a dynamic force of becoming that shifts in intensity and clarity, depending on the ethnographer’s immediate position and immersion.’ Realising that my own experiences of containing and connecting data was a matter of incorporating the sense of ‘unfinishedness’ (Biehl & Locke 2010:320) that my research participants also illuminated for me, was critical to me ‘trying to find my feet in all sorts of places’ (Geertz 2005:135). This ethnographic phenomenon is not unique to ethnographic studies of mental illness (Good, Subandi and DelViechchio Good 2007), and Jenkins (2015) attention to ‘precarity’ rather than mere vulnerability in these contexts, was indeed a useful lens to apply. Yet my ethnographic observations and experiences were also not specific to my fieldwork context.

Contemplating what it meant to try to contain and connect experiences during fieldwork left me, like my participants, with a sense of continual openness that need *not* be reduced to experiences of illness. Rapport (2003:66) posited that, ‘efforts at social-structural containment, reducing phenomena to contextualizing (and collectivizing) frameworks, have a fearfulness and inflexibility about them: a shying away from the original, the random, the limitless, the individual, and from taking creative responsibility for these.’ To take ‘creative

responsibility’ (Rapport 2003:66) for how ethnographic interpretations are contingent upon irreducible factors, meant attending to things as only temporally, partially embodied or connected or containable. Just as being with people who have schizophrenia can induce a ‘praecox feeling’ (see Sass 2014) of simultaneous connection and disconnection that in moments did indeed feel ‘extraordinary’ (Jenkins 2015), it was also, for me, the commonplace experiences that stayed with me beyond the intensity of fieldwork, and from which I have grounded my subsequent analysis. My receding from the more sensational aspects enabled me to understand how clozapine-treated schizophrenia patients make their ‘health’ in ways that are not specific to their diagnostic conditions.

### Health agency

*Individuals interpret their own oppression, just as they do their freedom.*

– Rapport (2003:84).

On the face of it, people with clozapine-treated schizophrenia face significant barriers to their sense of control over their lives and their ‘health.’ The clozapine clinics in this thesis only intended to focus on ‘mental’ and ‘physical’ aspects of patients’ health. Patients, however, reconnected their own *social* and personal meanings of health. As I have suggested above, ways in which patients did this became understandable to me as I embraced how contradictions do not forestall meaning-making. Rapport’s (2003) existential framework for understanding how people make their own meanings out of their circumstances builds on Friedrich Nietzsche’s philosophy of ‘will-to-power’:

For what Nietzsche wished to convey, particularly in the phrase ‘will to power,’ was that intrinsic to the person is the possibility, even the proclivity, of a self-becoming which amounted to a continuous self-overcoming. Rooted inside the individual was the power to create selves, and perspectives looking out from those selves upon the world, and to keep recreating these ... Nietzsche (like Sartre after him) sought to portray an appreciating of individual lives as continually evolving, developing, growing: of the essence of identities changing even as the energy, the creativity and the will that was foundational of individual existence remained the same. (Rapport 2003:35)

Continuous ‘self-overcoming’ is, arguably, particularly critical for people with schizophrenia (Sass & Parnas 2003). Yet the sense of ‘will to power’ can easily be overlooked, because of what appear to be conditions of incapacity – either because of residual symptoms appearing to wrangle control over one’s behaviours, or clozapine side effects defining one’s livelihood. Indeed, Australian nurse Ramesh had very low expectations for patients’ abilities to even

partake in my study. Yet, ways in which patients exerted hope and control *through* their circumstances suggested a personal power to keep reformulating and prospering in very subtle ways.

Admittedly, I was at first struck by how optimistic and resilient many patients seemed. Australian psychiatrist Adam also commented to me one day how patients often reported feeling “great” even when he observed their lives to be, “objectively, less than ideal.” Patients talked very casually to me about things that had occurred in their lives that, only later, when I was listening to interview recordings, would bring me to tears. The marker that, from an outsider’s perspectives, could override concerns about a patient’s ‘mental’ and ‘physical’ health was whether or not they appeared to have ‘real’ social support.

What ‘real’ social support meant, though, was ultimately up to patients. While receiving ‘attention from others’ is critical to one’s experience of a ‘social self’ (Aylwin 1985), this attention just needed to be controllable to some degree. Australian patient Daisy, mentioned above, spoke to me and clinical caregivers about her “eleven children,” whose existence I could not verify. Daisy told me that she spent most of her days “forgiving” and “praying” for her family and also the doctors in the clinic, even those whom she felt misunderstood her. Australian social worker Jill, who observed Daisy frequently brushing her hair, once tried to gift her some hair product, but knew she would have to pretend it was not a gift she had actually sought out:

I said, ‘Look, I was given this as a free sample, I don’t suppose you want it do you?’ And she’s like, ‘ohh...errr... oh, alright then.’ She was being nice, because they don’t want to upset you. They’re mistrusting but at the same time they want people to like them, because they’ve been abused, you know, all that stuff ... six or eight weeks later, she says, ‘Jill, I hope you don’t mind, but I’m not going to use this, or it’s the wrong type, or...’ She gave it back to me. Because she thought – I’m pretty sure, this is my surmising – that I wanted something from her.

For Daisy and many other patients, the predictable social world provided by clinical caregivers vis-à-vis clozapine treatment was sufficient to build upon, such that to introduce unexpected communications could compromise their sense of control. Unspoken elements to interactions between patients and clinical caregivers left more room for interpretation. Jill Continued,

I've lived on my own a lot, and I know how dark... I suffered from depression... always have, [be]cause I've had a bit of a... childhood... that's why I get on with... I understand... these people have helped me through my thing, I'll tell you that. [Be]cause I've seen people, and think, 'my God, that's *me*' ... But loneliness is so normal ... she [Daisy] does some crazy things just out of loneliness, not just out of being schizophrenic. She is desperately lonely.

Daisy, meanwhile, told me that she appreciated Jill because "she doesn't... talk about being *better* than me or be-, doing things more powerfully or living *more* than me, [be]cause I like to feel that I'm in control, that I'm not running away." Australian nurse Ramesh, on the other hand, was "too powerful" for her; Daisy would often run out of appointments with him before he had finished going through the clinical checks. I am not convinced that patients like Daisy felt themselves to be 'desperately lonely,' so long as she was doing things to improve her well-being in the immediate sense (as I explain further in Chapter Three), and to shape social interactions on her own terms. The thread that ran throughout all patients' sense of their health as part of managing specific 'parts' and contradictions of it was a re-construable 'social' constituent – regardless of whether their 'mental' or 'physical' health was clinically in check.

Rapport (2003:261) described how embedded in Nietzsche's 'will-to-power' was the idea that people do things with 'in order to' rather than 'because' motives: with 'an intentional and embodied consciousness in the process of meaning making' rather than with 'power external to that embodied consciousness.' Arguably, this applies to how patients imagined their health and their potentiality in the world, as a person among others whose unhelpful powers could be overcome. People worked 'in order to' unite with or overcome the perceived powers of others – as UK patient Christopher, quoted in the opening of this chapter, indicated in his "striving for everyone to be on the same page."

Health agency is intrinsically tied into a sense of having a control and power to carry oneself forward in one's social environment. All individuals have 'energy and momentum' such that external forces become 'dependent upon the forcefulness with which that life was prosecuted' (Rapport 2003:7). Although 'social defeat' is seen to be a critical cause and consequence of schizophrenia in Western societies (Luhmann 2007; Luhmann & Marrow 2016), an all-pervasive social defeat is not what I observed in the clozapine clinic, no matter how much patients' lives may have previously been defined by social defeat. The term 'social

defeat' is not symbolic or structural; it refers to an embodied, physiological defeat resulting from circumstances 'when individuals have repeated social interactions in which they subjectively experience failure,' from 'another person who demeans them, humiliates them, subordinates them' (Luhrmann 2007:152). Luhrmann and Marrow (2016) suggest how, for people with schizophrenia now registered in government mental health systems, ongoing social defeat can be minimised through modest non-pharmaceutical means. Namely, through secure housing and therapies that create meaning out of voices (if occurring), along with 'active social engagement' between patient and treatment teams that is fundamentally 'open' in terms of symptom interpretation and treatment decisions (Luhrmann & Marrow 2016:217-220). For clozapine-treated schizophrenia patients, these counteractants to social defeat are, to some degree, more available than in other treatment environments. While most patients lived in tenuous public housing that could be improved upon, no one I met was currently homeless (some had been in the past). Moreover, patients could make new meanings out of their health and their 'social' health that was not under demand at all. Although some patients like Daisy actively negotiated interactions with clinical caregivers, such that she could feel "in control, that I'm not running away," some patients could also reclaim meanings for their own sense of social connection in the form of their residual hallucinations and delusions.

Even when considering circumstances where 'delusions' and 'hallucinations' persist, I still found health agency to persist through a negotiating of imagined relationships.<sup>30</sup> Delusions may 'correspond to an inter-subjective situation bereft of the basic trust that could help to restore a consensual understanding of the situation and to co-constitute a shared, commonsensical reality' (Fuchs 2015:179). Hallucinations, meanwhile, refer to more temporal, sensory perceptions of 'others' as distinct from the self. Sacks (2012:289) described hallucinations as the feeling that there is 'somebody there'; a 'presence' and 'shadow person' with 'intentionality or agency which either raises the hair on our neck or produces a sweet, calm feeling of being protected, not alone.' Lovell (2007:335) found that among homeless people with schizophrenia in New York City, 'even delusional discourse reveals itself to be profoundly political, not simply because it condemns or reflects existing inequities and forms of domination and exclusion but because it projects possible moral worlds.' I observed clozapine-treated schizophrenia patients to experience Lovell's (2007)

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<sup>30</sup> This was not uncommon but clozapine patients rarely experience 'florid' psychotic states or 'episodes' while taking the drug regularly; one of the central clinical outcomes of clozapine is that patients rarely return to inpatient psychiatric wards (readmission to hospital is more likely to be for their 'physical' health).

notion of ‘moral agency’ in spite of their persistent ‘delusional’ and ‘hallucinatory’ presences. For instance, there was UK patient Alex, 48, a clinically categorized ‘clozapine resistant schizophrenia patient.’

Alex had been “fighting off” the presence of “Suey people”<sup>31</sup> for many years. The “Sueys” mainly visited Alex when he was alone. They did not to come into the clinic with him, in part “[be]cause they’re all American, so they’re all asleep now.” The Suey people would “come and go as they please,” giving a “childish” taunting of “ner ner ner, ha ha ha,” and “pushing and shoving” into Alex. When “walking through town, I’ll feel their fingernails,” Alex recounted. Of central import was that, “they *cannot* be trusted around children.” While sitting in the clinic together one day, Alex began,

Alex: The Suey people have been torturing their children... I witness that. Oh, that’s upsetting - that makes me *fuming*

JB: [cautiously] How do they torture them?

Alex: With their fingernails, and gettin’ inside ‘em, and hurtin’ ‘em.

JB: Do you feel powerless?

Alex: No, I fight ‘em; if I keep fightin’ ‘em, things can only get better and better and better. There is, I can see, an end to it.

[pause]

JB: And what would that end be?

Alex: Their destruction... their destruction.

JB: How do you think that would be achieved?

Alex: Doing what we’re doing now. They attack me, I fight ‘em back, hospitalise ‘em, perhaps they won’t do it again... If you hit somebody hard enough, they’re not gonna hurt you again, are they?

Talking about the Suey people, and being in the clinic, was another way of combatting them. During a later interview, when Alex and I had established more rapport, he described their assaults as “tantamount to sadistic paedophilia.” Alex had concerned himself with this social ill to focus on and “fight.” When I interviewed Alex the following year, his psychiatrist had taken him off an additional antipsychotic drug (aripiprazole, prescribed to augment clozapine), because Alex did not feel it had made any difference. Alex pointed out that, “on the plus side, they [the Sueys] won’t be around in future to mess up children’s lives and what not... if I’m saving 20 or 30 kids - it’s still a lot, you know.”

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<sup>31</sup> Suey is “the plural for pigs,” Alex explained to me.

While giving him grief, I believe Alex's preoccupation with the Suey people also gave him a sense of 'self-becoming' and 'self-overcoming' (Rapport 2003:35). He suggested to me at times during our conversations, although never quite confirming it, that he had been sexually abused as a child. "I'll *loathe* them for the rest of my life," Alex said of the Sueys. In terms of dealing with them, he surmised, "I'll have to do it on my own accord." Alex would crinkle his nose and look up at me in between talking, searching for clarification if I had understood him. He wore thick-lensed glasses that magnified his wide-open eyes that did not seem to smile with his mouth, often open ajar.<sup>32</sup> It sometimes felt like we were having conference meetings about what to do about the Sueys; it was all very serious to Alex and I took it seriously too. Alex told me, however, that "there's nothing you can do to help... unless you wanna kill a couple of them". On one occasion, he generously offered me a sip of his guava energy drink, which he had been gulping down quickly to refuel himself on a hot summer's day (I politely declined). He dressed with hints of what he might have worn thirty or forty years ago mixed with what he asserted and protected himself with now: loudly coloured board shorts, often a patriotic Union Jack singlet, a heavy denim jacket ("because of the pockets" and it was "comfortable enough"), thickly soled lace up boots and a large, full backpack.<sup>33</sup> I saw in him several personas: a generous child, a searching adolescent, and a frustrated but gracious middle-aged man, depending on the context of our conversation - and who else we were talking about.

When I had first asked Alex what "health" meant to him, he said, "not feeling upset, cynical," or "scared" toward other people. When I put his words to him a year later, Alex simply responded, resolutely, "I'm not frightened of them anymore ... I remember throughout my childhood I'd been running away from them all the time because I felt frightened. It was *their* fear, up there [he pointed upwards], I wasn't frightened at all, it was just *them*." With his potential to "fight off the Sueys", Alex also felt strong enough in his present and future capacities to deal with any 'physical health' concerns as they might arise.

Alex enjoyed smoking cigarettes and reflected that "the foregone conclusion [of life] is death," although he felt "a bit manic on the cancer front." He conceded that he was

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<sup>32</sup> Many participants exhibited a loosely opened mouth, sometimes drooling, a common side effect of clozapine. Misleadingly, this suggested a carelessness in expression, which I found to be juxtaposed by expressions of *care* in regard to less clinical topics of conversation.

<sup>33</sup> Heavy shoes and jackets, along with back-packs were common accessories for patient participants, for protective layering and practical commuting purposes.

“poisoning” himself “over a long period of time” with “alcohol, tobacco.” He said that his throat “doesn’t feel right,” so he had been “checking” it “every day.” However, the feeling “just comes and goes,” so he could not be sure. He said he would only quit smoking if he got cancer, but his reasons for this would not have been obvious without the context of his social life – when I asked him how he would react if he got cancer, Alex replied,

Alex: That’d scare the life out of me

JB: Why?

Alex: Being given 6 months to live, when the Suey people are *nearly* annihilated...

[shaking his head, agitated again]

JB: So, you want to live long enough to see the end of them?

Alex: I want another 30 years, yeah

JB: So, you can fight them off, completely-

Alex: Yep

JB: Because if you died, in the next couple of years, you wouldn’t be able to see them off?

Alex: Nope.

JB: So, in a way, they’re kind of your *mission* in life?

Alex: Uhuh

JB: Their extinction?

Alex: Yeah, their extinction, yeah... yep, their extinction is my... *task*.

Feeling that he could take on the Suey people to protect other children (and perhaps salvage his own childhood somehow), had become central to Alex’s life “task.” Defeat from an early death would come from not being able to outlive the Suey people, who he felt were now “*nearly* annihilated.”

The pursuit of doing or fighting *something* towards unknowable ends, accompanied by a presumption that Alex, by his own means, is gradually poisoning himself but checking for signs of death every day, indicates a sense self-efficacy and purpose: a ‘life-project’ of sorts.

In Rapport’s (2003:5) terms:

[I]ndividuals who see their lives in terms of the pursuit of a certain life-project, who see the meaning of their lives significantly in terms of the achievement of a particular goal or goals, can succeed in giving their actions a certain robustness, power and independence such that they escape the influence of external forces and of other individuals who might have wished to direct them in other ways. ‘Control,’ I understand, then, as extending both the ‘objectivity’ and the ‘subjectivity’ of meanings or interpretations.

Life-projects for all clozapine patients revolved around socially oriented ‘control’ as part of managing their overall health. At the other end of the spectrum from Alex were ‘good outcomes on clozapine’ patients, such as UK patient Martin (described in the Introduction) and UK patient Joanne, 53.

Joanne epitomised what it meant to continually strive for connections and feelings of control over one’s future. Joanne, despite having just ridden her bike, gone for a swim and picked up groceries for family or friends on the way in, was always neatly presented, with delicate accessories. She carried more shopping bags than seemed comfortable to manage, and this was analogous to her general determination to “keep going” in the face of challenges. Joanne now understood the “voices” she once heard, linked to her first suicide attempt, to be “negative thoughts” from her mother (who “found it very difficult to let go of me”) and her “bossy” older sister. Joanne explained, “if I *don’t* think I can challenge my thoughts and try and work with them, if I let this be voices then I’m almost, I’m giving up, I’m *saying* that there are things that I can’t control.” Having once worried that she could not think for herself, Joanne had continually “*challenged* that ... in order to get stronger ... get more confident in myself.” When Joanne experienced the thoughts that were critical of her, she reminded herself to:

Think ‘thank you, that’s not nice’ ... there’s no reason why I can’t be as good or as kind as anyone else who tries to be... so if they come back now, I can identify them as being influences from my mum and my sister ... which hasn’t been positive, and therefore, I don’t want to think about it, thank you very much!

Joanne reflected, “I think I *can* say I’m thankful for what’s happened, I don’t want to go back and relive it, but I’m not going to, but I have to think it’s right to learn from the past, and I have to keep learning.” Joanne still saw her family because “we need to accept each other,” but surmised that so long as “there’s no kind of *power* dynamic” with the people she is in the company of (family, friends or work colleagues), she could “keep up with” those whom she cared about.

By the time of our last interview, Joanne had decided that “it’s giving *up* control, that’s important,” while also “being assertive.” She said, “I’ve still got my basic, *disposition*, whatever, you know, I’ve still got schizophrenia,” but was now “having the courage to say something, even though it’s very uncomfy” when in the presence of others whom she found

difficult to be with. She concluded, “People you know stay with you, and if you can keep those positive memories then you're lucky ... in the past I've majored on loss and relationships which weren't there, and now, I just don't care about those, I just live in the present, with the people I've got ... a framework of relationships, keeps me going forward.”

While these insights were gathered inside the clinic, and mostly pertained to life outside the clinic, the following chapters show how the clozapine clinic regimen itself, as a biological and social enterprise, complemented patients' sense of vitality; that their lives were ‘continually evolving, developing, growing’ (Rapport 2003:35). In spite of significant reasons for clozapine patients to feel oppressed, I observed patients instead to embody hope and control in making or imagining their own health. Health agency, in sum, refers to the personal power felt by patients to exert a sense of control, however fleeting, that is contingent upon but not determined by one's social circumstances – including how different aspects of health are clinically rendered and worked upon. Meanings of ‘health’ were made through a “framework of relationships,” as Joanne put it, commanded by patients themselves.

## Conclusion

This chapter has mapped out my ethnographic endeavours involving my own partialities, partial truth-making with participants, and how I located health agency as something personal but also socially embedded, and orientated, despite how the lives of clozapine-treated schizophrenia patients might sometimes appear. There were of course contradictions, but these contradictions can be as useful as they are delimiting. As I expand on throughout this thesis, the clinical prioritising of dualistic ‘physical’/‘mental’ health matters did not preclude capacities for connection-making and imaginings for a more holistic experience of health.

I did not observe clozapine-treated schizophrenia to be a story of oppression or defeat, even when clinical caregivers could only provide a baseline of physiological checks with seldom expectations for patients' competency. There was a persistently *hopeful* power to be appreciated; a ‘will-to-power’ toward health. As I now turn to illuminate more specific forms of health agency that I found in the clozapine regimen, beginning with the blood monitoring, I reify a request from Rapport: *‘I ask an indulgence of the reader, then: to entertain the possible truth, the viability of the version of the world, which sees the individual as gaining control over his or her life through the composing and living-out of a certain life-project’*

(2003: 12, original emphasis). If we substitute ‘life’ with ‘health,’ this is what I would ask readers of this thesis to do also.

## Chapter Two: Blood Work

*Moral activities do not restrict themselves to talk, to verbal exchanges. They also come in physical forms ... in the logic of care the action moves around.*

– Mol (2008: 87, 92).

*External forms impinge on the individual's life-world, but there is no necessary, direct, singular or essential effect that they have within it.* – Rapport (2003: 259)

In further problematising notions of objective truths in clozapine-treated schizophrenia, or enduring compartmentalisations and connections when considering the condition ethnographically (Chapter One), this chapter attends to the taken-for-granted matter of clozapine blood work. Clozapine blood monitoring is the most clinically distinctive, temporally containable aspect of treatment monitoring to which the clinic and patients are accountable. As UK pharmacist Ros summarised, “the bleeding and the tablets” comprise the baseline “clozapine activities” of clozapine clinics. While clozapine tablets are prescribed by those with psychiatric authority, the ultimate decision to dispense them month-to-month depends on the entire clinical circuitry, including patients. Over the course of my fieldwork, it became clear to me that the significance of blood ran through not only ostensibly objective checkpoints, blood work often marked clinical relations, individual interpretations of clozapine and agentic practices.

This chapter argues that, despite being the most ‘objective’ aspect of clozapine treatment, patients creatively manipulate the blood work they are subjected to, without merely resisting clinical principles in order to experience their healthy agency. Blood literally and symbolically circulates and connects all parties involved in clozapine treatment. Blood work, in every sense, legitimises the temporal prioritising of what is continually ‘at stake’ (Kleinman 2006). The continuation of clozapine first and foremost depends on blood levels. As the opening quote by Mol (2008:92) asserts, deciphering the active role of the patient versus that of the clinical carer in medical treatments is irreducible as it ‘moves around.’ In exploring ‘the logic of care’ as a question of ‘what to do and how to do it’ (Mol 2008:26), Mol (2008:26;95) positioned diabetes patients as ‘not a target group, but crucial members of the care team,’ who ‘need to actively take their care into their own hands and yet to let go of whatever it is they cannot tame.’ Clozapine-treated schizophrenia patients make for no exception to this logic of care. Just as their active participation in clinical care moves around, so, too, do the boundaries of what can be worked with in terms of achieving desired blood

test results. Further, blood ‘flow’ configurations were actively drawn on by participants to assert control and to emphasise the fluidity of health and illness statuses. The metaphorical fluidity of blood also accords with patient experiences of negotiating clozapine-treated schizophrenia as a continual effort to maintain livelihood.

The significance of blood has not yet been ethnographically attended to in the context of treatments for chronic schizophrenia. Jenkins (2015:95) posited that ‘treatment that is primarily or exclusively biomedical, focusing on symptoms and psychotropic medications, is not only reductive but also counterproductive in that it fails to acknowledge and support an active struggle in which persons have the capacity to develop strategies for living.’ It is, she suggested, the combined themes of ‘bodily sensation, toxicity, clarity and velocity of thought, balance, control, discipline, identity, normality, and daily life,’ that depict ‘an existential totality weaving together interrelated levels of meaning and experience’ (Jenkins 2015:58). While Jenkins’ ethnography found these themes beyond the clinical setting and clozapine, I observed these themes happening inside the clozapine treatment setting itself.

Contrary to what I might have expected, the biologically focused clozapine clinic regimen in my study still provided much for patients to work with. Jenkins developed an argument for her participants’ agency as ‘an active process of struggle’ and ‘endurance despite distress’ (Jenkins 2015:95). Jenkins (2015:266) footnotes that her explications for patients’ navigation of ‘suffering’ intends to cover ‘resiliency, resistance, creativity and agency’; to bridge ‘the concrete experience and raw existence of human beings with broader social, cultural, and political economic forces and conditions.’ What I wish to add to Jenkins’ work is the material available for personal refashioning *during* the ostensibly micro-level, objective, biomedical clozapine treatment monitoring itself. While the notion of agency being an ‘active process’ resonates considerably with my own ethnographic findings, I also found that patients exhibited creativity that began at the level of the blood work regimen, as patients operated imaginatively in between the folds of struggle or resistance to this part of their treatment.

This chapter thus builds on Jenkins’ (2015:63) brief observation that the ‘interiorization of the clinic’ was a ‘final relational quality of medication,’ here examining how government-funded clozapine clinic monitoring in the UK and Australia become a central relational aspect of treatment. Jenkins described the privately funded US clinic in her study as ‘a kind of societal embodiment that involved not only the ingestion of medication but also the

incorporation of the clinical ideology as transmitted by doctors, other services providers, and the myriad social actors who claim moral and working knowledge of mental illness and its treatment' (2015:63). When reflecting on the notion of clozapine (and other atypical antipsychotics) as a 'pharmacotherapy,' though, Jenkins concludes:

[T]he term *pharmacotherapy* is widely employed *as if* prescribing psychotropic medication were on a par with psychotherapy. While clearly symptoms must be elicited and monitored and prescriptions must be called in to pharmacies, what happens as a social matter of engagement when you have a "therapy" and there's no one to interact with? Not much, if the pharmaceutical imaginary has been transduced by the social/relational quality of psychotropic medications evident in the data we obtained. (2015:64, original emphasis)

While I agree that clozapine treatment is not comparable to psychotherapy, Jenkins' observation that there is 'not much' that 'happens as a matter of social engagement' is not what I observed in the clozapine clinic spaces described in this thesis. What is more, compared to the inclusion of 'group therapy' in the treatment circuit available in the clozapine clinic included in Jenkins' study (2015:32), the clozapine clinics I observed offered *only* biologically-focused treatment registers. Yet, to claim that 'there's no one to interact with' during the regular monitoring undertaken with clinical staff, and that treatment experiences are only nested in wider cultural imageries of the drug itself misses the powerful relations and imageries evoked, circulated and tinkered with during even the most 'reductive' aspects of clozapine treatment monitoring: the various types of blood work.

Clozapine patients require, at minimum, blood monitoring every 28 days, to check that white blood cell count has not been reduced by clozapine enough to make patients vulnerable to infections, which can become fatal. Clozapine can only be prescribed on a month-to-month basis for this reason. I first explore the clinical circuitries involved in blood monitoring, blood work as a benign social contact, and then the extensiveness of blood markers in clozapine treatment, before turning to how patient participants took an active and creative role in their blood tests that drew on rather than resisted clinical frameworks. In doing so, I pick up on Rapport's (2003) claims to how all human agents can make confining circumstances their own. It will be seen how, just as blood symbolises life whereby the 'quality' of it and the rhythm of it travelling through the body is construed to be a key determinant of health or illness (Scheper-Hughes & Lock 1987:18), applicable to anyone,

blood is also a substance that can be enacted upon beyond clinical delineations of ‘blood work,’ speaking to Mol’s (2008) ‘logic of care.’

### Clinic circuitries

Clozapine treatment introduces multiple and mechanical registers to clinical psychiatry, as ‘physical’ symptoms and bodily measurements are assessed more precisely and less subjectively than cognitive functions. Ironically, this corporeal focus could be looped back to the time when ‘mental’ illnesses were first pathologised under Hippocratic medicine’s attention to bodily networks of blood and nerves (Porter 2002). If schizophrenia could be pathologically located today, it would be via brain scans illuminated by cerebral blood flow and cerebrospinal fluid or via ‘biomarkers’ within blood (Rose & Abi-Rached 2013). In lieu of biomarkers, the blood work attached to clozapine makes it as unique as its apparent efficacy in alleviating psychiatric symptoms.

Australian nurse and clozapine coordinator Kerry, who described clozapine as “the best drug” for schizophrenia because “everyone responds well,” albeit “everyone responds to clozapine differently,” pointed out that: “all the other antipsychotics can have the same group of side effects as the clozapine – the major ones being the blood disorders and cardiac problems – but the clozapine people are very lucky that the monitoring that goes with it watches all those sort of things, so that, you know, it’s the safest drug for them to be on.” This clinical assurance was not lost on patients. Australian patient Charlie, 35, said that when you take clozapine “you’re secure, and they [doctors] feel confident in you, and if you don’t take the medication, you don’t get all that.” The monthly blood tests and clozapine visits increase this confidence and also reduce the sense of dealing with bewildering medical emergencies otherwise experienced in psychiatry. UK psychiatrist Kate suggested she was drawn to chronic schizophrenia and clozapine treatment because “I just sort of realized I liked the *slow stream*,” as opposed to “*acute psychiatry*.” Moreover, the slow stream of clozapine treatment was connected only through the blood work, which extended to much wider ranging bodily networks as well as clinical networks that could speed up in their connections depending on specific needs associated with the administration of clozapine rather than with schizophrenia more broadly.

Clozapine clinics encompass a mixed treatment register of heavily regimented physiological monitoring of the ‘vital signs’ in the body, alongside ‘mental state examinations.’ Phlebotomists, pharmacy technicians, pharmacists, nurses, psychiatrists and official clozapine haematologists form the main orchestra of clozapine licensed clinical registries, while General Practitioners (GPs), cardiologists, dieticians and support workers are often called upon too. This assortment of treatment registers comprises the main way in which clinical membership is more about what it means to be a ‘clozapine patient’ rather than a schizophrenia patient.

In the clozapine clinics involved in my study, what it meant to be a clozapine patient depended on the treatment register concerned at each point in the monitoring circuit. Having no previous exposure to anthropology, UK lead nurse Clive said that he found my ethnographic attention to the “whole” range of happenings within the clozapine clinic curious because “usually researchers are only interested in one aspect of treatment.” Meanwhile, Australian psychiatrist Adam reflected to me one day, “medicine is ideally about listening to a piece of music as a whole, while academics study the notes, but it is questionable whether all notes need to be studied individually.”<sup>34</sup> Attending to matters in turn was, however, the clinical approach in clozapine clinics. Clive, who experienced all clinical aspects of clozapine (from phlebotomy to psychopharmacology to social work and ‘mental health’ assessments, both inside the clinic and in people’s homes) said that despite awareness of the entire orchestra, he deliberately kept his focus specific to one treatment area at a time - “otherwise I’ll be all over the place.” Clive was an exception in his ability to move from one clinical task to the next, but the order of tasks depended on the patient. Priorities generally depended on the patient, the staff member available, and while blood work was the first checkpoint in terms of biomedical testing, I did not observe clozapine patients being attended to according to a ‘biological trajectory, a linear progression’ of clinical points on a checklist (Warin 2010:43). Checklists were neither consistent nor ordered – *except* for the baseline certification of blood counts.

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<sup>34</sup> Kleinman (2012:182) has noted this pressure within the practice of biomedicine, generally, and I have discussed the practicality of clinical compartmentalisations in Chapter One, as well as for psychiatrists involved in clozapine treatment (see Brown & Dennis 2017). Earlier on in my fieldwork in the UK clinic, I chatted to a psychiatric registrar about her research on ‘QT intervals’ in cardiac function in clozapine patients and was struck by the breadth of detail in this specific area of enquiry, such that when we subsequently spoke of clozapine without such a focus point the conversation opened up in ways that felt difficult to tame or close. During my follow up in fieldwork in the UK clinic, a visiting American neuroscience student spoke to me about the dilemmas of the de-contextualised ‘brain,’ remarking how neuroscientists get “lost” as soon as they step back from the focus point (such as a neurotransmitter receptor); prompting us both to further understand the difficulty in addressing matters holistically, and why people like to stick to their specialty ‘area’ rather than risk ‘getting lost.’

Even though the broader plan is to stay on clozapine as long as possible, blood monitoring means that patient and clinical caregivers can only afford to approach the regimen on a provisional basis. Blood work constitutes a more nuanced and short-term ‘treatment plan’; where the ‘various frames — biomedical, psychiatric, organizational, and bureaucratic — exist at different levels of awareness for frontline providers’ (Brodwin 2011:190). While Brodwin (2013:91) applied a Foucauldian lens to general community psychiatric treatment plans such that clients are ‘disciplined according to professional norms and set on the recommended path toward better health and independence,’ the clozapine clinic apparatus and blood work component mean that treatment ‘goals’ were highly conditional. All is dependent on the blood work. Brodwin (2013:95) noted that ‘the technology of treatment planning demands that the team distill people’s complex lives into discrete problems amenable to clinical tools at hand,’ which creates immediate shortfalls, however blood work creates micro-focus-points. What is more, perhaps because of its biomedical reducibility, the blood work of clozapine treatment monitoring was not a source of ‘medical futility’ insofar as clinical caregivers and clients did not get ‘stuck’ in what might otherwise be a dearth of ‘objective possibilities for action’ in the ‘therapeutic time’ found in community psychiatric treatments settings, where the main power lies with the prescription pad (Brodwin 2011). Prescribing clozapine, while it did have its role (Chapter Three), it could only be done *after* blood counts were certified.

Blood counts are the primary physiological markers that determine, month to month, whether clozapine can be continued, based on signs of infection (low white blood cell count), ‘therapeutic’ dose certification, clozapine toxicity, and patient compliance (plasma levels as evidence of consumption). Blood results are entered into national online databases, which also distribute clozapine monitoring guidelines.<sup>35</sup> Clozapine blood results are coded like traffic light colours: ‘green’ to signify safe to continue; ‘amber’ to signify the need to investigate (and re-test) before continuing cautiously; ‘red’ to indicate immediate cessation of clozapine until white blood cell counts raise to produce ‘green’ readings. Red results are not just the responsibility of the immediate monitoring circuit: results are handed over to an external authority. The clinic therefore also serves as a site for a biometric data collection, who hold responsibility if ‘red’ results are not redressed.

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<sup>35</sup> The UK database is the Denzapine Monitoring Service (DMS), while the Australian database is the Clozapine Patient Monitoring Service (CPMS).

On paper, patients become ‘data’ and seemingly devoid of agency when blood results are in the red range. Red results are uncommon,<sup>36</sup> but when they occur a haematologist employed by the national clozapine registry is called upon as the highest authority. Concerns about the patient are temporarily focused wholly on blood counts and whether to restart clozapine. For instance, Clive emailed these instructions from the Denzapine [clozapine] Monitoring Service (DMS) haematologist, to the clozapine clinic staff (and me) following a ‘red’ result of a patient we saw:

*Hi – I’ve spoken to the DMS Haematologist this morning, who suggests:*

- *Repeat FBC daily ([local hospital] urgent?): if WBC and neutrophils recover to ‘green’ result quickly, he will support rechallenge to get [patient] back on clozapine quickly. It would be useful to get folate, B12 and blood film done too as this will help indicate if low counts are related to alcohol, rather than clozapine.*
- *Please check whether [patient] has had any recent change in drug treatment, or infection, that might have affected white cells*
- *Consultant Psych please to refer [patient] for review by local haematologist in case there is any other underlying issue causing the low counts.*

*In the meantime, [patient] remains ‘red’ i.e. no clozapine – **please remove any remaining tablets from him**. If the blood recovers quickly, we may be able to restart him within a day or too. If not, will need to consider alternative antipsychotic.*

[Bold font in original]

In between the specific checks to determine why the ‘[patient] remains ‘red’,’ the patient’s capacity to influence their ‘red’ status via alcohol consumption was posited alongside the potential roles of clozapine, ‘recent change in drug treatment, or infection.’ Nonetheless, responsibilities for ‘blood recover[y]’ moved to Clive, to the Consultant, to a local haematologist, and to those who can ‘remove any remaining tablets’ (nurses, support workers, informal caregivers) until further assessment and actions can be agreed upon collectively.

Although implications for the patient’s agency were temporarily sidelined when resolving a

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<sup>36</sup> Pharmacist Ros recalled, “I can think of one person who was a genuine clozapine red, who’s white count dropped virtually to 0, and we... he was somebody who’d been on clozapine for a number of years so that was sort of quite unusual. He was at the monthly blood test stage, and we wanted to admit him to hospital for his *physical* health, [be]cause he had virtually no immunity... we had great difficulty persuading him to come in. So, he’s a case when clozapine was immediately stopped, and we ended up having to give him Filgrastim to stimulate his bone marrow, to bring the white count back. And he’s somebody who’d be a *risk* to rechallenge on clozapine. Again, he’s the only one I can think of who’s been an absolute, genuine, clozapine red.”

‘red’ result, this does not reflect the lived involvement that patients have. As Barrett (1988:285) remarked in regard to psychiatric patient interviews he observed, ‘the relation between data and conclusions was an interpretive circle’ and ‘what was circular in interaction was always portrayed as linear in writing.’ Record keeping, and accountability to the clozapine database is, as Barrett (1988:268) noted of quantitative measurements within psychiatric treatment situations, ‘the principle tool of supervisory control.’

Just as receiving and recording any kind of qualitative and quantitative information only appears to alienate the patient and diffuses accountability, caregivers also need to work with patients to obtain qualitative information. Clive said that when he runs into patients out of work hours and they share medically relevant matters with him, he faces a double bind: to remember to update their medical notes later but at the risk of them not disclosing such things to him in the future. This is not the same as the ‘medical futility’ as Brodwin (2011) described, because there it is the potentiality rather than futility that created the conflict for Clive. Further, in regard to ‘mental health’ records, Clive commented how the one-way exchange of information, from patient (or informal caregiver) to medical files that patients and family members could not easily access (or decipher) can be fatal because between the various inputs to confidential clinic records there may have been *non-quantifiable* warning signs: “these patients, they do kill, then you go to court and the family say, ‘we’re the ones to say *we warned you.*”<sup>37</sup> The ‘you’ refers to every possible member of the treatment team. Australian Psychiatrist Adam felt frustrated by this reality, telling me about his observations of bureaucratic protections where most of what gets written up about patients does not get fed back to them, but rather provides insurance protections and a sense of job tasking for staff. Yet, in regard to quantitative markers like blood counts, patients and informal caregivers were only formally estranged from the interaction pertaining to the record. As Barrett (1988) suggested, records misrepresent the more circular actions taken to yield information. In considering the case of consult-to-record making regarding his ethnographic participant Paul, Barrett (1988:285) asserted:

[T]he patient was constructed as passive. Paul, the intentional, unified subject – an

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<sup>37</sup> Australian psychiatrist Sandra agreed and used her position of authority to include family where she could: “I feel very passionate about looking after families and making sure they’re included and involved as much as possible, I think there’s a big trap that we fall into in mental health, in perhaps being anxious about it, or perhaps hiding behind this idea of patient confidentiality. Because at the end of the day it almost seems farcical, because at the end of the day when we’re looking after people we won’t disclose information to their caregivers but all of a sudden we discharge patients into their care, but we haven’t provided the information they need to look after their family members properly ... so that’s something that a lot of [psychiatric] registrar’s notice – if you’re working with Sandra, there’s a lot of family meetings!”

agent who could exert control over his behaviour and over those around him – could not be described within the format of the case record. In its place emerged a definition of Paul as a combination of part objects, each affecting the other like moving components in a machine. The documentary Paul was not a person doing things to other people but a summation of resultants – a passive conglomerate which lacked agency.

Insofar as the ‘summation of resultants – a passive conglomerate which lacked agency’ contrasts with ‘the intentional, unified subject,’ the former is still available during the interaction. As I elaborate below, the more involved clinical caregivers were throughout the process of blood work to tablet dispensing, the more potential there was for the activity of the patients also. The activity of blood work opened up a space for a more ‘generalised’ attention to the patient as a whole person.

Clinical caregivers not directly involved in the ‘mental health’ aspects of treatment work to navigate a role that connects to the broader implications and experiences of clozapine, blood and the clozapine clinic. It was only in the UK clinic that patients were ‘bled’ and their blood processed on site, and this made for a tighter circuit of communication. UK Pharmacist Ros said that this allowed her “a chance to see people who are otherwise just a name on a prescription chart.” Having worked at the pharmacy hospital for some time meant that she had sometimes known people taking clozapine since they were hospital inpatients. The opportunity for “see[ing]” people also extended to connecting other aspects of their ‘bodily’ experiences when their blood was being drawn: “sometimes people might say they’re feeling a little bit *dizzy* when they stand up, or something like that, and then I’d say we need to check your blood pressure because that sounds like it’s *dropping* when you stand up... [but such connections are made] more in the context of if *they* raised something.” Ros thus inferred how onsite blood work opens up potential “raising” of patient assertions about what are otherwise clinically separate concerns – including separable blood related concerns – such as blood pressure “*dropping*.” Blood taking also provides a setting for patients to raise other concerns without direct clinical pressure to do so.

Phlebotomist Tina, who had initially worked as a receptionist for the clinic, told me how she had gotten to know patients significantly more since withdrawing their blood. She noted the benefits of “just having a general conversation, asking ‘how’s your day been?’, ‘how have you been?’” She remarked, however, that “one thing I’ve noticed is that if you don’t ask, they

don't tell you," and that "every individual one of them is different." The notion of all patients being individuals resonated with other clinical caregiver views (as I build on in Chapter Three). When I asked Tina if she thought they liked being asked, she replied, "yeah, I think that they do because they feel that someone cares." That day she had talked to a particular patient about a number of "other problems" aside from clozapine and the patient said to her afterward, "I know you're busy but thank you for listening." When Tina said to let her know if there's anyone else she can refer her to for more help, "she said 'no, no, I've got it all under control,' and she seemed to be fine." I return to the social aspects of clozapine blood work in the next section of this chapter, but here I note how patients were given opportunities to report other general concerns that help to facilitate the connections between other nodes in the clinical circuitry.

The clinical circuitry could be connected through patient activity as well as clinical caregiver's actions. UK patient participant Hannah, 33, who had initially gone to her GP for blood tests, found that attending the clozapine clinic was "a more convenient option." This was because she no longer had to rely on a parent to collect her medication for her from the hospital, and she could decide for herself what was of concern to the clozapine clinic. As well as finding that, "they're very good at taking the blood samples and it's usually quite quick, and you also get someone to check your physical health as well," Hannah did not mind liaising between her GP and the clinic. Hannah said that her GP did not check her overall 'physical' health as such but rather discussed specifics, like her Irritable Bowel Syndrome. Hannah consulted the GP and then reported back to the clozapine clinic nurse, for their records. Thus, clozapine patients' proactivity both within and beyond the immediate monitoring circuit could be as useful as clinical inputs in terms of how to optimise treatment efficacy (Mol 2008).

In the Australian clinic, where the clinical network was more dilated, patients had to work harder to connect the clinical circuitry. Australian patient Marie, 54, had a long range of topics she brought up throughout our interview, which mostly concerned references to blood. She had been on clozapine for 5 months, which meant she was having fortnightly blood tests, soon to be spaced out to monthly. When we met, it was her low blood pressure that was concerning her, as she resolved to book in with a GP for follow-up after she had overhanging concerns that the nurse, Ramesh, was unable to reassure her about:

Marie: I s'pose I have to make an appointment next week, it might be a good idea, [be]cause it might not be good for my health to have it too late, my blood ...  
[Ramesh] said it [was] low and last month, when I come, he was, he, he s-said it was low then too, so must have been low [at] least a month.

JB: So, did he say to book an appointment with the GP?

Marie: No, he said when are you going next but he didn't say I *should* -but I think I probably should. He didn't say ring, he just said next time you go maybe you should ask him to check your blood pressure.

JB: Oh, okay, well look if it's something you're worried about, then-

Marie: Yeah haven't heard anything about it much but maybe it's a sign – tw-twice its been low, means about a month, it's been low, it prolly [sic] not a good idea if I leave it, anymore, I better tell the GP, next week.

JB: Well, I think if you're concerned about it-

Marie: - [be]cause you're not meant to have low, or high. I never had high. I better tell him.

JB: I think for peace of mind it's probably-

Marie: I better make an appointment, I better [sounding increasingly anxious]

JB: [reassuring tone] I'm sure Ramesh would have said something if it was worryingly low, but -

Marie: He'd say you better ring. He would have, wouldn't he? But he didn't, I'll have to do it myself – better ring.

Marie had decided the most suitable course of action to take regarding her low blood pressure, drawing on her own concerns in spite of the nurses' dismissal. Marie thus held herself accountable to seek further action by drawing on additional medical resources available to her (Petryna 2004). Marie then told me about her "low lymphocytes," and that she was "supposed to have my blood test 12 noon or after [be]cause every time I have it in the morning I had to repeat the blood tests same week [be]cause the lymphocytes are low... I think it effect[s] my health, and the low blood pressure now." When I asked Marie what clozapine felt like, she said, "I feel real sedated, in my head, like real sedated, might be because blood pressure's low, low lymphocytes, not very healthy; I don't feel very well." Moreover, while Jenkins (2015:46) noted that the efficacy of clozapine could be derived from 'sensations of tingling and numbing both in the brain and elsewhere in one's body such as the legs or bloodstream,' patients like Marie drew quite specifically on blood imageries that corresponded to blood markers enlisted by treatment monitoring.

As suggested earlier, the focus on blood work allowed patients to situate themselves within more ordinary socialities of fear and anxiety that was less about their specific psychiatric diagnosis. Marie disliked blood tests but saw herself as one of many: "some people don't like

blood tests.” When I confided that I did not like them either, she shrugged, “it’s just the sorta person we are.” Of what it was that made her uncomfortable, though, Marie’s concerns were more personal. She explained,

Marie: I’m scared [of] germs and unclean, but they clean it and... I don’t-, [be]cause I’m not a drug addict either, I don’t... shoot up and I’m not a drug addict.’

JB: No (reassuringly)

Marie: [Be]cause I feel like one with this blood business, it’s making me feel like I’m like a drug addict, you know like drugs... see *I* don’t, but the neighbours do.

Marie then reasoned and reassured herself that “they clean it” (the needle used to draw blood) but she could not entirely dismiss the associations with drug addiction because her blood work experiences could not be neatly differentiated from her life experiences. Marie’s concerns, generally, seemed to be all connected to what she described to me as “shame” felt about her past, particularly around her sexuality, religious disaffiliations and unresolved disconnect with her deceased mother – “my mother never related to me, and she should’ve explained but she couldn’t ... she was brought up very Catholic.” Marie said that her mother disapproved of her “promiscuous” behaviour and, “she was worried I’d get AIDS.” When I clarified whether it was “okay, though, in the end” because she had not actually contracted AIDS, Marie retorted, “no, but it’s left scars, someone said, it leaves scars [be]cause I always... [had] partners that didn’t really love me.” While the clozapine clinic could not provide romantic intimacy, it was a place of socio-moral redemption of sorts. Before returning to how Marie perceived clozapine treatment to be helping via the social contact made available through the monitoring, I first discuss the potential self-assurances provided through the blood taking ritual itself as patients began to learn how much control they had over the interaction – something they often did not have in other aspects of their lives and were not expected (or pressured) to have during clozapine monitoring.

### Creative care

From blood work preparation through to the bleeding process, patients and clinical caregivers took an active role of care toward yielding the desired result. Patients were able to take a creative agency throughout the clozapine monitoring, once they could ‘actively take their care into their own hands and yet to let go of whatever it is they cannot tame’ (Mol 2008:95). What they could and could not tame was a moving question, however. The process of

‘bleeding’ people was not simply unidirectional, and patients could effectively bring its circulatory nature back into focus, as well as what the ritual meant to them.

On the one hand, for people who knew what clozapine treatment was prescribed for but were still experiencing residual delusions, blood work could be felt to pronounce a patient’s diagnostic status in ways that may otherwise be more concealable. UK patient Hannah described her main concerns as, “I think I have quite a bit of stress about relationships mainly, and sometimes people who I meet at work – it can be colleagues or customers, I think they can hear my voices in their head.” This concern extended to how her walking into the clinic might appear to people not attending the clinic. No matter how discrete and efficient Hannah felt her clinic visits to be, she worried about the public implications: “I think because you have to go for the blood tests and, um, you have to take the medication regularly, there’s some issues with having to... just disguise to people that you have mental illness.” On the other hand, once inside the clinic, and when it came to the blood work in particular, the implicated role of clozapine as treating schizophrenia was diffused in the ways described above. Indeed, UK phlebotomist Tina told me that she “would like to know what clozapine actually does – whether it works on the blood cells, the brain cells?” Meanwhile, phlebotomist Sam, who held a Bachelor degree in psychology, said that he is continually mindful of patients who are “harder to bleed,” and also general anxiety issues around blood work.

There could be a shared, embodied experience of anxiety around blood work between phlebotomists and patients. Sam explained, “you’ve seen these people for a long time so you know where the vein is, and sometimes it doesn’t work, sometimes the vein... just doesn’t respond [which] makes you feel deflated.” Sam reflected, though, that, “me succeeding in getting blood is at the very bottom end of the scale ... it’s about their *experience* when they walk in through the door ... to try and reinforce to them that coming here is not a *negative* thing.” This meant chatting with patients who are in the waiting room “whenever there’s a few spare minutes” so that “they’re not just sat there, in isolation, waiting.” I observed Sam chatting to, and smoking with, patients outside the clinic’s entrance, too. When it came to Sam’s role in bleeding patients who disliked the process:

A lot of it has to do with anxiety training ... to try and tell people that the best you can do is to sit in the chair, after you’ve had the procedure, until your anxiety comes

down ... the idea is try and let the body adapt to that environment first ... if people are constantly having an amber result, then all we can do is try and tell them to, um, drink water again... I mean we don't really know what effects the neutrophils and things like that, whether it's something that *they* do, like whether being dehydrated effects that, because the neutrophils is all part of the infection control system, and blood is blood at the end of the day; it needs water, so whether they're being hydrated and *that's* one of the causes.

Sam thus suggested that both he and patients were personally involved in the 'adapt[ation] to' blood work spaces and the making of desirable blood results.

In the UK clinic, patients who had become familiar with the process exercised a degree of control over the blood work ritual, too. Weiner (2011:473), who undertook ethnographic research with bipolar patients, suggested that there are 'certain kinds of *provisional* or *distributed* agency' at play with how bipolar patients 'self-manage.' Although Weiner (2011) distinguished this provisional agency from that available to schizophrenia patients, I contend that patients of any kind make for no exception to her observation that 'agency resides in the negotiated spaces between action and inaction' (Weiner 2011:477). For clozapine-treated schizophrenia patients, 'provisional agency' was either explicit – such as instructing the phlebotomists or nurses to use a butterfly clip while taking their blood or suggesting which vein to try, or asking for extra cotton wool and multiple layers of tape over the bleeding spot, or asking for water – or more subtly steering the degree of interaction with the staff. I also observed ongoing interest in 'what to try next' to yield the mutually desired outcome (Mol 2008) of a 'green' blood result.

As with the 'hopeful' potential for psychiatrists to learn more specifics about how clozapine actually works at a neurobiological level, while patients were more inclined to just accept its "magic" qualities (Chapter Four), the blood work was more flexible to interpretation than at first assumed. Both staff and patients could utilise the uncertainty given by a reality that, as Sam admitted, "we don't really know what effects the neutrophils and things like that [have]." In regard to encouraging patients to increase their fluid intake before doing blood tests, Ros said that she was, "sometimes surprised by how many people respond like it's the first time they've heard it." I found, however, that patients tuned into information that was the most personally meaningful and drew on this information to strategise with.

When I first met 36-year-old Australian patient participant Max, he had only started clozapine three months prior and told me that he felt like “a bit of a guinea pig half the time, when it comes to [at first] being at the psych ward and coming here and having your bloods done, blood pressure and temperature done.” Even then, though, he was “accepting” of clozapine because, “I haven’t noticed that much difference but other people have.” After a year of clozapine treatment, Max echoed Rapport’s (2003) descriptions of agency when he described his current situation as, “having a bit of imagination, a bit of creativity, [which] can lead to this sort of *essence*.” As I observed patients like Max getting used to clozapine, their imagination and circumstances seemed to continue such that their sense of meaning and self-purpose evolved.

Blood work was subject to continual, personal readjustments that exemplified Rapport’s (2003) observations about ‘self-intensity’ and embodied ‘life projects.’ As I have previously written about in the case of 53-year-old UK patient Joanne (see Brown & Dennis 2017), who felt able to avoid ‘amber’ blood readings by swimming laps of the pool beforehand, this reliable regimen was instigated following a throwaway remark by a trusted pharmacy technician (Linda) that exercise could ensure a ‘green’ blood result. Trying this out for herself, Joanne had found this to be true, such that when ‘one of Joanne’s pre-holiday blood results came back with ‘an amber’ ... [she was] initially frustrated with herself because she had not fitted in the time for a swim that morning, which she *knew* would be consequential’ (Brown & Dennis 2017:374). She resolved to ‘change plans for tomorrow and Friday – I’ll go swimming tomorrow *and* Friday’ (Friday being the day of her next blood test) (Brown & Dennis 2017:374). Further, preparing for blood work could also mean maximising one’s chances of an efficient bleeding process.

UK patient Hannah, 33, felt that when it came to the actual process of blood withdrawal, she “used to find sometimes it was difficult ... and I used to think, I have to exercise the day before?” She said this with a quiet intonation, as though she was self-conscious of what I might think of this logic. Like Joanne, Hannah sought to improve her chances of unproblematic blood work by exercising beforehand, but then, “I was sort of exercising regularly anyway” (swimming once per week and doing Pilates via a DVD) and felt that keeping up with this routine of weekly exercise had more long-lasting impacts on her general circulation: “they thought it was like poor circulation, they’d like stick the needle in a few times and try and get it [her vein] ... but it’s fine now,” thanks to her regular exercise regime.

Thus, rather than following instructions around fluid intake, as Sam and Ros may have suggested, Joanne followed Linda's more casual advice and Hannah took on a more general approach to facilitating her blood circulation. Both women attended to what might work and stuck with strategies that have worked, finding a personal means of contributing to some aspect of the blood work. The active strategising around blood work is more about personal creativity within acquiescing to the regimen than it is about resistance to it; 'patients can actively participate in the system of which they are a part to create new possibilities for themselves within the clinically objectified frames at hand' (Brown & Dennis 2017:374). While the implications of patients attending their designated clozapine clinic for blood work are compliance, visibility, and a period of waiting for results that is outside of their control, 'the art of care' on the part of any (general) patient is, 'to persist while letting go' (Mol 2008:32).

Part of persevering at the same time as compromising some control was due to the near impossibility of retaining all information pertaining to clozapine treatment monitoring, and the dearth of 'unknowns' (to be discussed further in Chapter Three). Part of enacting personally selected knowledge over repeated clinical advice may come down to the dissonance between blood markers and experiences of these markers, and how they can be potentially followed up on. For instance, dizziness and constipation were common side effects, especially upon starting clozapine, although patients could reimagine the confines of these experiences. Australian patient Keith was quick to dismiss his dizziness because it was "just when I get up, I've gotta' hang on to something." Marie, on the other hand, spoke to me of her fears about constipation: "I often freak out because for some months I hardly ever went, I thought I'd just get *so big* if I was eating, don't go to the toilet, I get a bit... I was *scared*." However, this was "helped" by two things: "two sachets" of a particular laxative and also her menstrual blood: "I think the blood acts as a laxative perhaps, in the body." Marie had found a 'personal medicine' regime (Deegan 2005) that also happened to include blood imaginary, which she was otherwise conflicted by in regard to possible contaminations (Douglas 1966). This illustrates Marie's authorship over blood work experiences.

Clozapine blood monitoring could in some instances console patients' personal desires rather than fears. While patients like Marie worked to overcome fears of blood work due to "drug addict" associations, other patients could productively draw on the familiar feeling of previous substance abuse and the methods of delivery they grew to enjoy. Australian patient

Charlie, 35, who had started clozapine a year ago was also taking methadone. He told me, “the reason I don’t like taking clozapine is, because I have to do it every day... it’s like methadone, it’s like a... liquid handcuffs they call it, you know - a form of control.” However, compared to the feeling of “itchy blood ... like ants running up and down your veins”, when he was withdrawing from a previous drug addiction, at least the clozapine blood withdrawal may have complemented his “need to do an injection.” He explained,

Charlie: You can’t pop a pill and think ‘Oh I’ve had an injection.’ It doesn’t work the same way. Just like you can give a person a nicorette tablet but they still *want* to smoke a cigarette. They’re not sweaty or messed up from the withdrawal anymore, but they still want to *smoke* their cigarette

JB: They want the process...?

Charlie: They want the process of what they’re *doing*, yeah. It has to be that otherwise it doesn’t satisfy the *control* ... Anyone who’s not getting their behaviours needs to be *consoled*. They need to be consoled by their behaviours. Most people have sex, most people have food, you know. Other people like me do *injections*. It’s a more unnatural behavior, but it still counts the same. It works in the same way.

While I did not directly discuss the blood withdrawal process with Charlie, nor get to observe it due to the Australian clozapine clinic set up, I suggest that Charlie might not have minded the bleeding as it was closer to his ‘consolation behaviour’ of doing injections. He had also cut his wrists numerous times, remarking to me, “not everyone can razor blade their wrists, some people can’t do that, but for me it was very easy.”

For other patients, however, experiences of clozapine treatment may also be helped by clinical caregivers creating their own means of relating to patients. Australian Clozapine-Coordinator Kerry had a number of life threatening chronic health conditions of her own, including Type I diabetes and Multiple Sclerosis, that required ongoing management. She said to me, “I can relate to my guys and the side-effects and stuff, you know, if they talk to me about it, I’m really sympathetic – I don’t like how some people [other staff] just dismiss it.” When it came to how she advised patients who were not yet comfortable with the clozapine regimen:

At different times with patients ... I will disclose that to them, and say, ‘well I inject myself every day,’ and particularly when I was on Interferon, you know, ‘I had this horrendous drug, and I can relate to the side-effect profiles of drugs, so I can relate to the side effects that you experience’ ... to come in here for clinic, and, you know,

have all these silly questions thrown at you, whereas, you know, if you're like me, you just want to wring people's neck and go away! [laughs]

Kerry continued, "I thought: you guys are putting up with all these shitty side effects, and it's just the same as what I put up with so I sort of understand." Kerry also reflected, "I do wonder what it's like to live in a healthy body because I don't – I don't live in a healthy body ... I feel like shit most days; I push myself." "I don't see someone with a mental health issue as any different to some that has a physical health issue," Kerry said. After having been on sick leave for a few weeks, Kerry said to me over the phone that she herself had been feeling "psychotic" lately, due to a combination of a new medication she was prescribed by her neurologist and a steroid cream from her GP that had given her "rashes," all culminating in an inability to sleep. Nonetheless, Kerry would never disclose to patients any 'mental' health troubles she was having, and her sympathies in regard to clozapine monitoring depended on whether patients were taking clozapine or not. Kerry liked to reinforce how some patients went from being "as mad as a meat axe" to people she quietly admired and could openly sympathise with in regard to the physiological monitoring requirements. Necessarily, this sympathy was limited to conversations in the 'safe' clozapine treatment context, and I observed this boundary to be of benefit to patients too.

### Social contact at a negotiable distance

The very reducibility of monthly clozapine monitoring to matters of blood and 'vital' markers that did not require personal conversation but rather a social 'role' as partaking in the routine monitoring was productive for patients. As GH Mead (1932:184-5) posited, '[i]t is only by taking the roles of others that we have been able to come back to ourselves.' Archer (2004:255;261), in her attention to the 'social self,' contended that 'not everyone can succeed in becoming an Actor – that is in finding a role(s) in which they feel they can invest themselves.' Clozapine patients were able to invest themselves as social actors through the clinical monitoring process. Part of this social investment was about being in a space where they could be 'noticed' (Aylwin 1985), but also because this attention was usefully limited such that social boundaries could be tailored to suit individual needs.

Linda, a long-serving UK clozapine coordinator and pharmacy technician who said to all of us at the clinic that she would like to continue volunteering at the clinic after her imminent retirement, remarked to me:

You can tell when people come into the clinic for the first few weeks, you know, they don't speak, and they're very quiet, and they're very... *withdrawn*. And as their dose goes up and they start to feel better, and more sort of at home with coming to the clinic, how – you know, then they'll start *talking* to you, you know, they'll *initiate* the conversation ... it can be really tiny things, really tiny things ... so then you *know*, after that if they go quiet again then perhaps there's something not quite right.

The idea that a patient, like a patient's blood, in a different sense, is simply '*withdrawn*' until the patient becomes 'at home' (including clozapine dose adjustment), highlights the importance of two-way transactions that are at once regimented and personalised. There was clinical leeway to allow patients to '*initiate*' exchanges during blood work (or other clinical checks), for patients to work with as they became more acquainted with the processes.

While the clozapine clinic constituted a private space in terms of conditions of entry, the space itself was shared yet discrete enough for patients to feel a part of something while also steering levels of intimacy. Indeed, Corin (2007:282) posited that for her Canadian ethnographic participants with schizophrenia, dipping in and out of publically shared spaces:

[O]ffers a way for them [schizophrenia patients] to relate to others without having to commit themselves in personal interactions. One might say that this behavior provides patients with a kind of "social skin" that both contains and protects an inner space and mediates their relationships with the outside world. We could see it as a concrete metaphor of a relationship with the world that weaves a dominant "distancing" stance with interrelated threads. Connecting with the world paradoxically appears to be secondary to the ability to remain separated from it – to stay at a distance and introduce a kind of "blank space" into the social fabric.

Clozapine blood work could be said to provide a 'social skin,' while keeping patients and staff at a safe 'distance' from one another. Critically, this socially "blank space" could provide a safe platform for patients who found it difficult to trust others. Despite many patients in my ethnographic study experiencing persistent paranoia and the invasiveness of the presences of others (real and imaginary), none reported such invasions while in the clinical space itself. Take UK patient, Alice, for instance.

Alice, 36, told me that she wanted "to be very private"; choosing to live alone because she found it "quite hard to be with people"; to "trust" them. Having experienced sexual abuse throughout her childhood, she would "rock" herself to sleep. "Suddenly, when I was 26," she

recalled, “I stopped rocking ... and that’s when I got the presence.” She described the presence as “someone looking after me all the time.” But Alice also experienced “bad hallucinations” that invaded her space, triggering “panic attacks.” Whether clozapine alleviated the latter experiences was never as clear to me as what participating in the treatment monitoring itself meant for Alice. She seemed to willingly partake in as much clinical activity as she could, although, like other patients, did not feel concerned about *not* being directly included during decision making processes about her treatment.

In the UK clinic, I sat in on several ‘home treatment’ clozapine initiation meetings that were scheduled in after clinic opening hours, all of which were necessarily attended by a pharmacist, a consultant psychiatrist, the bureaucratic Line Manager and Lead Community Psychiatric Nurse (the latter who had clozapine prescribing rights). For the initiation review meeting for Alice, we met in George’s office, with George, Ros, the Line Manager, Clive, a student nurse and me present. We went through the letter from the referring psychiatrist, who advised that clozapine had first been discussed with Alice last year, but that Alice had initially declined due to the blood tests. Alice had recently heard positive reviews about clozapine, however, from friends (in her art group, I would later learn).

There was a lot for both Alice and the clinical team to potentially dread, yet the main emphasis was on getting Alice started on treatment, upon her own request. The clozapine initiative review was slightly closer to what Brodwin (2013) described as a community psychiatric ‘treatment plan’ in the sense that it was more future directed than ongoing blood work. As Alice had already been in the clozapine database for one month since referral, Ros was concerned that Alice’s registration might have lapsed and that she would need to reapply, delaying the start-up date. The current risks discussed were a mix of quantitative and qualitative: her already high BMI (54; ‘morbidly obese’), delayed QT (heart rate), along with her history of overdosing with olanzapine – a similar drug – after she had threatened her mother and brother with a knife, 12 years ago. It was concluded that because her pulse had been ‘normal,’ weight gain was less likely to be ‘risky.’ The actions from the review were (formally recorded by the student nurse): 1) ECG next week or tomorrow if possible; 2) QT monitoring to see if it reduces because clozapine may ‘prolong’ it further; 3) to check medication history (it was unclear how many antipsychotics she had tried already); 4) psychiatric review with George the following day in order to start clozapine titration the following week; 5) check living company; 6) organize the spare large Blood Pressure cuff for

the home treatment team; 7) refer back to the psychiatrist when he returns from leave. Clive, the student and I then moved to Clive's room so that he could explain QT intervals to us and check we were up to speed, before returning to the waiting room to discuss the titration plan with Narelle and Sam. Nurse Narelle at first queried whether it was necessary for Alice to be put on clozapine given that she seemed psychiatrically stable, but then Narelle recalled how during a recent therapy group she had assisted with as part of her other job (on non-clozapine clinic days) Alice had shown more vulnerability when pressed about past family relations. Assuming that George would approve of clozapine initiation upon reviewing her the following day, the focus returned to the blood work: Clive, Narelle and Sam planned out the home-visiting schedule between them for taking Alice's blood daily for the first 18 days of monitoring.<sup>38</sup>

When I first met Alice in person, I wrote in my field notes that, 'Clive explained she'd be seeing a lot of us if she goes on clozapine, and she seemed pleased, as though the clinic is a new exciting place to be.' I still recall her smile and seemingly uplifted spirits as she looked back at us as she steadily made her way up the steep and narrow staircase from Clive's room up to the other areas of the clinic. Having started treatment and daily bloods, Alice reported feeling initially dizzy, constipated, needing to urinate frequently, drooling, but soon felt herself to adjust: "I feel better, though, already in the fact that it's like... the sort of, I feel more motivated to *do* things ... It's only early days, it's like... only day eight or something, but already I've noticed a difference."

Conveniently, Alice also lived down the road from the clinic. This made it easier for her to attend regularly. Despite her preference for her own company, Alice attended the clinic more than necessary during her treatment initiation, accompanying a fellow patient for their appointments, even if it meant returning an hour later to have an ECG, an interview with me, or drop by with biscuits to thank the clinic team for their efforts during the titration period. The clinical contact, no matter how bio-medically focused, seemed to be supplementing the company of Alice's guardian "presence" at home. The clozapine clinic was allowing her intermittent contact, in ways that she seemed to trust.

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<sup>38</sup> Week one requires three times per day at two hours and six hours after dose: 9am dose; 11am blood observation; 3pm blood observation (then after-hours service takes over for the evening); Week two requires two blood tests per day, week three is once per day. Titration under the community treatment team (home visits instead of hospital-based) is also more gradual (starting on 6.25mg of clozapine rather than 12.5mg).

The opportunity for regular social contact was explicitly mentioned by UK patient Luke, who said he appreciated the “human contact” at the clinic, and Australian patient Marie. Marie said that connecting with people was what she felt she could gain by clozapine clinic treatment. “I don’t like the blood tests, I don’t like them ... [but] there’s a lady there, she likes me ... and I believe she - it’s a good thing, [be]cause maybe she feels she can help me.” Marie added that her attendance at the clozapine clinic came with social “care” that she felt she needed:

The care at the clozapine clozapine, the care ... they help me ... metabolic screening... but that helped the care, [be]cause I was changing medications... and I *wasn't* in hospital... when I’m having bloods the nurse’s nice, yeah, I did those courses at [the clozapine initiation clinic], so short but helping me... [be]cause I’m being social, because I have to be social ... my mind has to be around people, my brain, because ... the brain can’t live alone.

As Marie saw it, the clozapine clinic was not as biomedically reductive as it might first appear. Indeed, UK patient Peter, 54, said of getting his bloods done, “people are concerned about me, so it makes me feel better straight away.” Clinical caregivers could provide enough familiarity for patients to safely rebuild their sense of having a social self with. The potential for mundane sociality was not unnoticed by clinical caregivers, either.

When I asked Ros about the importance of “therapeutic contact” during the blood taking process, she said “absolutely, and for somebody like Linda, who has been with this service *so* many years, *and* will have known many of the patients when they were inpatients maybe 15-20 years ago, yeah I think that is, hugely important.” Ros gave me the example of how, when Linda is away, “people come in and *notice*, ‘Oh, no Linda today.’” While Ros conceded that, “I don’t know if it’s actually solidarity as a *clozapine* patient, I think for a number of patients who’ve been coming here for *years*, there is a *social* element to it - not because of *cloz* - but just because they know each other ... through *years* of their lives, and then they come here, and that’s reflected in conversations in the waiting room.”

Patients could negotiate the degree of interactions with other patients as part of asserting how much time they could comfortably spend with others. UK patient Trevor, 55, said to me, “I do meet up with friends from the past every so often at the clozapine clinic.” Yet, like most patients, he insisted:

I like my own space, you know, I've got my own flat, I don't have to share with anyone, I like my own space, but also like company as well from time to time. You know, a combination. I don't like other people impinging on my life, you know. If you're in a care home living with a group of people it's very, very hard because you clash and fear with each other, you know?

Arguably, the clozapine clinic stood distinctive from places that “impinge” too much on patients' lives. Critically, Trevor said that when it came to the clozapine clinic's blood work and physiological monitoring:

I think it's a very good idea, to keep an eye on exactly what's happening with you and many aspects, you know? Because they measure various things and they can see what's happening from month to month, you know, and if you're getting any health problems its likely to be picked up quite quickly. Isn't it?

Patients liked being able to talk about clozapine treatment in 'physical' terms. I observed that the 'social element' to the clozapine clinic that Ros and Trevor had acknowledged to some degree was found in its emphasising of mundanity in blood work, which came with the familiarity of biochemical imagery, people and spaces to interact with. As such, clinic socialities could be compromised and resisted when the conditions and care were not conducive to patient sensitivities.

#### Clinical rhythms: Blockages and flow

*We haven't got that many private spaces and people are constantly kind of coming through. So, there's part of me that feels like it would be really nice to manage everybody through their GP. And they just went and had their blood test at the GP, like everybody else, and they went to the chemist to pick up their tablets. On the other hand, I think we do catch a lot of people as they're beginning to deteriorate because of the very fact that they're coming here. – Ros, UK pharmacist*

As suggested in Chapter One, the boundaries of clinical space and relations in the UK clinic were more porous, and patients and staff both frequently passed one another when attending different nodes on the clinic circuit. In the UK clinic, the waiting room was specific to clozapine patients and thus perhaps more 'privately shared' insofar as treatment concerns went.

In the Australian clinic, the blood tests, which were taken at general pathology centres on a

Monday or Tuesday before the clozapine clinic on Thursday or Friday, had expired by the time patients came in for their clozapine appointments. As such, Australian patients had their body temperature checked for infection as a next-best assurance of white blood cell count.<sup>39</sup> Australian patients had to have their blood taken earlier in the week, and, from what I observed, had to be reminded and chased up more often than patients attending the UK clinic did. One of the most distinctive differences between the UK clinic and the Australian clinic was that blood work was only performed on site and ‘in time’ in the UK clinic, mirroring the synchronous nature of clinical connections. In the UK clinic, blood was drawn, mixed and analysed within approximately 15 minutes, with a psychiatrist in the next room to sign off on the dispensary of tablets. In the Australian clinic, despite the CPMS guidelines specifying that a maximum 48-hour period was required in between blood withdrawal and clozapine dispensary, the process usually took three to four days. Blood took three hours to process at pathology centres, before the clozapine coordinator could proceed to make the CPMS entry, then request the script from a psychiatrist, none of whom worked in that particular clinic every day, then fax the script to the pharmacy with a 24-hour turnaround time, picking up the clozapine from the pharmacy, before the patient’s attendance at the clinic, assuming that the patient did indeed attend pathology for the blood test at the beginning of the week.

There were sometimes ‘false starts’ in clozapine clinic activity flows in the Australian clinic. For instance, a few days before Christmas (necessitating careful renegotiating of blood work, clozapine supplies and appointment times for patients who were due to be seen during the week the clinic would be closed), no patients could be seen yet as the blood results had not yet been entered into the CPMS. On another occasion, a temporary clozapine coordinator developed a migraine but realised that her CPMS registration had expired anyway, such that the general clinic’s team leader had to renegotiate who would run the clinic that afternoon. Moreover, the continuity in care during the process of ‘bleeding’ through to ‘tablets’ was different between the UK and Australian clozapine clinics.

In the Australian clinic, clozapine patients were also ‘outside’ the clinical spaces, sectioned

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<sup>39</sup> The Australian clinic was also more concerned by people exhibiting symptoms of a cold in case this would take their WBC into the risky range. Clozapine coordinator Kerry, elaborated, “say they get a full on cold, or a chest infection, their white cells go sky high because they’re fighting the infection, so, during the period when the white cells and the neutrophils are really high, we increase the monitoring, just like we do when they go ‘amber,’ we increase the monitoring so it’s twice weekly bloods until the white cells come down into the green range, but then you’d be mindful that they’ve had this infection and that they don’t slip right down into the ‘red’ range.” Having little access to the clinical nodes beyond the nurses, I never observed this extra monitoring happening in instances of patients having a cold, however that is not to say this protocol was not followed.

off by security doors that patients would pass through for their appointments with the nurse or psychiatrists. In regard to Ros' point about potential privacy issues for patients if clozapine was mandatorily managed at a General Practice, this was more of a concern in the Australian clinic, which was not specific to clozapine. Before I first interviewed him, Australian patient Keith asserted his wish to not speak with me in the general waiting room of the clinic about what his participation would involve, because "no-one out there needs to know." I wondered whether the UK clinic set-up may have put Keith at any more ease while he waited for his clozapine appointments.

The UK clinic, on the one hand, could be seen as lumping all the potential 'stresses' together. While most appreciated the subtle opportunities for social interactions, a few people preferred to seek personal assurances more formally, elsewhere. UK patient Geoff, 53, declined to do a follow up interview with me because, as he told Clive, "it was too traumatic" last time. I felt very concerned about the ethics of this, yet Clive waved my question away and replied, "*of course it is* – even coming *into the clinic* can be traumatic for our guys." Indeed, Geoff had told me he saw his GP "every six weeks" for a "general chat" about "whatever personal questions bother me at the time." When I asked him who his main support was he said, "probably Dr [X], who's a psychiatrist [not working at the clozapine clinic]." He kept his interactions with clinic staff to a minimum, although he still did not opt to have his blood work done through the private system.<sup>40</sup> On the other hand, some patients in the UK clinic nominated to attend the clozapine clinic weekly just to collect their medication in between their monthly bloods because this had become a reliable routine for them – and, arguably, social contact. UK patient Trevor collected his medication from the clinic every week, and he, like a number of patients, often elected to come in and talk with me on 'non-clinic' days. As Corin (2007:282) suggested of the Canadian schizophrenia outpatients in her ethnography, patients participating in public life benefit from the '[r]hythm and routine,' which 'can add structure to patients' spatial and temporal worlds.' I pick up on this point in Chapter Four. Arguably, clozapine clinic attendance gave patients something to plan around, and even dress up for – I observed many patients doing this in both clinics and some explicitly mentioned doing so. The clinic routine, however, operated more smoothly when

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<sup>40</sup> Monitoring and collecting clozapine through a GP, a psychiatrist and hospital pharmacist was an option for patients who could afford it, but I did not have access to knowledge about these patients. I am unclear as to whether or not this would have been financially feasible for Geoff.

there were greater expectations of accountability on the patient's part and predictability on the clinical caregiver's part.

First, all patients appreciated accountability. The UK clinic had recently started an appointment system allocating 15-minute time slots in which patients could expect to have their bloods done, and the clinic opening hours moved to earlier in the morning. This was George's idea to see if patients would sleep less if they had somewhere to be, and they did. Patients would often be waiting outside the clinic even before the staff arrived. As well as staff noticing the differences this made to uplifting patients' spirits, many patients spoke to me about how much they appreciated this. Trevor said, "I think the appointment system's working very well, you know, you know when you've got to arrive and when you do arrive you don't have to wait very long ... there's not a huge number of people in front of you - it's a lot better." When I mentioned the possibility of earlier opening times to Australian nurse Ramesh, he dismissed the idea immediately and could not believe that patients in the UK would really wake up so early.

In the Australian clinic, not only did patients have to be regularly chased up about their bloods and clinic attendance, there was less opportunity for consistency in interactions. When I asked Australian patient Daniel, 33, about how he found his clozapine clinic interactions, he at first said that he did not recognise other patients that came in, but then said "sometimes I'll see people regularly here." I described the UK clinic situation and how some people liked socialising while others kept to themselves. Daniel then asked, "and would they then socialise outside or?" When I said that some did, he replied,

Daniel: Yeah, I don't mind, you know, seeing the same person every month and, you know, talking with them, when we're in the waiting room together or whatever. But I don't socialise with them outside ... I don't put so much emphasis on being here on time ... I mean, that, that thing in England sounds good, though! [Be]cause you go in - how does it work with the blood test - you have it in the morning? Like, [be]cause they must...

JB: Well, they've got the machine on site as well so they can process the blood within ten minutes.

Daniel: Wow! That sounds good, because, yeah, I have to go in on Monday... If I start working again, sort of once a month, I'm gonna have to, you know, sort of work that into my day.

Daniel thus suggested a wish to be held more accountable to an earlier and more efficient

blood monitoring process, and potentials for the routine to better complement options for patients were felt able to work. Indeed, Charlie, although perhaps not minding the “injection” part of the blood tests, did say to me at one point that he found the clinical circuit, particularly the ECG, “a hassle ... because it takes an hour (and I’ve got to get the slimy stuff on me),” but Charlie also said of coming to the clinic, “it’s not a big deal, I mean, it’s a mild inconvenience, *but I’m not working*, so.” At the UK clinic, George, who said the clinic team was “challenging ourselves continually, in order to improve what we do,” was in the process of trying to extend the clinic opening times to include a 5-7pm slot on a weeknight, “for people who are working – help them to engage better.” This possibility was hard to imagine in the Australian clinic.

In the Australian clinic, the blockages in clozapine treatment monitoring were partly dismissed in terms of patients simply finding the treatment to be of general inconvenience. Despite the UK clinic being in a city with one third of the population size as the Australian city, the UK clinic had triple the number of clozapine patients and were keen to expand their services. The Australian clinic, not specific to clozapine, had a more general ‘team leader,’ Tony, who was not involved in clozapine directly but rather managed staff and liaison matters. Tony described to me the “static” uptake of clozapine clients in the service because “it’s an expensive drug, with the blood tests, its *invasive*, [be]cause you have to have blood tests every month, um, so that’s one thing that’s held back the service.” While Tony’s concerns about the blood tests being invasive were indeed an initial concern for some clozapine newcomers, these views were not congruent with the experiences of staff and longer term patients directly involved and acquainted with blood monitoring, and who all had roles to play. However, “*expanding* the [clinic’s] activity” (George’s words) via accountability and predictability in regard to appointment times added new levels of potential ‘control’ for patients and staff that required careful upkeep.

Clear communication was important to keep the flow of clinical interactions operating smoothly. When I returned to the UK for the second visit a few patients remarked, solemnly, that I had not returned as soon as I had said I would the previous year, as though I had let them down. I had to rebuild rapport in some instances before interviewing them again. One morning, the phlebotomy team in the UK clinic started taking bloods early because there was a queue of patients waiting and they thought they may as well reciprocate this commitment to punctuality. Unfortunately, there was a new phlebotomist joining the team who had less

experience using “thicker needles,” resulting in a messy blood spray and no blood being drawn – also delaying appointments for the other patients who had turned up early. Clive, who was attending to another patient, had to quickly come up and take the blood, but was confused about why the team had decided to start early under these circumstances. Moreover, when UK patient Ben, 44, arrived only a few minutes late to his 9.30am appointment slot that day, he quickly sought reassurance from the receptionist about whether he was late as there were more people waiting than usual. Ben, highly conscientious, agreed to do our interview while he waited but then asked me to check if he was due for the general ‘physical health’ monitoring as well, even though the receptionist had not suggested him to be. The mix-up of his initial plans seemed to make him warier, during that particular interview too, and when he exchanged “hellos” and a “see you tonight” to a friend he passed in the corridor on the way back up to the waiting room, he did so more hesitantly than I had previously observed when the routine was more predictable.

Critically, patient participants tended to open up more communication channels when they were ‘seen’ as autonomous individuals during clozapine appointments, as UK pharmacy technician Linda indicated above (upon familiarity with the regimen, “they’ll *initiate* the conversation”). The importance of patients being ‘noticed’ on individual terms (Aylwin 1985) could be compromised by either familial or clinical neglect. First, in regard to the former, from what I observed patient agency that consisted of ‘struggle’ or resistance, instead of creative care, was more commonly expressed in the clozapine clinic when patients were accompanied to their appointments by informal caregivers. While psychiatrist Adam warned me that, “we have to remember that what we’re seeing may be an anxiety in parents that wasn’t there before their child’s diagnosis” and that making judgements “is a trap that young clinicians fall into, when what the parents really need is support,” I observed significant communication difficulties in the clinic when parents were present.

Australian nurse Zoya told me about a female patient in her twenties who engages with treatment monitoring at a very minimal level. Zoya posited that this was largely because this patient’s mother insisted on attending appointments:

This lady has not been given the opportunity to express herself independently of the mother, so the mother actually – you can see the dynamics between the client and the mother – she doesn’t talk when the mother is there. ‘Okay, so what about this?’ ‘Oh, no problem’ – that’s how she answers, but if the mother is not there, I think she’ll

feel freer ... You just keep trying, and it depends on the family dynamics – she might not have access to go out. Her mother is like hovering over her, she can't ask questions. You know, she says 'yes' or 'no' to a question and the mother rolls her eyes, you know - *disapproval*, and then she just shuts down in that case. The first time I met this lady, I said 'Why are you here?' It was the mother that was the one answering the questions, and I said, 'Excuse me, Ma'am, can she answer the questions?' I saw, she doesn't even know why she's taking the medication, she doesn't even know what time she's taking the medication, how many milligrams of the medication she's taking... and she's an adult ... You don't want to upset the mother, because she's the support person and the carer of this lady, and so you have to play it carefully... not to ignore the mother, and then at the same time, not to neglect the patient herself, of what her responsibilities are – what she needs to do. She has not been given a chance to have an independent life. She is not responsible for anything and that's why she still looks up to her mother like a five-year-old.

I asked how family involvement translated to treatment outcomes in the Australian context and she replied:

It's *relative* times two! It's a relative thing... Some people have family support and they are great, they are fantastic, and they are functioning well. Some people, they don't have anyone to rely on, and they're fantastic and they're doing very well. So, it depends on the dynamics that find themselves... or the situation that person finds themselves.

There were several patients partaking in my research with residual and troubling symptoms who spoke to me of trying to find "independence" from their parents. I discuss this in regard to consumption behaviours in Chapter Three, but in terms of clinical interactions, Australian patient participant Trent, 24, and UK patient participant Holly, 40, were noticeably more anxious when attending the clinic with their parents. Both patients, of markedly middle-class backgrounds who always wore 'smart' and distinctive clothing closely matching their parents' tastes, of which I observed upon meeting the parents who dressed smartly and sat cautiously in the waiting room amongst the patients, disinviting potential engagements with anyone else.

During appointments with parents, patient and nurse, the consultation rooms filled with a palpable tension between the parents' power over the appointments, and the patient's own driving of information flow. Both Trent and Holly sputtered between appearing more reticent, in some moments, and brazen, in other moments, depending on who had the nurses' attention. As Trent's father took an interest in my research and proceeded to speak of his

own academic career that he hoped Trent might one day follow too, Trent was hastily but silently picking his nails, wiping blood from his thumb, jumping on moments to contribute to the conversation himself, but with difficulty. Similarly, when Holly's mother attended the clinic with her, Holly sat hunched over in her chair, hands between her legs, eyes to the ground, yet with a cheeky grin when daring to look up, responding both meekly and provocatively when asked by her visibly uncomfortable mother to "tell Clive what you did." Holly and Trent both spoke more freely and confidently when their parents were not present. Moreover, these social dynamics extended to clinical caregiver inputs, which were difficult to balance.

In the Australian clinic, staff dynamics were less reliable and this made for mixed clinician-patient communication flows. As discussed in Chapter One, Zoya's 'warmer' approach to patients resulted in unfortunate consequences outside of the clinic walls, when she was physically assaulted and subsequently judged by other staff members who were "not surprised" because she was "too trusting." Inside the clinic, however, I observed Zoya's warmth to go a long way. Zoya and Australian social worker Jill both occasionally hugged patients they had built rapport with. Zoya joked with patients and tailored 'health' advice to what she thought they might best respond to, sometimes getting up and dancing to demonstrate how to "get moving again." When the main clozapine assistant nurse, Ramesh was away for a few weeks, I saw patients who were usually more reserved smile and even laugh along with Zoya, the way they sometimes did with Clive in the UK clinic. Although patients like Marie would still use whatever advice she received to reconnect the clinical circuitry for herself, Ramesh would give flippant advice to patients and admitted to me his dislike for his job. When I wanted to clarify what certain measurements meant in terms of 'changes' for individual patients, Ramesh said dismissively, on a number of occasions, "we're entering information for the records only." While some patients were grateful despite Ramesh's generic approach to them,<sup>41</sup> thanking him profusely after each visit, others seemed negatively impacted.

Patients who seem to be negatively impacted worked to redirect the clinical rhythms that they perceived to not be working for them. For instance, Australian patient Daniel generally

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<sup>41</sup> For instance, despite Trent trying to tell Ramesh about his one particular 'voice,' who also had a name: Bon Chance (Chapter Four), Ramesh, after checking with Trent that there was "no drugs or alcohol these days?" - when Trent had never taken drugs - went on to refer to "the voices" as "they."

wanted to keep social exchanges to a minimum. The clozapine clinic formed a comfortable medium for him until the exchanges began to feel futile. He explained to me that his “paranoia” increased with the level of social exposure. Whereas not feeling “truly alone” tended to be a “constant” fear for Daniel at home, it was less so in predictable interactions such as attending the clinic or going to the shops. Drawing on clinical language, Daniel said that when he socialised, “the ability for ideations of reference via interaction with people ... goes up.” He thus ensured that time spent in the clozapine clinic was transactional and brief. When interpersonal dynamics were not enough for him, Daniel experimented with them, because it was, he perceived, all he had to work with, as “my only routine/connection to the outside world”. Daniel continued, “but it is repetitive and droll ... I’m not big on small talk.” Daniel clarified that he did not mind doing interviews with me because “I’m not the only one in your study and being an anonymous data point is good,” and that “this is not as annoying as the constant repetitive stuff.”

Daniel explained that his clinical and social engagements flowed so long as the direct pressure was off him to converse and that he could just participate in social activities rather than the attention being completely centred on him:

I’m not much of a social conversationalist or whatever, like, I’m really awkward in social settings ... like, I went to a wedding about a month ago ... and they sort of just gave me a camera and said, ‘here you go, take as many pictures as you want,’ so I had a ball! It was much better than socialising for me ... You’ve got something to do, and ... there was a couple of catering ladies that were doing the food, and stuff there, and they’d duck out back for a smoke, and I’d go out back for a smoke with them and a chat and what not, which was really weird because I could like talk to them ... But yeah, I mean, no problem standing around having a smoke and talking to them, but just when you’re sitting at the table ... it’s not so much pressure, it’s just, you know... feels a bit, I don’t know... boring. You’re sitting at a table with people you’ve never really met, you’re never going to see them again and you just talk about... stuff. You know... what’s the point? [laughs]

Daniel had explained that, “that’s why I like smoking too... because I can just get up and go for a smoke, and to be polite you’ve got to, you know, go far away somewhere away from smelling distance so your smoke doesn’t bother them.” Moreover, Daniel told me that he enjoyed the sense of “control” he felt in regard to sticking to routines that he could anticipate and compliment with clinical expectations and clozapine consumption (Chapter Three). Yet these routines were switched up as soon as the “novelty” wore off. By the time I returned to the clinic the following year, Daniel had decided to switch up his clinical interaction routine.

Having not seen Daniel in six months, his preferences for sociality were epitomical of the pervasive ways in which sociality is utilised by the human agent. Daniel had decided to not participate in verbal exchanges with anyone except shopkeepers. During his clozapine appointment, he had written on piece of scrap paper that he had lost his voice, and thus simply nodded along to the “routine” questions. When the nurse asked, going through the clozapine checklist, whether he currently smoked cigarettes, Daniel gave a more pronounced nod, before then looking over at me, eyes half rolling with a small grin that we quietly shared while the nurse’s attention was elsewhere, and then holding up his bottle of Coke Zero for more ‘evidence’ of his consumptions for her to account for.<sup>42</sup> Daniel and I had previously scheduled in an interview for the following week, however I received a text message from him when I got home from the clinic that day:

I hate 2 let you down, but just don’t feel like speaking 2 anyone (except random shop cashiers), I don’t mind communication non-verbally, my answers will be the same tho. Nothing 4 me has changed since we last talked, except my place of residence. If u have specific questions, I’m happy to answer them. If appointment nxt wk requires me 2 talk, it’s prob best I cancel. Really Sorry 4 the hassle. Dan.

I reassured him that it was no hassle, that I was happy to communicate non-verbally if he wanted, and we ended up arranging a non-verbal interview for the following day. As he wished, I asked Daniel questions verbally for him to respond to in writing, however he broke his silence a few times towards the end of the long interview to clarify things and thank me for allowing him to write instead of talk. My point here is that clinical rhythms need to work for both patient and clinical caregiver to flow and be productive, and that power and creativity should be fluid in this sense (Mol 2008).

Finally, patients took heed of the notion that blood work did not ‘move’ beyond the clinical circuit and clozapine clinic database. While I was in the UK there was a public call-out to donate blood. Upon hearing this, a patient at the clozapine clinic asked Clive why they could not donate their blood after it had been analysed because that it seemed like such a “waste” that it was simply discarded each month. Unlike the meanings of blood circulating through

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<sup>42</sup> Ramesh had left the clinic by this point and this nurse was filling in as the clozapine assistant until the clinic found a replacement. This nurse openly told both her manager and me that she did not want to take on this temporary role as she was unfamiliar with the clozapine protocol, but there was no one else available as Zoya was still recovering from the assault and Kerry had also taken indefinite leave due to her ill-health.

the social body and individual donors or recipients (Erwin 2006), the social contract at play was a short-lived yet open-ended exchange (insofar as ‘green’ results and clozapine are clinically valid for 28 day cycles). Just as clinical streams were continually channeled in the face of unpredictability, so, too, could patients re-channel what blood work meant by attending closely to implications of the blood markers inside their bodies.

### Blood markers and wider bodily networks under clozapine

Clozapine blood markers also included clozapine plasma levels, blood sugar levels, blood pressure and pulse and blood flow through the heart and body, which were checked and utilised by both staff and patients to gain reassurance and control. As I discuss further in Chapter Three, side effects of clozapine were, according to the UK clinic, generally more apparent when clozapine plasma levels are above the ‘therapeutic’ range (0.35-0.5). I observed that patients who were clinically regarded to be ‘higher functioning’ tended to be on ‘sub-therapeutic’ (exhibiting plasma levels below 0.35), rather than ‘therapeutic’ doses of clozapine, and therefore had fewer side effects to contend with. Patients on higher doses tended to not only experience more side effects, they were not clinically regarded to be improving in psychiatric functioning.

First, patients who did not comply with clozapine consumption were quickly identified by checking plasma levels. In the case of non-compliance, Clive hypothesised this to mean that patients were “stuck” somewhere between pleasing medical authorities enough to stay out of hospital (by attending the clozapine clinic) and taking back control by not taking their clozapine as they were otherwise advised. This, like in the case of parents of clinical caregivers being less receptive during clozapine clinic interactions, speaks to the kind of agency via ‘struggle’ that Jenkins (2015) posited. To unpack experiences further, though, the felt influence patients could have over clozapine blood plasma levels was more ambiguous than a push-pull between compliance and non-compliance.

UK patient participant Nathaniel, 36, felt himself able to negotiate the control of clozapine within his very blood stream, to the point where he had to be taken off clozapine for ‘objective’ reasons of blood readings that could not be agreed upon. Nathaniel told me:

The second time around on the blood test he [George] said “Nathaniel, you’re not taking the medication, I want you to come off of it,” because it’s dangerous for him

to prescribe something if I'm stockpiling it or not taking it. Now, I have no explanation *why* it read 0, and it, it's kind of like a losing battle for me because I *know* I was taking it, and he says no, and I know I was, and the results showed no. The only thing I can think of is that I *mitigated*, at every situation, so I tried to mitigate the effects of the medication. I smoke, and it does say that if you smoke it lowers the content of the medication. So, if I'm taking the medication, I might have 2 or 3 cigarettes within half an hour 45 mins to *lower* that stuff out of my blood stream.

Drawing on clinical discourse around nicotine and clozapine and the emphasis on blood indicators, Nathaniel navigated the extent to which clozapine could circulate through his body, which he reclaimed influence over, however questionably. He had been taken off clozapine and when I interviewed him again a year later, he was relying on nicotine to remedy his self-described memory and concentration difficulties. Nathaniel said to me, "our way of being is going through a change ... what gives my life *meaning* is *knowing* that we're going through this change." While this might suggest a relapse into 'delusional thinking' to a clinician, Nathaniel's sense of agency – drawing on clinical imagery about nicotine and clozapine interactions – suggested to me a more ordinary means of asserting a 'life project' for himself (Rapport 2003). Blood markers are continually subject to change and finding equilibriums<sup>43</sup> just as patients work toward finding 'an extended environmental homeostasis' that elicits a sense of freedom 'within which the self continues to flourish' (Rapport 2003:225).

Patients frequently drew on clinical discourse when explaining or predicting additional blood markers. Clive explained to me that, when people have "clozapine-resistant schizophrenia," there are augmentation strategies to enhance the effects of clozapine if blood plasma readings already exceed the therapeutic dose (above 0.5) *and* side effects are intolerable. Such clinical strategies change depending on the latest research: when I was in the UK clinic, aripiprazole, another atypical antipsychotic, was prescribed for patients exhibiting Obsessive-compulsive symptoms (OCS) and/or with increased appetite.<sup>44</sup> UK Patient participant Felix, 45, thus explained to Clive and me during a conversation about his OCS that it was "because clozapine has gone up in my blood." Arguably, there was also an opportunist, 'provisional

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<sup>43</sup> In the UK clinic, once the therapeutic level of clozapine blood plasma is ascertained, the clinical goal, too, was to start working towards lowering the dose of clozapine towards the 'sub-therapeutic' range.

<sup>44</sup> I discuss OCS further in Chapter Three. For patients complaining of sedation, on the other hand, amisulpride, another atypical antipsychotic, can be prescribed, however it raises prolactin levels – the hormone that triggers lactation. Clive checked for this side effect by subtly observing whether patients had raised breast tissue or wet patches on their clothing around the nipple area; a blood test was not necessary.

agency' (Weiner 2011) here that mirrors the nexus between objective and subjective interpretations.

Blood sugar level checking was something that required commitment on both the part of patient and the nurse. The Australian guidelines around additional 'physical' health monitoring were less regimented, out-of-date, from a different jurisdiction, and did not yet include nurses as part of the treatment circuit (but rather psychiatrists and GPs). Individual patient medical records were also attended to inconsistently by different members of the clinical circuit. It was thus often up to patients to clarify the validity of blood sugar testing. Blood sugar levels could not be tested unless the patient had not eaten for a number of hours, yet this was rarely clarified until blood readings were a cause for concern. For instance, one day when Australian patient Keith had a 'diabetic' level blood sugar reading, the nurse was alarmed, until Keith said he had just eaten "3 or 4 pieces of toast with jam"; when the nurse took the reading 20 minutes later, it had dropped to a 'normal' range. Another Australian patient, Phillip, 40, said to the nurse nearly immediately when entering the appointment: "I've just had lunch, so there's no point in doing my blood sugar." Patients became attuned to how clozapine and other consumptions could skew their blood markers, and this seemed to help them gain confidence in how clozapine impacted their bodily systems, generally.

As I build on in chapter Three, confidence in how the act of consuming clozapine was first negotiated before it could be incorporated into a system of personal beneficiaries allowed patients to interpret the monitoring process for themselves. During an interview with me, Ned said that he had at first been cynical about clozapine, thinking "I'm not gonna take this because it's not gonna work ... I can rough this out on my own, I can, you know, make myself better" but "when I first started taking it I could see myself getting better." He added, "it does knock you around to begin with ... I just remember sitting there and not being aware of what's going on around me, and just being really sleepy ... after about 2 weeks, I started feeling a bit better" – namely, in regard to an embodied "concentration" (to be discussed in Chapter Four). Like many participants, he resolved the side effect of salivating at night ("just gotta' wash the pillows") and bed-wetting ("you've just gotta wash [the sheets] more regularly"). As the bed-wetting had now stopped, I asked him what he thought this might be due to, to which he responded:

I guess, ah... I don't know, it might have been me sub-consciously, like, going 'okay this is bad,' and now I wake up, go to the toilet, go back to sleep ... put[ting] a bit more emphasis on it ... it probably would've seemed like a really... bad thing to begin with, and that's probably stuck in my head, so, if I even feel... I try not to drink water before I got to bed as well.

Therefore, although Ned subscribed to clinical explications on the whole, his embodied 'self-intensity' and creativity (Rapport 2003) was still apparent: he felt himself to be able to control the bed-wetting by both limiting water intake before bed and "sub-consciously" deciding that it was a "bad thing" to be mitigated by his personal "emphasis on it." An individual's agency can extend to what ebbs and flows through the body in ways that complement, not merely resist, implications of being on clozapine and undertaking physiological monitoring.

## Conclusion

This chapter has argued that accountability and agency over clozapine and blood work enters both patients and staff into a fluid contract of compliance and creativity, whereby control is with the patient insofar as they are willing to consume clozapine and to have blood tests. There are, however, circuitry blockages to navigate, both within individual bodies and between clinical checkpoints, which are continual but most pronounced upon clozapine initiation. While for some, the clozapine clinic could constitute a form of 'struggle' outweighed by 'endurance' (Jenkins 2015), this manifested in ways that could not be reduced to schizophrenia per se. Clozapine patients engaged in blood work in ways that paralleled Mol's (2008) 'logic of care,' where their personal input was both necessary for clinical efficiency and their own assertions of agency throughout biological processes that are otherwise understood to be beyond clinical and patient reach.

I observed blood work to be dynamic and relational, involving personalised interpretations and agentic practices. Patients were able to experience the monitoring process in ways that went toward fulfilling a need for 'social contact at a distance.' The clozapine clinic was a space in which patients did not feel intimately threatened the way they might otherwise feel if more direct social interaction is expected of them. Further, the deployment of what Rapport (2003) described as an embodied 'self-intensity' is afforded to anybody, no matter their circumstances, because, 'no other knowledge matches the potential self-knowledge that the body possesses ... the immediacy and inescapability that it can know itself – and no other can

know it in the same way' (Rapport 2003:220). As Rapport's quote at the beginning of this chapter posited, '[e]xternal forms impinge on the individual's life-world, but there is no necessary, direct, singular or essential effect that they have within it' (2003:259). In Chapter Three, I discuss how mind-body imageries pertaining to clozapine treatment and health were actively drawn on by patients to similarly complement personalised desires.

### Chapter Three: Working with Ambiguities and Mind-Body Imaginaries

UK patient Robert, 48, appeared to me significantly older than he was, and, like a number of patients, seemed to me to have visibly aged even between my two field visits. He had been on clozapine for 15 years, and said that it made him “feel better in some ways, and in some ways, I feel worse”; “it seems to me like it works, the more you take it, the better it works, for me *personally*.” His dose was in the higher range (575 milligrams, going up to 625 milligrams by the time we parted ways for the final time a year later). While considering himself to be “so happy spiritually” due to regular Jehovah’s Witness engagements, Robert felt less confident when it came to his “physical” and “emotional” health. As well as taking clozapine for schizophrenia, Robert took medications for Type II diabetes mellitus, high cholesterol, blood clots and constipation, and was “used to” frequent stomach pains, dizziness, a hernia, and chest pains – the latter of which he attributed to smoking cigarettes. When I asked him about his Type II diabetes, he said, “I know it’s diet controlled”; “I just take metformin”; “blood sugar levels are fine, so, um, nothing to worry about.” In regard to the “piles,” which he did associate with clozapine, he said that, relative to previous experiences of “quite large, ah, ruptures,” he felt that “in the last couple of years it’s been much better,” with “hardly any bleeding and my bowel routes are quite good.” He had Weetbix and laxatives every morning. Of his general diet, he reflected, “I don’t eat *too* badly, I have lots of fruit smoothies and, ah, I could eat a bit more veg to be honest ... I do love takeaways occasionally, which aren’t very good for you, obviously, but I try and have proper meals when I can,” and “I have fat free and sugar free, and things to lose you weight.” Robert was keen to remind me, “I’m not the worst-off person in the world, am I! ... I’m on clozapine, so – a lot of people who are on it have stomachs out here [gestures], so, um, I think I did quite well.”

In regard to seeing a GP, Robert said, “I’m gonna have a health check soon ... I think you’re supposed to have them once a year but I haven’t had one for quite a few years.” Robert was reluctant to follow up concerns about his chest pains with the nurse. When I insisted we tell nurse Clive, after no action was taken by Robert over the course of a few visits to the clinic, he agreed and Clive offered to book him into the GP. But Robert politely brushed it off and said he would call the GP himself. It was a Tuesday, and when Clive asked when he would call the GP, Robert replied, “on Thursday.” Clive suggested sooner, “such as this afternoon” (it was currently still morning). They compromised on “tomorrow.” Robert thanked us all for

“caring.” I later asked if he thought the GP will think his health will be “okay.” He replied, with a nervous laugh, “not really, no.” Robert mentioned that when he had last followed up with a GP about his longer-term chest pains, they “thought it was, um, psychosomatic, you know, in my brain – but I don’t; I think it’s the smoking.” Robert’s main incentive for potentially quitting smoking was that “Jehovah’s witnesses believe that it pollutes your body.” “He [Jehovah] knows our bodies better than we do,” Robert posited, and in regard to what Jehovah would think of his body, “he wouldn’t be very pleased with it.”<sup>45</sup> Although, Robert neutralised: “I pray to Jehovah and give him all of my problems.” As for what health meant, he said “healthy body, or healthy mind”; “I suppose they’re related.” Robert described himself as often “suffering” with ongoing “paranoia and anxiety” and “quite a lot of head pain.” Every day between 2pm and 6pm Robert would lie down, which he explained “rests my body” and alleviated his chest pains. “I find mental illness very emotionally and physically straining, and that’s why I need to lie down.”

In continuing my explication of how patients achieve health agency through the very confinements that might be understood to disempower patients, this chapter turns to how the ambiguous impacts of clozapine and mind-body compartmentalisations are reworked and complimented by patients – as well as clinical caregivers – to maximise potentials for health. I explore how patients partake in interpreting and regulating the ways in which clozapine impacts their ‘minds’ and ‘bodies,’ and how these superficial dualisms become as useful as they are delimiting in terms of negotiating experiences of ‘health.’

I argue that due to the ambiguity in clinical knowledge and how it is enacted, experiences of clozapine treatment yoke both ‘mind’ and ‘body’ imageries that are open to continual reworking by patients. While the concept of ‘mind-over-body’ did feature heavily in patients’ experiences, so, too, did bodily activities inform feelings of a healthy mind. In exploring the manifestation of health agency via clinical and experiential ambiguities, I address the public health questions of apparent ‘health gap’ trajectories that truncate life spans and challenge

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<sup>45</sup> Robert added that, “you know, Jesus didn’t smoke when he was on Earth.” I tried to keep the question open by responding: “well, you never know! Maybe there weren’t any cigarettes available?” Robert responded, gravely, “yeah, well, he wouldn’t anyway, too perfect really.” This notion of Jehovah being “perfect” was not, though, something he felt to be necessary for his own general well-being. Although Robert was well aware that smoking “polluted” his body, and he intended to quit, he had not been totally stagnant in his efforts: He had cut down his cigarette smoking from “30 or 40” to “20 a day” over the last few decades, and had recently purchased an “e-cigarette starter kit.” He also mentioned a card he had for the local community Quit service, to “maybe see if I can see if I can have a one-on-one session.” Of e-cigarettes, he said, “the good thing is you can smoke it just like a cigarette ... except you don’t get the... you get the nicotine but you don’t get anything else, the tar or the chemicals.” Alas, “sometimes I just forget, and then sometimes it’s motivation ... I haven’t used it much to be honest ... will start using it again tomorrow morning.”

clinicians in the context of what ‘recovery’ means. In regard to antipsychotic drug use, the constitution of selfhood can be situated within transient meanings arising from the experience of ingestion and the imaginary pertaining to biological explanations (Jenkins 2010). Although agents may be interpreted as ‘neutered’ and deadened by the input of clozapine as the active (drug) agent controlling one’s insides (Jenkins 2010:29), it was the notion of patients themselves searching for an equilibrium or a ‘biochemical balance’ (Jenkins 2010:36) that was most evident in my participants’ experiences.

The notion of equilibrium however can be expanded further when considering where ‘health’ resides and what it feels like in terms of mind-body stasis beyond clozapine. My central phenomenological questions to patients concerned the *feelings* of taking clozapine, having schizophrenia, and experiencing health and ill health. As discussed in Chapter Two, patient engagements with blood work suggested pursuits of participants’ ‘extended environmental homeostasis’ Rapport (2003:225). I demonstrate how, in the context of clozapine treatment, this homeostasis draws on personalised consumption relationships, as well as biochemical, and clinical imaginaries and ambiguities.

### Health in fluid terms

Clozapine patients were able to experience and reconnect their health despite the effects of clozapine that suggest a totalising power adhering to a ‘mental’ stability at the expense of ‘social’ and ‘physical’ health. Patients undertook this in ways that speak to ‘existential power’ (self-energy), which arises from forms of both ‘democratic violence’ and ‘nihilistic violence’ (Rapport 2003). ‘Democratic violence,’ Rapport (2003:250-251) explained, draws on Wallace’s attention to ‘equivalence structures’ and ‘contracts,’ where ‘[i]ndividuals learn to trust that in certain routine situations others’ behaviour is predictable, and can be habitually and confidently interrelated with actions of their own.’ As described in the previous chapter, predictability and accountability at the clozapine clinic also accords with Mol’s (2008) ‘logic of care.’ Rapport (2003:251) attended to the ‘individual construction of a diversity of possibly incompatible and mutually contradictory life-projects and world-views – living beneath an ambiguous surface of social-structural calm, within behavioural contracts that individuals continue to share.’ When opportunities for anticipatory interactions break down this constitutes ‘nihilistic violence.’ Yet, even in this latter case, individuals persist on their own terms.

Rapport (2003) took the case of the Jewish Holocaust survivor Primo Levi, who took it upon himself to write about those who did not survive the '*Lager*' (literally meaning 'warehouse' in German and the word Levi used to describe Nazi concentration camps) who nonetheless did not feel totally dominated by the fate of the gas chamber closing in on them. Rapport (2003:248) posited that, if we think about the concentration camp as a 'place' where 'hundreds of thousands of different lives were led and lost, made up of countless experiences and interactions,' then we 'continue the Nazis' dehumanizing process of massification.' Rather, we can appreciate individuals' imaginations of being 'elsewhere.' To take the extreme case of 'violence beyond logic' in the *Lager*, 'it was not symbolic negotiation or exchange to which one (powerful) party to the interaction was interested, but physical obliteration' (Rapport 2003:250). Yet, the smallest persistence of individual character can help people to feel free, however momentarily. Levi observed a man who, when merely exhibiting '[a] gesture of his, a word, a smile had a liberating virtue, they were a rip in the fabric of the *Lager*' (in Rapport 2003: 255). There was still room for an individuals' power to be felt.

I am not saying that clozapine treatment monitoring can be assimilated with brutal and totalitarian regimes like that of Levi's *Lager*, wherein people were 'confined to the present by feelings of hunger, fatigue, cold and fear; they lived without reasoning, reflecting, observing, comparing, remembering, or expressing themselves' (Rapport 2003:244). As has already been suggested insofar as the blood work goes, patients can express themselves within the monitoring regimen and creatively manipulate the physiological and clinical processes of which they are otherwise seen to be merely subject to. *However*, all clozapine patients face circumstances that can threaten their lives in ways that seem, from the outside, deterministic. If patients stop taking clozapine at regular intervals, their situations could quickly become fatal due to blood issues alone. In continuing to take clozapine, it could still kill patients (quickly or slowly). Australian patient Trent, 24, was fearful of this: "it can *kill you*" (Brown & Dennis 2017:373). Taking clozapine daily could also be accompanied by a feeling of confinement. In Chapter Two, Australian patient Charlie, 35, had described his daily doses of clozapine as "liquid handcuffs ... a form of control". Clozapine treatment became more mundane and 'controllable', however, the longer a person took the drug (Trent and Charlie were clozapine newcomers). The regimen thus aligned much more with 'democratic violence' than 'nihilistic violence'. Yet because clozapine itself was understood by all to

represent an ongoing danger at the same time as providing security and structure, there were ongoing ambiguities to manage.

The plethora of unknowns could be interpreted either way, and it was such flexibility in interpretation that became productive for both clinical caregivers and patients. Just as those subjected to confinement and death in the *Lager* all ‘lived (and died) the *Lager* in their own way’ (Rapport 2003:247), clozapine-treated schizophrenia patients found health (and interpreted life-threatening side effects) in their own way. This was amenable to a clinical rendering of patients as individual people, responding to the drug in different ways.

Contrary to what one might see from the outside, Clozapine patients were able to negotiate what their health meant and subsequently prioritise ‘parts’ of it in their own terms, to yield a holistic feeling of control over their lives. While this was not the same as negotiating life in the *Lager*, patients were able to supersede clinical attempts of managing their clozapine dose to alleviate clozapine side effects. Patients were, in Rapport’s (2003) footings, able to steer the implications of clozapine side effects as being simultaneously within and beyond their control. An individual’s ‘power,’ Rapport (2003:82) said:

[I]s an attribute of individual being – an energy, a drive – which is constant even as the outward form of things and relations to which it gives rise change. There is at once, then, a constancy to power and a diversity *and* fluidity concerning its effects ... Analytically, however, one might say that all behaviour is one: embodiment of an existential drive to make sense and maintain individual-plus-environment.  
(original emphasis)

When it came to clozapine, people exerted a certain determination to achieve a personally felt homeostasis in regard to the impacts of clozapine. No one could be sure of how clozapine or individual efforts worked or did not work in desired ways, but patients worked productively with this fluidity of power.

Predictable clinical interactions could help this process. For instance, UK patient, Kevin, 34, and nurse Clive remained open minded about concerns and options during one of Kevin’s ‘physical health’ checks.<sup>46</sup> Kevin first mentioned that his mother had suggested he ask for a clozapine dose reduction, because he had been feeling drowsy. Clive said this was possible.

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<sup>46</sup> Clive was filling in for Narelle, who was attending a nurse training course.

Kevin then continued, “I’m getting a bit fat, aren’t I? I don’t know why, though – I exercise all the time and I eat well; I don’t snack.” Kevin always wore his “exercise gear,” attending the clinic in between playing golf or tennis or going to the gym. As he sat in the chair in front of us, he squeezed the bulge around his belly, and suggested, “it must be the clozapine – do you think so?” Kevin was now looking around and directing the questions to both Clive and me. I said nothing, while Clive nodded a few times, considering the proposition, before replying, “but it can be managed.” Namely, through dose reduction and/or more regimented diet and exercise.

The idea that clozapine-associated weight gain could be managed allowed patients to decide for themselves how much they were willing to compromise. Clive asked Kevin to stand on the weight scale, with a height measure attached, and got me to go over and read out the measurements to him so he could type them into Kevin’s file notes and calculate his current Body Mass Index (BMI).<sup>47</sup> Kevin’s BMI reading was in the ‘obese’ range. Kevin told us that his father had recently lost weight by cutting down his portion size, and asked Clive if he should try this too. Clive suggested that he instead try to substitute more of the foods on his plate for vegetables.

When I interviewed Kevin a month later, he did not recall the advice about portion size, but had decided that he would like to “try” getting his clozapine dose lowered. He felt fearful of this resulting in “relapse,” but after consulting further with clinical staff, including his psychiatrist, Kate, it was decided that it was worth trying because he was, relatively, ‘mentally’ stable. Besides, Kevin was on a higher dose of clozapine, yielding higher plasma levels, and Clive had said to me during another conversation, “from what we’ve observed here, those patients with weight gain that is shooting up, when you check the plasma levels, they’re *really* up there, you see, even if they’re not out of the range, but they’re always, like, hmmm...” Then again, altering Kevin’s clozapine dose did not simply translate to weight loss. The apparent and embodied effects of clozapine were once again open to Kevin’s remaking.

Experimenting with Kevin’s dose did not reduce the ambiguity nor expectations about

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<sup>47</sup> Body Mass Index ‘is calculated by dividing your weight (in kilograms) by your height (in metres squared)’ and places people in categories ranging from ‘underweight’ to ‘obese’, indicating chronic disease risk factors (Heart Foundation 2018).

clozapine. The situational ‘logic’ ensuring a clear ‘democratic’ rather than ‘nihilistic violence’ slipped, but the ‘diversity of individually created meanings’ pertaining to a ‘democratic violence’ was still available (Rapport 2003:253). By the time I interviewed him a year later, Kevin had asked to have his clozapine dose reduced slightly further so he would have more energy to exercise, but this was for his ‘mental’ rather than ‘physical’ health. Kevin had not noticed any changes in his ‘mental’ state since lowering the dose so far, yet was nonetheless cautious in asking for further reduction just in case this resulted in more “paranoid thoughts.” Contrary to clinical expectations, Kevin had put on some more weight and recalled a recent bout of what he described as “physical problems,” which amounted to being “very tired ... I just lost all my energy,” such that he could not exercise for a month. Kevin told me that he pursued sports for “a combination of keeping busy, and I just enjoy it.” Playing golf, in particular, “is good for my frame of mind,” and “if I’m concentrating on my sports I’m not concentrating on *myself* ... I don’t worry about mental illness, not in my focus; sports are in my focus.”<sup>48</sup> I thus assumed that, for Kevin, exercising improved his ‘mental’ rather than ‘physical’ health.

Yet, as Rapport (2003:43) posited, ‘human beings refuse to take conceptual absolutes too seriously ... irony represents an endemic reaction against [what philosopher Richard Rorty referred to as] ‘final vocabularies’’. When I asked if not exercising had therefore impacted Kevin’s “mental health,” he replied, “I don’t think so.” I said that I wondered about the impact of exercise on mood. He shrugged, “my mum always says exercise makes you feel happier but I don’t notice anything.”<sup>49</sup> This was despite him saying earlier that he enjoyed sport. Rapport (2003:54) distinguishes between ‘because’ and ‘in-order-to’ reasoning that people make, the former hinging on external determinants and the latter referring to ‘individuals’ infinite and ever-vital imaginations exist[ing] on their own terms, beyond the sway of the intentions of others.’ While Kevin had been taking on board ‘because motives,’ his experiences of health aligned more with ‘in-order-to motives’ in terms his personal reasoning. Kevin had taken on board clinical advice (such as not eating in between meals and trying to eat “well,” such as eating more vegetables), and had been eating more “salads” to try to lose weight. He was also contemplating a caloric restriction diet on his mother’s

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<sup>48</sup> This theme of ‘focus’ in regard to the notion of ‘flow’ is discussed in Chapter Four.

<sup>49</sup> Very few patients did experience this endorphin rush, and when I spoke with psychiatrists about it they were curious but unclear whether this was another side effect of clozapine or something to do with the individual, as I explain later in this section.

recommendation.<sup>50</sup> Alas, he said, “the problem is that, *I enjoy my food so much*, I’m not sure I wanna *starve* myself ... I might have a little extra weight on my hands but I don’t wanna change my eating habits”. He reiterated, “my main pleasures are probably golf, playing tennis, having a nice meal.”<sup>51</sup> This is not unique to how anybody might reason their ‘health’ behaviours should they have to explain them. Further, Kevin persisted with sports primarily because it helped his “frame of mind” – his chief concern, and although not quite fitting the clinical imaginary, ‘mental’ health was also the clozapine clinic’s chief concern. Clive’s suggestion that Kevin’s weight gain “can be managed” translated to Kevin’s sense of being able to choose for himself.

Being able to choose for oneself extended to reclaiming different ‘parts’ of one’s health, to produce a dominant sense of agency over the impacts of clozapine. Australian patient Angus, 39, who had been taking clozapine for over ten years, said of his ‘health’ experiences, while pushing firmly down at his large stomach, “it’d depend on what it’s about – I’ve got bad parts, like, I’m gaining weight, but also my mental state is alright... [ex]cept for, other things that happen,” such as, “I get this problem with my brain, I feel gravity, it’s, I feel like I’m being pulled towards the centre of the earth ... I just feel like a drop.” He attributed this to clozapine. Angus had also associated the drug with his ongoing constipation, which became “really uncomfortable” when his bowel “presses up” on the metal plates in his pelvis (a consequence of one of several pre-clozapine suicide attempts). Angus described how the properties of clozapine tablets were problematic for him insofar as “they don’t have lactose,” making them “very *dry*” – “I think they said the milk makes it easier to digest into you ... maybe it’s [a clozapine tablet] not passing through you as well.”<sup>52</sup> Angus preferred not to take his prescribed laxative every day (“I’d rather just take it when I need it”), and had recently started drinking a probiotic drink, which “actually really helps with the insides, so that’s one good thing; it’s what I’ll use now.” He said he used to rely on cannabis to help with his bowel movements but this had compromised his ‘mental’ health too much. Personal compatibility was important to Angus: Clozapine had “a power about it” because he understood it to be “from the UK, and that’s where *I’m* from.” Angus was negotiating his weight gain on his own terms as well:

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<sup>50</sup> Namely, Michael Mosley’s popular 5:2 diet, where you limit your caloric intake to 500-600 calories per day on two days each week and eat normally for the other five days (Mosely & Spencer 2015).

<sup>51</sup> Kevin also played golf and tennis for “social reasons.”

<sup>52</sup> Angus also suspected clozapine made him “allergic to cow’s milk,” as when he had since tried other medications *with* lactose they had not been “working properly.”

I'm sort of doing exercise everyday – just crunches and walking every day, some weights as well ... I don't wanna keep getting bigger and bigger, and I've seen people on this medication die from it, what I perceive as they did die from it ... heart attack, or brain problem, strokes ... sometimes I feel this dropping feeling is like a stroke ... I've been on blood pressure medication, but now I've stopped taking that, it's gone back to normal, but that's from a lot of work, just trying to walk every day.

Although making particular efforts to exercise, in regard to his diet Angus remarked: “I know what's right to eat and what's not, I just eat too much, it's like just being hungry all the time, and that's what makes you hungrier as well.” Angus had previously quit smoking due to a “partially collapsed lung.” “I've swapped from unhealthy cigarettes to unhealthy eating,” he reflected. He now enjoyed eating because his ability to taste food had returned, such that he found food “addictive.” Angus had dreams about smoking and contemplated starting up again, “to lose weight” by suppressing his appetite, but had resolved that, “it's good just to live every day, and enjoy every day.” He liked to eat “both healthy and unhealthy foods,” and would do one big shop on pension day to cover this range – although it was usually the “vegies” that were eaten last, toward the end of the fortnight. Angus drank “not much soft drink anymore,” and found that “cranberry juice helps” because it is “full of vitamin C.” Angus, like Robert and many others, felt an ordinary sense of well-being: “we've all got things going on with us ... there's people overseas that have it a lot worse than I have.” He made of his situation and knowledge about clozapine what he could, yielding agency and a sense of relative ‘health’ in light of his past experiences, what he had yielded to be presently reliable, and how he imagined the situations of others. Furthermore, patients decided for themselves how particular consumption practices impacted them, combining experiential and clinical knowledge.

### Cleansing consumptions

Patients spoke to me of certain health consumption behaviours they did persist with, to ensure some kind of health with, in spite of other consumptions. I have observed people in all walks of life to draw on various kinds of information in deciding on their consumption practices, imagining how these practices will or will not mitigate potential ill-health. Indeed, I myself have several daily food remedies that I have adopted over the years. Some reflect common health imaginary, like eating muesli every morning, while other remedies are a little more personalised. For instance, to ward off feelings of being run down during fieldwork, I started

to make an ‘anti-inflammatory’ and ‘cleansing’ homemade drink consisting of turmeric, black pepper and apple cider vinegar. This recipe is based on information that I have heard about these ingredients, along with positive *experiential* feedback. In continuing to consume it each day, I *feel* like I am protecting my health. There is no certainty in this remedy, but it informs my health agency and has become reliable in my lived experience.

This phenomenon is vividly reflected in what Warin (2010) found with her ethnographic participants with anorexia, whose conditions she de-spectacularised. By drawing on wider discourse that one has “read somewhere” (or heard somewhere), and the ‘embodied effects’ of consumption, people can work toward minimising the ‘indeterminacy’ of what ‘ingestion’ might result in (Warin 2010:117). Warin observed that, ‘[a]norexia was a practice that removed the threat of abjection’ in regard to food (2010: 127). Warin (2010:112) situated the experiential ‘object’ between the structuralist, ‘semantics’ approach of Douglas (1966) and the psychoanalytic, ‘subjectivity’ approach of Kristeva (1982), to explicate the consumption experiences of ‘clean’ and ‘dirty’ foods for her ethnographic participants. Arguably, like I do with my turmeric drink, clozapine patients felt able to negate ‘dirty’ health experiences through a process of counter-balancing with ‘clean’ consumptions.

While feelings of health efficacy via consumption was mostly through making daily efforts to eat something consistently perceived to be “healthy,” in spite of other “unhealthy” cravings or consumptions, it should first be acknowledged that some patients engaged in more *imaginative* means of expelling “unhealthy” consumptions. For instance, Australian patient Liam, 38, said to me when we started talking about body weight, “I’m a bit obese.” He then described taking religious steps to expel unhealthy elements from his food and drink, explaining how he ate:

Liam: Lean meals – low fat, low sugar. When I eat and drink a lot of fat and sugar, I do a prayer to God and he takes away the fat and sugar and leaves all the protein and the vitamins and minerals and the complex carbohydrates and all of that. It’s like I’ve eaten less fat.

JB: Wow! So that works to eliminate-?

Liam: Yeah, the fat and sugar. I’ve lost weight recently because I’ve been drinking sugar free energy drinks and sugar free cola.

While I could not discern whether or not Liam had recently switched to “sugar free” drinks, Liam reasoned that praying to God eliminated fat and sugar from his body in the same way

that drinking sugar-free drinks and eating “lean meals” would. While he attributed weight loss to the latter, praying made him feel “like I’ve eaten less fat”, when he had actually consumed “a lot of fat.” Liam’s intention was to mitigate “fat and sugar,” aligning with clinical advice he had been given but not always subscribing to it in ways that would be appreciated by the clinic. During one of Liam’s appointments with nurse Ramesh, Liam posited: “I’ve lost weight ... how much weight have I lost?” Ramesh did not respond as he was entering Liam’s current weight into the computer. When Liam left, I asked Ramesh whether Liam had indeed lost weight and Ramesh responded, “I don’t think he’s lost; he may have gained.” He then checked for me: “he was 111.8, now he’s 111 – might have been the keys [during the previous weigh in].” Ramesh sighed, “I don’t bother.”

Just as health professionals in Warin’s study tended to assume that people with anorexia ‘take everyday, common-sense dietary guidelines to the extreme’ (2010:105), clozapine clinical caregivers sometimes assumed that greater *awareness* of strategies to overcome weight gain would result in greater uptake of ‘health’ behaviours. UK Pharmacist Ros commented: “we tend to assume that there’s so much stuff in the media generally that people are aware of the benefits of exercise, or that switching from sugar in your tea to sweeteners in your tea can mean that you can have a fairly painless reduction in your dietary intake, but I’m sometimes surprised by how *little* our patients seem to be aware of that.” I found, however, that patients’ reasoning for sugar intake, in particular, was about a reapplication of information for one’s own purposes rather than a dismissing of this information altogether.

Arguably, the abandonment of a singular imaginary for one consumption behavior across different contexts helped to produce a non-confined sense of well-being through feelings of infinite potentiality. As Kapferer (2003) and Dennis (2016) posited, the way in which contradictory practices can be understood may not concern a means of compensation (a functionalist understanding), but rather by considering such logics as a means of innovative praxis. Herein, context-specific health logics become powerful tools of self-assertion.

Patients worked within the logics that suited their needs at hand, and a central motif for sugar consumption was premised on the intention to generate energy even if patients were otherwise living with Type II diabetes that they also associated with sugar. When taking clozapine at a time of day when they did not want to fall asleep, patients looked to preserve their ‘mental’ energy by consuming highly caffeinated or sugar-based foods and drinks. UK

patient Luke, 45, said of energy drinks, “I need the energy don’t I, to motivate myself, sort of pick me up ... I need to pick myself up to feel positive.” UK participant Alan, 43, addressed his clozapine-induced Type II diabetes by “cut[ting] out about 60 per cent of my sucrose intake.” Alan, however, explained to me that he also deliberately consumed sugar to counteract drowsiness, which he felt to be an ephemeral and negotiable side-effect of clozapine:

Well, I take my dose of clozaril [a brand name of clozapine], between half 3 and half 4, and have been, and it has a very sedative, *soporific* effect - what I mean by that is that it can knock you... into being sort of like a, very tired, very dizzy, ah, but what I do about *that* is, after I take my clozaril, is perk myself up a bit with a snack. Like I take some fructose or, or sugar or, you know, ‘couple of biscuits.

Alan was more concerned by the immediate impacts, and momentum he could build. He was aware of the different forms of sugar available to him and consumed it in a selective way to mitigate the “*soporific* effect” of clozapine. Consuming sugar after consuming clozapine became quite a separate matter from his diabetes concerns. Alan took separate pieces of information about sugar: that, a) he needed to “cut out” his “sucrose” as it contributed to his diabetes, a longer- term side effect of clozapine; and that, b) “fructose” or general “sugar” (such as “biscuits”) could be useful when it came to countering the more immediately undesired side effect of clozapine. The two (contradictory) associations were irrelevant to one another when it comes to feelings of fatigue and the desire for feeling more in control in the moment.

Sugar could also be felt to alleviate ‘mental’ health symptoms. UK patient Christopher, who also had Type II diabetes, supplemented clozapine with sugar-based foods. Christopher explained to me, “when the voices are worse, I have to eat more.” He said, “they’ve used that appetite to their own advantage, really, so, that’s how the voices and the thoughts pick up on things - you’ve got the true hunger in your appetite, but they pick up on these appetites and they use them in a different way.” Christopher continued,

There is a big link between eating and how much the brain is working, really. It’s all linked together. Food, stress, concentration, medicine, and all this stuff ... I’m trying to eat better. When I’m hungry, and I need to eat something fast ... It’s hard to cook... cooking with a numb mind isn’t the best thing, burning things, making big messes that you’ve got clean up and all that kind of stuff. It’s kind of off-putting when you’re hungry and you’re able to cook Bolognese and there’s all these different things to do.

Christopher reasoned, “it’s just sugar, really, because I got diabetes as well - my blood sugar can go quite low and get kind of hypo type thing.” He – unlike some patients – did directly link his diabetes to clozapine, explaining, “when I was first in the hospital on clozapine, I was eating about six bowls of cereal with sugar on it every morning - basically, that’s the rituals you have there: food, medicines, cups of tea, cigarettes.” Yet Christopher’s needs for sugar were, at the same time, normalised:

Different situations take more sugar. In a supermarket, sometimes it’s a bit of a weird place for me. Sometimes I feel that there’s something going on in there. It’s like the Savannah, it’s like the watering hole, where everyone goes to drink water and replenish their supplies and everything like that, and, um, so yeah. You’ve got different kinds of animals, some predators, some not, some birds, some can fly away and things like that. So, I go there and find it quite stressful. So, getting a bit stressed, then realizing ‘oh, yeah, I’m stressed, what’s happening there?’- ‘oh, right, eat something.’ And it brings the sugar back up and it brings you back to a level where... I don’t fully understand it, but yeah.

Christopher saw his needs for sugar and food as context dependent but ultimately something that brought him back to an environmental homeostasis (Rapport 2003). He also held out potentiality for overcoming stress altogether: “at the end of the day, I think that the virtuous things will win out, but there’s a lot of pain along the way.” He felt he just needed to “keep trotting on, keep my brain safe, trying to do what’s right.”

Patients’ intentions were very much toward improving their health, and specific foods were seen as a source of ‘mental’ nourishment. UK patient, Ian, 40, commented, “the food I consume makes me feel good - it stops, um, mental illness.” Ian was conscientious of what he ate and planned his mealtimes:

In the evening, I’ll have bolognese or chicken, I buy weight watchers. In the afternoon, I have a lunch time meal, I might have a small portion of food, yeah, like a few portions of fruits, and a drink, that’s all I have, yeah. If I’m hungry I’ll have a sandwich, a toasted cheese sandwich ... then in the morning, Alpine Porridge or breakfast cereal ... food, makes me feel good yeah.

When I asked Ian in what ways these foods made him feel better, he replied, “I don’t know, just makes me feel good, yeah?” I asked if there were any other particular foods, and he replied:

Ian: Bolognaise, bolognaise, yeah

JB: And describe to me how you feel after you've had the bolognaise?

Ian: I just feel much happier yeah? Yeah

JB: So, is it a mood thing or *physically* do you feel better?

Ian: Not sure, not sure, I don't know.

Somewhat similarly to Ian's desire for foods that give simple 'happiness,' Australian patient Daisy, 51, had said to me before an interview that she wanted some "hot chips" and that, "I need my sugar hit" – proudly showing me her "special" blood orange soft drink bottle. She later said of what the term health meant, "my tummy, when it's happy." I asked Daisy if she was happy now, and she said, "very happy, because I'm eating chips now." She was not actually eating chips yet, but the imaginary of eating them after our interview seemed to be enough. I asked if there were any other foods that made her and her tummy happy and she replied (with a cheeky laugh), "chocolate coated ice-creams!"

Some patients did not imagine a direct relationship between clozapine and their weight gain, and weight gain was sometimes felt to be a "healthy" thing based on initial positive feedback they had received about their appetites during the medical treatments. UK patient Hugo, 25, said, "I've put on some weight in the last couple of years ... my Mum reckons it's [be]cause of the clozapine, but I'm not sure." UK patient Josh, 48, had developed Type II diabetes that he said was brought on from eating "too much sugar" but not because of clozapine per se. When I asked him about what health meant he said, "if you're healthy you have to eat food, don't ya? Sometimes if you eat too less it's *unhealthy* innit?" Josh told me that he had inadvertently lost weight some time ago while living in supported housing, and "they made me go see the GP and he took some blood, and he said that my blood's very good - you know, the [caregivers at the] house said I must *eat* well." The former advice gave Josh reassurance and hope for his health while the latter advice gave him reason to eat more (not less, despite his weight loss not yielding worrying blood results). Moreover, when Australian patient Max, 36, said that one of the factors that made him feel in control was "eating well," he elaborated that this meant "good food! Something that's yummy, hearty, filling." Appetites on clozapine could be seen as health-giving rather than health-destroying.

The meaning of 'healthy food' primarily pertained to notions of 'hearty meals' and were associated with the nourishment first experienced in hospital. Many patients told me how the

weight gain began in hospital as a part of being cared for (such that eating anything at all felt like a step toward health). For instance, UK patient Robert, who described hospital as a “refuge” said: “I had meals, you know three or four times a day, cooked for me, nice meals, tasty meals.” UK patient Alice, 36, who was ‘morbidly obese’ by clinic measurements, said to me that she used to be “underweight if anything” when she first went into hospital some ten years earlier, recalling that “the nurses would watch” her “to make sure I ate every meal.”

Another aspect to consuming food in conjunction with clozapine was about healthful feelings of freedom to choose for oneself what to make of one’s circumstances, as distinct from being in hospital where patients often had little or no freedom to choose their food. As suggested above, grocery shopping constituted an important structure in many patients’ fortnightly routines. UK patient Holly, 40, recalled,

Holly: The day I was put on clozapine, I asked them, ‘can I go to the supermarket?’ and they said yes, and I bought loads of chocolate!

JB: So, do you get particular cravings because of the clozapine, or?

Holly: Yeah, I do. Certain things, like I think of a jam tart or if, like, I see like a cake on television, like a carrot cake, I’d have to have that specific thing.

Holly enjoyed being able to satiate her desire for a “specific thing.” Australian patient Ned, 27, also said, “I get cravings all the time, like you get cravings to eat fast food ... when you first start taking clozapine you just eat, eat whatever, like you’ll be going through Mars Bars and noodles and takeaways.”

Patients who had lost weight – after initially gaining it during clozapine treatment – did so by feeling able to find a balance themselves. UK patient Tom, 54, said that he would advise clozapine newcomers to “be careful of the high dosage, and then also to do some researching on the internet maybe, and watch your weight – [be]cause you’re gonna get that, you’re gonna get fatigued, you’re not gonna be able to have so much energy... you’re gonna get drowsiness in the morning and you’re gonna put the weight on – do you want that?” When I asked if there was a way, then, to “prevent” weight gain despite higher doses, Tom answered, “yeah probably, yeah, I don’t know, I don’t know if I would’ve stopped if someone had told me what I know now – would I have grasped it, would I have understood it, which is – so easy if you can get something to relieve the... schizophrenia ... but now I’ve got the happy balance, so it’s alright now.”

Tom was now on a sub-therapeutic dose of clozapine and engaging in intensive and regular martial arts exercises such that he was back to his original weight of 11 stone, having initially gone “up to 15 and a half.” UK patient Joanne had similarly “come down in stages from 14 stone” to “11-ish” stone, although while staying on a ‘therapeutic’ clozapine dose. Rather, she had sought help from a local weight loss support group: “people have kind of challenged me a bit, and I’ve sort of decided to run with it.”<sup>53</sup> Joanne had first begun to strategise while in hospital when she ate bread because, “it’s less sugary, so I was trying to be sensible and not to *have* a lot of sugar, but at the same time my body was telling me [to eat it].” She recalled how she “used to go to the [hospital] kitchen and I used to have just bread and butter, and more bread and butter, and more bread and butter ... I guess it is sugar number one, and otherwise kind of filling up your tummy.” Joanne tried to go with the latter, allowing herself a certain number of “carbs” recommended by the weight loss program. She said, “I wanna keep on being in charge of my weight, you know, and sometimes I do graze and sometimes ... the next couple of days I’ll have to watch it - so, I go up and down a bit” and “you’ve got to keep a sense of humour and keep proportion, so, you know, ‘I’m in charge of it,’ that’s what I like to say, I feel I’m in charge.”

Patients also actively experimented with how much they relied on consumptions. I asked UK patient Steve, 21 – who often attended the clinic with a large bottle of soft drink – whether there was anything in particular that quenches his thirst. After some initial clarification of what I meant, “I dunno,’ not really... it’s like I chill out, and then like, feel alright, and then it’s like okay ... it’s like when I’m *relaxed* I feel more fulfilled, more relaxed in my head.” In other words, while he knew he could achieve the feeling of being “relaxed” in his “head,” Steve still felt the need to “have a drink”. Joanne also spoke of how “you might find that you get to the end of your line and you end up going into a cafe, and having two cups of tea and a nice pastry or something! Because you’ll feel better after it or be able to go on, and proceed.”

Like Warin (2010) found in her ethnographic study with anorexia patients, there were a range of personal preferences for particular foods, leading to particular relationships with those foods, that made the concept of cravings more personal than a biochemical framework would

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<sup>53</sup> It is beyond the scope of this thesis to comment on the effectiveness of weight loss support programs that were not tied to the clozapine clinic however perhaps because Joanne and Tom were seen as neither clozapine patients nor as schizophrenia patients by their respective weight loss program or martial arts group, and thus treated like any member of the community, this may have helped them to build even more confidence in themselves.

allow. Australian patient Daniel said that, “when I was on a higher dose of clozapine I went right up to 120, 125[kg],” and found that clozapine “definitely increased your appetite too, or lowered my ability to discipline myself.” Daniel, like Joanne, said that with his dose reduction and lower weight, he liked to “challenge myself.” As well as going through “phases” of eating the same food type for days on end (cheese sandwiches for a week, then crisps, then fun size chocolates), Daniel said that “ideally for me I only like to eat once a day, yeah, I like to have one real tasty good meal a day.” He would also “see how long I can starve myself, just like to *see* how disciplined I could be ... I just, I do [be]cause its fun too, [be]cause being hungry, um, for a prolonged period of time, *that* can give you a buzz.” He told me this enthusiastically and then laughed, “I have no discipline at the moment, um, and I just... I eat, I eat fast food, I eat, you know, Chinese food ... I eat too much of it, [be]cause I love to just sit down in front of the telly and gorge myself.” Such behaviours made different impressions on clinical caregivers. UK Phlebotomist Tina felt that, rather than clozapine cravings, “with most of them it’s comfort eating, like [out] of boredom.” But patients did not mention to me navigating boredom; patients rather created new potentials for themselves around what their consumptions would mean.

Inconsistencies between registers of meaning may dissolve in the presence of novel feelings of productivity, no matter how ephemeral. In regard to understanding witchcraft, Kapferer (2003:22) suggests that ‘it is a process at the moment of fusing or crossing different registers of meaning and reasoning.’ Further, Dennis (2016:92), in her ethnographic research on cigarette smoking in the context of heavy public health deterrence, illuminated how pregnant mothers who smoked cigarettes confidently reasoned that they did not abuse additional substances readily available them. Dennis’ participants felt as though, given the multiply of risk-ridden opportunities at hand, the proactive choice to *only* smoke works to represent ‘something good, positive and healthful for their unborn babies’ (2016:92). The suspending of judgement around what a consumption practice means, under the guise of health warnings, suggests that internally redressed knowledge, however tenuous, may project beyond holistic health imaginaries.

While Kapferer (2003) and Dennis (2016) suggest that incongruent ideas may, in lived experience, be ‘fused’ together to open up new potentialities, lived consumption meanings in the context of clozapine treatment may also reinforce what is clinically kept apart, and out of clinical reach. When I asked Daniel if he experienced cravings for coke, he responded, “no, I

just like to drink it because when I drink it, it sort of um, I'm not sure if the word is, um, sat-i-ates, or?" To try to cut down on how much he drank, Daniel smoked cigarettes to contribute the feeling of satiation. Because he could essentially substitute what he consumed to achieve a level of satiation, the notion of craving did not qualify. In this way, he felt he could control the quantities and substance he consumed.

Ownership over the time of consumption was also important to patients, as it was to Warin's (2010:59) ethnographic participants with anorexia. Daniel, who had begun smoking "to stay awake" while working as a taxi driver, said that: "I used to smoke, in my down time while driving cabs and then at home, and then when I was psychotic and I was in hospital a lot, my smoking just sky-rocketed." To remedy this loss of control over when he smoked, Daniel now tried to smoke at regular intervals and only a specific amount: "its basically my main daily routine, is every half an hour I go out back and... depending on where I'm at, sometimes I'll think 'ah I'm gonna quit now' so what I'll do is, I'll still go out back every 30 minutes, on the dot, for a cigarette, but I'll just smoke ah 3 or 4 puffs and then put it out." Daniel elaborated that clinic staff "always say, you know, if you wanna quit we can give you patches, we can help you with that" and while, he said, "I appreciate the offers and the suggestions ... I'm pretty stubborn, I think, um, if I wanna quit, I'll quit."

Certain elements to cigarettes, like 'clean foods' (Warin 2010) could similarly constitute a sense of well-being and relative consumption 'purity' (Douglas 1966). Australian patient Charlie, 35, said he *lived* for smoking cigarettes; that it was "probably one of my favourite things to do" (see Brown 2018). He explained:

I smoke rollie cigarettes so they're just really fresh and nice. They don't have as many chemicals in them. Yeah, it's just nice to have a cigarette... yeah. If you're addicted to cigarettes, you wanna have cigarettes ... but I don't need to smoke cigarettes ... It's almost a control. There are some behaviours that can be almost a control, but not quite.

Charlie felt a sense of choice to smoke hand rolled cigarettes that he believed to be relatively "really fresh and nice" without "as many chemicals". Further, during my fieldwork UK patient Alan took up clinical advice to vape electronic cigarettes instead of smoking tobacco, viewing them also as "cleaner." Both smoking and vaping allowed Alan to "prep" himself for activities, with ambitions to keep improving his health (Brown 2018:163). Alan also felt

efficacy in being able to manage his Type II diabetes, and intended to “get some exercise, and it will be perfectly manageable with the metformin [diabetes medication].” He also hypothesized that “a little bit of exercise might even improve the clozril function a little bit, maybe.” There was thus scope for incremental improvements in the same way that little details in personal health imaginaries revealed agency over experiences that might otherwise be viewed as broadly ‘unhealthy.’ Moreover, the uncertainties about clozapine facilitated the ways in which people felt efficacious.

### Tipping points

*I don't see how increasing clozapine will help me stop worrying about the fate of humanity every time I wake up in the morning!* – Donna, 40, Australian patient

Building a narrative around what oneself was experiencing in regard to the ambiguous influence of clozapine – particularly in regard to dietary appetites and remedies for side effects – was empowering for patients. As suggested in regard to the blockages and flows in regard to bloodwork in Chapter Two, there was potential to overcome physiological ‘blockages’ pertaining to bodily experiences. Whether this was by taking laxatives or fluids, satiating cravings or consuming particular foods or beverages that provided self-assurance of ‘health,’ patients were able to work toward finding their own sense of balance from the ambiguous experiences and knowledge of clozapine, and which side effects were negotiable.

As indicated above, patients did not see their weight gain on clozapine as entirely unmanageable; there was a ‘will-to-power’ over the way it might impact their bodies (Nietzsche in Rapport 2003:82). Australian patient Donna said, “I would really like to try another medication, because I’m so sick of being overweight, I’m sick of being fat, I used to be really trim before I went on clozapine,” but reclaimed some control back by persisting with a “healthy diet.” She began her day with “Weetbix with banana, or muesli with yoghurt,” and felt able to manage cravings: “I don’t eat a lot of rubbish ... I like to have a milo after dinner, that’s as far as those sweet things go.” Donna experienced ongoing anxiety and said that, “sometimes I just can’t cope ... Like I’ll go to a social function or a lecture or something, I’ll turn up and everybody... I feel like everyone knows who I am and that I’ve entered the building! You know that feeling of being famous, and watched, and monitored?” Her remedy for this was drinking alcohol, “3-6 standard drinks,” every night. As I discuss later, this had become a reasonable remedy according to her social worker too. What was

more, Donna qualified her general diet as “healthy.” She explained she would “only eat meat once or twice a week,” and she enjoyed cooking “mostly Italian I suppose, like pasta and risotto, and stir-fry.” Similarly, UK patient Gary, 27, commented that “it [clozapine] makes me hungry all the time ... I try to be as strict as I can so I start losing weight, [be]cause I need to lose weight.” Gary explained how he “put on 2 stone in 2 weeks” during his hospital admission and clozapine titration; “all of a sudden I got fat.” While the vast majority of patients gained some weight on clozapine, not all did (and some, as we saw above in the cases of Tom and Joanne, felt able to control it).

The inconsistency in weight gain between individuals on clozapine gave clinical caregivers reason to question the role of clozapine per se. Australian nurse Zoya noted, “not everybody has weight gain with clozapine, not everyone - some people stabilize, some people lose weight and gain weight, even though the medication is the same.” Further, some clinicians had their own theories and knowledge to imagine different outcomes through.

As Meyers (2013:90) observed in his ethnography on adolescents being pharmacologically treated or ceasing to be treated for opioid dependencies, for those who are both clinical caregivers *and* researchers, they ‘can only “hope” that the results of the research study align with the realities of treatment and care.’ Yet, as (Meyers 2013:90) posited, ‘even more revealing is how these “things” fail to find proper grammar in the research narrative, turning the realities of day-to-day medical care into abstractions’ such that ‘the “clinical” (as the event of treatment) is held apart from the aims of research science.’ In talking with UK neuropsychiatrist George about whether more could be done to help patients with weight gain, he said:

With the hat on as a researcher, there are a few things. We are doing a meta-analysis. Some evidence suggests that *adding* metformin [Type II diabetes medication] to people who are on clozapine, even if they are not diabetic, that helps to reduce weight, so it’s something we should be doing ... we need to understand a bit better why people put on weight ... you may have seen at the clinic, a *lot* of our patients gain weight but *not* all of them, and I have had patients with 800 milligrams per day, which is a *massive* dose and not even smokers, and they were *slim* ... there are different metabolic weights that we need to study.

On the other hand, Australian psychiatrist Adam, not as involved in the neuropsychiatric research world, imagined that weight gain was an “appetite thing” attributed to clozapine and

patients not recognising when they had eaten enough food: “it’s not about looking for the reward”; rather “for reasons that we don’t quite understand these people don’t experience *satiety* – they just *know* that they’re hungry all the time ... These people simply don’t know that they’re not hungry.” Patients felt their appetites to be at least *associated with*, if not directly caused by, clozapine. UK patient Steve, 21, commented in regard to his appetite, “I’ve thought that there’s something missing”; “and I sit there, like, playing the PlayStation or something, and I feel like something’s missing, like, I don’t feel full, like I could use something, so I drink, or something like that. It doesn’t always *completely* work.” As discussed above, Steve found that being “*relaxed*” allowed him to “feel more fulfilled.” Moreover, the flux of clozapine’s experiential impacts and the personal means for negotiating feelings like cravings were helped by lack of specificity when it came to the biochemical efficacy and impacts of clozapine.

There is no clear threshold when it comes to prescribing or consuming, and thus the degree of accountability in terms of how clozapine interacts with individuals consuming it, and what can be done about side effects problematises who and what is to blame when patients are experiencing a clinically questionable quality of life. Australian psychiatrist Sandra commented,

It’s always a balancing act with prescribing, there comes a tipping point, you might be chasing an improvement, a reduction in certain symptoms, but you’re actually – the side effect burden is just going exponentially and you think ... we have to dial this back a little bit ... sometimes you can become, um, a bit too blinkered in your treatment, you know, you think I *must* control the voices or, this person’s delusions must go away, but I’m not sure that necessarily translates into quality of life, or function.

Of her professional role in clozapine treatment, Sandra said, “clozapine is a very special thing”; that “it’s unique to tertiary psychiatry”; “it’s the only treatment that *only we do*, you know, other doctors don’t really know about it, and they don’t understand the unique qualities of this drug, and the unique challenges.” But on the limits of such particular medication-based solutions, she acknowledged how one can become “a bit too blinkered” in chasing the alleviation of psychotic phenomena, at the possible expense of a patient’s overall “quality of life, or function.” Sandra, who initially thought that psychiatry was too “woolly” in practice, ended up pursuing it because, “I was really bored with internal medicine” and “wasn’t interested in their physiology, I was interested in their *person*.” An awareness for

personal, social and familial factors cemented this decision when her own brother fell ill with schizophrenia during her medical training.<sup>54</sup> Sandra noted that her and her colleagues, can both hold “control” and lose it. Uncertainty, and striving for control, concerned finding an appropriate clozapine dose.

There were plenty of constructive ‘unknowns’ in regard to clozapine dosage. While clinicians in the UK aimed to reduce the clozapine dose as soon as patients were stable, in belief that side effects were largely caused by therapeutic and toxic doses of clozapine, as opposed to sub-therapeutic doses, I did not observe this approach to be enacted in the Australian clinic (despite clinicians suggesting a degree of agreement with the UK approach). UK prescribing nurse Clive confirmed that “we’ve got quite a few patients on sub-therapeutic doses.” As well suggesting UK patient Kevin’s weight gain to be attributable to his clozapine dose, there were also other side effects that Clive linked directly with clozapine, such as symptoms of Obsessive-compulsive disorder (OCD) (Fernandez-Egea et al. 2018). Clive explained, “once you see that it’s so severe, there are high chances that when you check plasma levels, hm, plasma levels are so high ... OCD should *not* be there, not *unless* plasma levels are high. [but] there are systems that can be affected quite quicker than others.”

Meanwhile, Australian psychiatrist Adam said that although “a lot of the side effects are dose related”, that “we wouldn’t dose according to just *blood level*.” On the one hand, he agreed that, “it’s always worth a trial of dose reduction”. On the other hand, he said, “I don’t think there really is a *therapeutic level*” to be ascertained. In contrast to the UK clinic, Adam remarked that sub-therapeutic doses of clozapine were “uncommon” in the Australian clinic, and that plasma levels were “arbitrary” – especially when compared to drugs like lithium. He furthered, “clozapine levels are more about, ‘am I giving them an insufficient dose, that’s why they’re still unwell’ rather than, ‘they’re well, let’s see how I’ve done with a really low level.” Yet, conceded, “we’re using smaller doses accepting that when you have higher doses what are you really *doing*, apart from exposing people to side effects.” Australian nurse Kerry said, “the dose isn’t related to how unwell they are or how well they get, the dose is irrelevant, it’s customized to them personally,” while Australian clozapine assistant Ramesh echoed this view and perceived patients to be receptive to it:

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<sup>54</sup> He was subsequently put on clozapine, which he took for ten years before ceasing treatment a year before I met Sandra: “it’s been a huge saga since then ... I have one patient who really reminds me of my little brother, and I have to kind of monitor that, and think ‘well, it’s not my little brother,’ but it just tugs at the heart strings at little bit more.”

I've seen a lot of patients who are on the same dose for many *years* and they don't like to reduce that, because they think that's optimal dose for them, and the doctors don't try to reduce it for them, [be]cause... I'm not sure whether it's appropriate to reduce the dose right away just because they have drooling or weight gain or sedation – not very life threatening.

The primacy of psychiatric stability over side effects prevailed more strongly in the Australian clinic. Adam suggested that dosage changes were also more to do with the 'type' of schizophrenia being treated:

It kind of makes sense that if someone has primarily a *paranoid* illness – they've got delusions and hallucinations – they tend to be more *sensitive* to treatment with antipsychotic medication, so you may see an improvement on a particular dose, as opposed to someone who's got a disorganised illness, who doesn't have as wonderful response, so you are more tempted to push the dose. It's just the way we practice medicine.

There was, however, reluctance from some patients to accept a higher clozapine dose. Donna, who felt that her weight gain was caused by clozapine, rejected her psychiatrist's offer to raise the dose further also because: "I don't see how increasing clozapine will help me stop worrying about the fate of humanity every time I wake up in the morning!" Donna's 'paranoid schizophrenia' had not responded to clozapine in the ways expected by Adam, and Donna, like other female patients in my study, found it hard to accept weight gain.

UK pharmacist Ros acknowledged the differing role of personal 'acceptance' when it came to the impact of clozapine on a person:

The perfect situation would be the person who can just get on with their life ... and not having their quality of life compromised by side effects, whether that be weight gain ... getting very breathless because they're out of condition and they're very sedated, and not getting side effects like hyper-salivation or constipation ... it is interesting in terms of how much people differ in terms of what they're prepared to accept.

Further, clinicians were left to deduce what they could from their own experiences, too. UK psychiatrist George imagined that although he was "not probably aware because I haven't put on 10-15 kg, yet, but I've got the impression that has a massive impact on your ability to move, on your ability to feel energetic," and "you have all illness that is effecting your

cognitive levels, you have a medication that is causing you sedation and probably slowing even more your cognitive levels, on top of this you need to manage 10-15 kilos more than usual, that's a *huge* task."

The entirety of 'physical' side effects of clozapine were difficult to account for, between both health professionals and patients. Adam commented,

Sometimes people will come in with something they believe is a side effect, and we can't really *know* what all the side effects are. And as a clinician you may just wanna go 'nup, we don't see that,' which never goes down well. A better approach would be to say 'oh, I've never heard of that. How bad is it? Is it worth living with?' So, negotiate with the patient whether it's severe or not. And if the patient is really convinced that it's a side effect, and you're ignoring it, the patient will not take the medication. So, you're much better off being honest!

Patients were particularly aware of the incomplete clinical knowledge about the 'cognitive' side effects of clozapine and symptoms schizophrenia. For instance, UK patient Christopher, 39, explained to me, "sometimes I'm not on the ball - so, the doctor said it may be the schizophrenia, positive or negative symptoms or something like that, or it may be the things that the medicine might be doing." I asked:

JB: With the concentration and focus, did you find that it was okay when you were unwell?

Christopher: I don't know, because I've been on this clozapine ... nearly twenty years now. I never really had to use the stuff [cognitive skills], but now that I'm finding I have to use it – kind of remembering things, now that I'm having to use it, I'm kind of finding deficits in those areas. It's a bit... if I wasn't on these drugs, would I be better?

By the time I returned the following year, Christopher had become increasingly worried about losing his part-time paid and voluntary jobs due to his memory difficulties, so asked for a dose reduction: "I'm trying to see if I can cut down on medicine a little bit, because it's these things like, having to carry this around, and remembering things, and conversations, and trying to take in the information and stuff, so... I'm hoping that maybe if I cut down on clozapine, some of these things will go away."

Another 'unknown' tipping point in regard to clozapine interactions concerned the potential for 'reward' during exercise. Having been told by a psychiatrist registrar I met with in the

preparation for my fieldwork that clozapine patients do not experience “the same endorphin rush that we do” during exercise, the neurochemical interactions became a side-curiosity that I never got a clear answer for. When I asked George about this, he said it was “conceptually very interesting” – albeit “simplistic” – but that it “would be a very nice study to be done, honestly.” Adam, however, said that as a barrier to exercise, people with schizophrenia are not entirely unique in their experiences:

When you think about the level of exercise in the general population, it’s not that fantastic anyhow, but it *is* far more reduced in a population of people with schizophrenia. I mean, when you think about getting the *buzz* from exercise... I think it’s real [exercise] junkies that get that, but on the whole most people don’t really get it.

As to what did motivate people to exercise, I found that the vast majority of patients who exercised echoed Kevin’s reasoning (earlier in the chapter) about exercise being enjoyable but not quite constituting a ‘mental’ reward. However, a few patients who had exercised in their youth and were thus perhaps more inclined to pick up exercise again, described feeling some kind of ‘buzz.’ Joanne described it as: “I come back and I feel fresh and tingly, and less in my thoughts, I suppose, less prey to my thoughts or my anxieties, and worries, and it’s a nice place, it’s a nice feeling, it’s good”.

As well as elusive positive experiences that may or may not have been impacted by clozapine according to open clinical judgements, there were also personally perceived clozapine side effects that could provide authorship over uncomfortable experiences. UK patient Bradley described, “dry eyes, floaters in the eyes which make you go blind, basically, you can’t see properly.” I clarified the cause and he said, “that’s from clozapine,” and elaborated:

If I miss a dose I get diarrhoea, I get headaches... I get chest pains, head pains, have seizures in the night – well not seizures but I have seizures where I can’t, I *cannot* control my arm and my leg, so I’m just, my leg is just *jerking* away, I just can’t control it. The more I try to control it the more, the worse it gets and then... that’s clozapine. That’s what clozapine does to me.

Just as the ‘psychiatric’ withdrawal effects of stopping clozapine could not be assured, the longer term ‘physical’ impacts could not be assured either. This was in part because patients had not only previously tried other anti-psychotics, many patients were still on combinations of other drugs.

Australian patient Max, who was participating in a Narcotics Anonymous (NA) program alongside starting clozapine, said that he had “read a little bit about it on the information sheet that they handed us” and “we’ve researched it at the [NA] centre, like researched the side effects.” He experienced the feeling of “razor blades” and “we [at the NA centre] think it must just be some kind of side effect.” I asked how he thought clozapine was causing the razor blade feeling and he replied, “I don’t know. It’s like um, itchiness, like some sort of tactile hallucination.” Max, who was adamant that despite these ‘physical’ effects, that he would “rather be on the drug than not,” also reported experiencing “phantom sweats” from clozapine (“it feels like I’ve just stepped out of the shower, but when I go to dry myself off there’s nothing there”). A few other patients reported sweating as an ongoing side effect, if not as part of what it meant to be carrying extra body weight. As Adam had said, it was important to “be honest” and “negotiate” when possible. He continued that, “It’s a rather nebulous idea, quality of life... I guess I think about it in terms of dignity.” Just as patients differed in their experiences of clozapine side effects, implicating what they were willing to ‘accept’, providing dignity was also about the limits to prescribing clozapine.

Psychiatrists are most accountable insofar as what clozapine dosage is prescribed, but there are uncertainties as to where their role should end. UK psychiatrist Kate said, “I prescribe, so that’s my responsibility.” She then added, “I need to make sure that it’s monitored carefully – not just the FBCs [Full Blood Counts] but the weight, the cardiac, the metabolic side effects.” Australian psychiatrist Adam more cynically reified the reality of his obligation to prescribe first and foremost when he told me,

It’s unfortunate that over the years psychiatry has kind of descended into this thing about owning a prescription pad. There’s a lot more that would be nice to provide people with – sophisticated clinical management, very active community activities. And part of the job is to see what is there for the patient as well, not just writing prescriptions. Um, but, at the end of the day, medical *treatment* is essentially what psychiatrists are essentially in public clinics *for*.

Psychiatrists in my research were cognisant of the contradictions in terms of clinical priorities. At first, Kate simplified the situation when she described one of her female patients: “she would always say that she doesn’t like clozapine because it’s sedating and it’s made her fat, but it’s given her *life* back.” Kate described schizophrenia under the biological narrative of a “brain disease; it’s very, very debilitating ... and many of them don’t achieve

very much because of the negative symptoms.” Like patients, doctors could maximise hope from the ‘unknowns.’ Kate at first suggested that negative symptoms might be treatable with “aspirin” according to some recent research she had heard about, but on further reflection, she spoke of the importance of social support. When asked about whether she had noticed any changes in the prevalence of negative symptoms in the last twenty years of community-based care (deinstitutionalisation), Kate paused, and then stated: “I think it’s got much worse. Because there’s a silent... ah, yeah, those people are not recognised, they’ve fallen off the radar, they might be living in supported accommodation with no social contact, no meaningful engagement with society.”

These reflections on the impacts of deinstitutionalisation provided another vessel for clinical caregivers to channel potential for greater social engagement for their patients into. Clive told me one day:

If I could meet with David Cameron [then UK Prime Minister] I would take him with me on one of my home visits. I’d say, ‘Dave, man, come and *see* this.’ If he could just see it for himself, there would be no more cuts and a transport allowance would be brought back... Some of my guys that I visit out in the villages haven’t seen a single person since my last visit... Back when there were institutions, patients would have to get up every morning, shower, have their medication and breakfast, a bus would come and pick them up to take them to work - a factory job that suited their interests as much as possible, spend their money on socialising opportunities like lunch with other patients, a bus would bring them back and everyone would have dinner, be brought their meds... the voices didn’t *bother* people as much; people were occupied. The patients you see today complain of voices bothering them when they’re alone, *not* when they’re out doing things.

As I discuss later, the notion that symptoms can be managed through activities as well as clozapine was a key theme for patients, too. Yet, medication management, following the blood work, provided a means of providing potential further assistance to patients in lieu of limited formal support options. There were, however, further and differing clinical interpretations that also contributed to ‘health’ being held open to patients’ reclamation.

I was able to discern at least three further lines of clinical reasoning for cardio-metabolic associations with clozapine, which allowed for a fluid management of clinical and patient concerns and accountabilities. Rapport (2003) described how circumstances appear one way from the outside but different perspectives are held by those who are actually living them; so,

too, when these three rationales are taken together they provide a pallet of interchanging personal and professional liabilities for clinical caregivers and patients to canvas. These clinical explanations came up during an interview with UK neuropsychiatrist George, and simultaneously matched and contradicted what I heard from other clinical caregivers. Despite being such a specialised treatment regimen with physiological consequences, these varying interpretations ultimately provided a wider scope for clozapine imaginaries. The three interpretations yielding incomplete knowledge included: the role of schizophrenia symptoms; lagging holistic healthcare and questions of ‘habit’; and matters of individual motivation. I discuss each of these in turn, before building on the last and most politically contentious interpretation in the remainder of this chapter.

#### Interpreting and managing symptoms, and ‘body care’

The unclear role of clinical symptoms in light of ‘bodily’ appearances during clozapine treatment meant a minimising of the potential clinical reach when it came to patients’ contributing ‘lifestyle’ behaviours. Some phenomenological and psychoanalytic explorations of schizophrenia assert that the condition begins as a disturbance of the basic sense of being a body, leading to a traumatic interruption of the experience of being a self: patients may feel *dis-embodied* (Laing 1965; Fuchs, 2005). This can also be applied to a neurological framework of ‘neglect.’ UK neuropsychiatrist George remarked, “they know they are putting on weight but they are not as concerned, or they tend to *ignore* this part, or neglect in the sense of neurological neglect, so not ‘I don’t care,’ but ‘I don’t notice.’ Australian social worker Jill, when commenting on the messiness of some patients’ houses, similarly said, “they don’t seem to see it... and the personal hygiene, it doesn’t seem to bother them because they’re dealing with all this stuff in their head - that’s how I can see it, you know, they just have a different perception of themselves and the world.” Yet, UK psychiatrist Kate refuted this idea of not ‘noticing,’ instead flipping the issue back to patients not ‘caring’: “Nobody who is overweight has ever *denied* that they’re overweight. I suppose some of them just seem, not too *bothered* about it ... [but] some of them take great *care* of themselves – they’re immaculately dressed, wear make-up, the latest fashion, have nice hair – so, they clearly *do care* about their appearance.”

I observed, too, that patients were aware of their appearance but in very particular ways that did not necessarily observe concerns about bodily shape but rather how one prepared one’s

body. For instance, UK patient Robert was quite conscious of his appearance and particularly body hygiene, sometimes styling his hair and once apologising to me for body odour that I had not actually noticed: “Sorry I might whiff a bit today, I had a quick wash the other day but... it’s the hot weather, it makes you smell a bit.” On one occasion Robert said to me, “I was going to change into some clean clothes because I remembered I was seeing you today, but then I ran out of time.” This was an uncomfortable realisation for me that patients felt such judgement, but it affirmed that they did indeed ‘care.’

UK phlebotomist Tina commented that patients were “very aware” of having a “very, very, um, lack of hygiene.” While George said that in regard to schizophrenia and health behaviours, “you cannot plan very much in your head,” it was nonetheless imperative that patients took their ‘body care’ at their own pace. Tina gave an example of a patient who had not been able to catch a taxi home from the clinic one day because:

Quite a few taxis refuse to take them ... I asked him personally, myself, how come you’re still here ... he said ‘my taxi didn’t pick me up. He drove straight past when he saw me,’ and I asked him *why?* And he said, ‘it’s because I smell, and I *stink,*’ and I said ... ‘do you feel that you stink?’ And he said, ‘yes, yes, I haven’t had a bath for months’ ... I said, ‘why do you not have a bath,’ and he said, ‘I can’t be bothered’ ... And I said, ‘do you want someone to help you ... and he said, ‘no, I’ll have one, next couple of months, I’ll think about it’ ... I reckon that’s the initial illness from the beginning, that’s what stops them for some reason.

What is more critical to note is how, from patients’ point of views that I was privy to, patients had never let go of the possibility of taking action and there was not outright ‘neglect’ nor lack of ‘care,’ in terms of perception or actions taken toward negotiating one’s bodily presence. George said that in regard to whether ‘action’ was taken, “that’s part of the illness itself isn’t it .... They complain sometimes more about sedation, about the ability to do some stuff [rather than weight gain per se] - we forget about the symptoms, and some of the symptoms are lack of motivation.” When I asked UK patient Dylan, 33 – who had minimal psychotic symptoms but a stockier build – about the ‘physical’ side effects of clozapine such as weight gain, he replied, “well, I’ve never experienced that, so.” He said of clozapine, “there are no side effects, which is *really* good.” Then again, this may have just been relative to previous antipsychotics such that, “one I was like that [gestured shriveling up into a

paralysis], and I couldn't move – yeah, locked up, like that.”<sup>55</sup> Dylan said that health “means a lot to me, [be]cause it's my health” – specifically, “healthy eating, walking a lot.” He said that he walked “at least 5 miles a day.” When it came to his overall situation, he said “there are loads of things I could change but I don't like talking about it.” Thus, while Dylan was not in a position of ‘neglecting’ high risk weight gain, he dismissed side effects because, relative to other experiences, they did not weigh in and he was walking every day with the intention of maintaining ‘health.’ What as more, he felt there were “loads of things I could change”; he felt it was up to him.

The combination of symptoms, side effects and circumstances left interpretations open. Australian psychiatrist Sandra reflected, “my father used to complain endlessly that my brother was lazy, and I thought, ‘I'm not sure that he's lazy, I think he's got *profound* negative symptoms, and he's heavily sedated, and his life is also pretty empty’... this was on clozapine.” Australian psychiatrist Adam noted both ‘negative’ and ‘paranoid’ symptoms to be responsible: “With a lot of people with schizophrenia it's hard to motivate them, to do anything at all,” but “there can be a lot of [diagnosis related] reasons why someone might not exercise, from the very extreme – having very severe negative symptoms right through to ‘if I leave the house they're going to be talking about me and someone's going to hurt me.’” Indeed, UK patient Alice spoke of how she experienced “panic attacks” while walking outside so exercise had to be in her own space, using an exercise bike. When we last spoke she said she had been trying to cycle for twenty minutes per day, and she so far had not had any panic attacks “because no one is there [for me] to worry what they think.” Further, people's past experiences and ongoing delusions also meant that meanings of bodily health were – perhaps to one's *benefit* – protected from holistic view.

Rather than all bodily associations being experienced together, they could be usefully dissociated and thus controlled by patients. Australian patient Daisy, who experienced health when her “tummy [was] happy,” had an otherwise complicated relationship with her body due to previous experiences of sexual abuse. The happiness she felt manifested through the imaginary of foods in her stomach was held apart from other experiences of her body – reinforcing the innovative and flexible praxis purported by both Kapferer (2003) and Dennis

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<sup>55</sup> Dylan conceded that clozapine made him “very tired,” and he slept 12 hours per night and napped for a few hours each afternoon, but he did not mind this, on the whole, because, “it's lucky I'm still alive” and “when I don't sleep I just get really, *really* bad.”

(2016), discussed earlier. Within minutes of commencing our interview, Daisy declared, unprompted, “if someone rapes me again I don’t care what happens to my body, [be]cause I have the power of prayer – it’s solved it all.” She continued, “the medication takes, took, away the memory of the rape ... they took my... my right, of my life away with rape, and I tried to tell Dr [name], he should’ve talked to me, and talked to me, instead of *staring* at me – then I got raped.” When attending her clozapine appointments, though, Daisy squeezed her stomach and called herself “fat.” She would rarely, however, allow clinical caregivers, particularly males, to conduct any physical measurements. She also drew a controlled kind of attention to her body by, on the one hand, dressing up elaborately for her clozapine clinic appointments (alternating between complete sets of colour-coordinated clothing, accessories and carefully crafted make-up shades), and on the other hand, deflecting attention from her efforts. The first time I complimented her on her outfit she responded as though I was talking about her estranged sister, who Daisy said was “a fashion designer.” On another occasion when I told her she looked nice during a clinical check-up, she turned to nurse Zoya and said, “she does, doesn’t she,” looking Zoya up and down with a big smile. Daisy felt able to negotiate the attention given to her body, and thus expressed ‘care’ at the same time as saying that she did not care about what “happens” to it: It was her perception and steering of interactions that counted. Some patients, however, did not feel constant autonomy over their ‘bodily’ states. Although at face value ongoing ‘delusions’ might suggest a lack of agency, the awareness patients had for the consequences of what was happening to their bodies persisted.

Some patients construed their bodily health to be partly the result of the physical presence of someone else controlling their ‘lifestyle’ behaviours. While Cartesian dualisms dominate the clinical discourse of schizophrenia such that the ‘broken brain’ or ‘cancer of the mind’ stands in relation to the ‘often absent body’ (Warin 2000:116), the ‘bodily’ manifestations could be just as powerfully felt by my participants, as previous ethnographic evidence from Australia has also suggested (Warin 2000; Lucas 2004). UK patient Holly experienced “thoughts” instructing and daring her to do various inappropriate behaviours, which she said she “felt free” while doing regardless of the consequences. As well as daring her to do things with her

body that made her neighbors uncomfortable,<sup>56</sup> Holly experienced “voices” that told her to eat specific foods that made her gain weight. She elaborated,

Holly: The problem is that I have voices in my head which go, um, you need to *eat*, like chocolate, and that sort of thing. Um. So, I find that really difficult, yeah.

JB: Yeah, I can understand that, so do you ever get voices telling you to eat other kinds of foods or is it mainly-

Holly: No, it's mainly chocolate and crisps, and cakes

JB: And... do you always follow up on their advice?

Holly: Yeah, I do, yeah

JB: And do you feel better afterwards or?

Holly: I *enjoy* the food, the taste of it, so yeah... I don't feel *guilty* or anything, no.

The enjoyment of food can be effectively dissociated from the consequences. Holly frequently vomited up her food during the night: “I have, um, this dust bin bag at my bedside table and, so, so like, if I need to be sick, I'll go there, and it's quite handy [be]cause otherwise I wouldn't get to the bathroom in time.” Clinically, Holly may have been seen to be experiencing intrusive thoughts as a side effect of clozapine, or a ‘psychotic’ symptom of schizophrenia, or else ‘negative’ symptoms (for not caring about consequences like vomiting). She could also be understood as experiencing the ambiguous neurochemical appetite stimulation or dopamine regulation from clozapine, or else rebelling against her anorexic sister and highly weight-conscious mother, who tried to control what Holly ate as much as possible (and spent most of her time with Holly watching cooking shows with her). What is critical is how Holly sided with the voice telling her to eat certain foods, and in this way superseded the notion that the voices had complete control over her behaviour.

Patients could reconnect compartments of health on their own terms, especially when it came to the ‘social’ aspect not addressed by clozapine. Australian patient Trent, 24, understood his health situation as a “social problem.” He told me that his illness started with a “paralysis breakdown” during college: “I sort of got paralysed in my head to the extent that I couldn't even *think*, which is, my grades went down from As to Bs and Cs ... I lost conscious effort in my mind, like I just, I wasn't able to move, I wasn't able to be *myself*.” This paralysis was now associated with the felt presence of a young woman, who would make him have “aggressive outbursts” and “make me talk to myself in public,” until Trent agreed to take

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<sup>56</sup> On one occasion, we had a meeting with the police because Holly had reached out to touch her male neighbour's genital region in their hallway apartment without invitation.

clozapine. Further, Trent said, “she can control my hand and, well, she can rule my body ... she won’t let me do any exercise, she won’t let me do anything except for a couple of things a day.” As I discuss in Chapter Four, Trent’s female presence was helping him as much as hindering him – suggesting what Lavis (2013) has described in the context of the ‘presence’ of anorexia offering companionship to individuals. Similarly, but more ambiguously, Australian patient Myles, 41, attributed his weight gain to both clozapine and the felt coercion of a woman whose behaviours he felt himself to then embody. He explained,

I’m eatin’ less and puttin’ more weight on. I mean, I eat healthy ... *I’ve lived really healthy* all me life. I know I drink, I know I smoke... but that’s the only two unhealthy things I ever do ... And she’s the sorta person that, and she takes me, and then goes and eats all this junk food ... So, she’s livin’ her life as me, and makin’ me be unhealthy, as her ... She would get up in the mornin’ and smoke cigarettes, smokin’ me ... Now I have to take all the unfit problems, which were never *caused* by me.

Myles’s experiences – which outside of our interview exchange would have been clinically regarded as residual ‘delusions,’ non-responsive to clozapine and thus out of clinical reach – were tenuously still containable insofar as Myles could provisionally resolve the contradiction between his “healthy” intentions and “unfit” bodily outcomes. Myles was able to suspend certainty about the additional ‘unhealthy’ state he felt subjected to – mostly by this woman, but also by clozapine (although he blamed clozapine less frequently). During other conversations with Myles, he suggested that it was he who was consuming ‘unhealthy’ things.

The prominence of little details in what contributed toward health, also discussed earlier in regard to cleansing consumption practices, were indeed recognised by some clinical caregivers as well. For instance, Australian nurse Zoya noted that, “Some people are *very health conscious!*” When talking with UK psychiatrist Kate about body image concerns in the context of clozapine treatment, I clarified whether she had noticed changes from before and after clozapine, to which she responded, “No, I don’t think so, no, don’t think so... But I’m not sure it’s not something I’ve really asked.” When I asked Zoya the same question, she replied, “I’m not sure about that, you know, some people will tell you their story, ‘Oh no, I don’t *usually* take laxatives, I usually take prunes, I’m health conscious’,” as though they had always had these strategies.

Donna's drinking as a way of managing her symptoms was objectively 'unhealthy', but her social worker Jill was sympathetic:

It's the paranoia she lives with. She wakes up in the morning feeling dizzy and sick, and sometimes she actually throws up. She drinks alcohol to escape that because it just has enough effect on the frontal lobe, doesn't it, alcohol, and it just seems to take that problem away for her. Sometimes she drinks one or two in the morning, but mainly in the evening and she'll have four or five. And what I say to her is, 'You're not an alcoholic are you? You're not an alcoholic, and it does help you over that really difficult time.' I don't see a problem in that. I think she should keep an eye on how many she's drinking... if that helps her over that really difficult time, and if she's not drinking more and more each day, you know, I don't know what she would do if she didn't have that.

Jill had a similar view when it came to patients' choices to keep smoking. She told me that she recently went to visit two schizophrenia clients with a nurse, and both clients were smoking. The nurse asked the clients about how many cigarettes they were smoking and if they had considered quitting, which appalled Jill:

I thought, 'what are you doing?' ... keeping the rapport is more important than trying to get them to quit. They will never ever quit ... what have they got in life, you know? It's one thing they *can* do ... If you said to them, 'maybe if you smoked less, you wouldn't cough so much, and you'd be able to do that.' But there's nothing else in their life they seem to want. I suppose I'm thinking of the people I know that are just content with what they've got and they just don't want anything else. They don't want to change, they've just accepted it all.

While this may at first be seen as Jill being resigned to somewhat inevitable 'reality' rather than these health behaviours being potentially 'controllable,' Jill also highlighted how patients in these situations were "just content with what they've got" and that this was their prerogative: "They don't want to change." This therefore takes the emphasis away from the illness per se and places the agency back on them.

It was clear that many patients were – in more ordinary ways than not – 'body conscious,' despite ongoing schizophrenia symptoms or attributions to clozapine. Patients' awareness around body weight and how it may have changed since taking clozapine was noted by other staff members. When I asked UK pharmacist Ros about whether she thought patients were self-conscious about weight gain, she rebutted, "Yes... I don't know why they'd be different from anyone else." UK phlebotomist Tina furthered, "I feel that they are quite self-

conscious,” and gave an example of how, “some patients that come in with difficult veins, or deep veins, and people say ‘it’s maybe because I’m fat, that’s why you can’t find my veins,’ which is not, true ... then they’ll say ‘well I wasn’t fat’; ‘I used to be this and that’; ‘I used to be active, I used to be sporty, but since being on clozapine this is how its changed me.’” Australian nurse Ramesh suggested that, “they’ll be very concerned about their body, like they’ll tell me, ‘look I’m gaining a lot of weight, the medication is causing me to gain a lot of weight.’”

A final and more deterministic clinical view was in regard to how schizophrenia interacted with socioeconomic barriers. Australian nurse Team Leader Tony surmised of the main ‘health barriers’:

With the clozapine therapy, you’re looking at the diagnosis of schizophrenia which is... it causes disability, a loss of function. That’s one of the major effects of the illness. So, with the declining function means declining earning capacity. You’re mainly on the pension ... your choices on buying capacity are reduced. So, you will buy foods that are cheap or readily available and often those cheaper foods are higher in sugar and fat and not as good for you.

The narrative around ‘physical health’ outcomes for clozapine-treated schizophrenia patients could not neatly be differentiated into individual, biochemical or social factors. Like with the blood work, people worked with what they were given and their fates were never clear.

#### More could be done

*We need to be aware of the kind of things that can happen, and we need to know where to refer people to, to get these things addressed, and maybe we need to know how to treat them ourselves. But, um, changing clinical hats can be very difficult ... The Royal guidelines say that that’s what we ought to be doing, but the Royal guidelines say to make sure that our patients have GPs and we’re giving them good instructions about what to look out for. It’s... one of those things that falls through the cracks, all too often. – Adam, Australian psychiatrist*

For clinical caregivers, hope for more holistic health prospects were partly helped along by the idea that psychiatry and primary care had not reached its full potential in providing adequate communications and support for patients. The strained relationship between psychiatry and other healthcare supports, particularly with GPs, meant that there was always potentiality for more to be done. All four psychiatrists, George (UK), Kate (UK), Sandra

(Australia) and Adam (Australia) were wary of systemic shortfalls when it came to addressing the ‘physical health’ of patients. George commented, “I don’t think as psychiatrists that we should just pass all the responsibility of physical health to the GPs; I think we should be holding a lot.”

There was an assumption that patients could achieve weight loss via health activities if they were only given greater assistance in doing so. When it came to potential courses of action when clozapine patients put on excess body weight, George said that, as a clinician, it was critical to provide “advice about diet, asking them to increase their physical activities, promoting the access to physical activity, involving more the social workers, from people in the team.” He said that it was important to “teach [patients] how to do this”; “it’s having someone to help them to move on, to access all these activities.” Similarly, when I asked UK psychiatrist Kate, she responded,

There’s lots that can be done, but we don’t have the infrastructure, or the time. So, you could increase their activity, you could support their smoking cessation, but that requires staff and we don’t have enough staff to facilitate that. But, yes, there’s lots that could be done. And I’m unaware of any third sector organisations.

When I asked Australian psychiatrist Sandra, she responded, quite eagerly, “Oh, absolutely! I have this *dream*, this day dream, I’d love to do it.” She continued, “every now and then you see the [local government] advertising health promotion grants for organisations, and I think, you know what we could do, we could get a personal trainer, who would be here, a couple days a week.” Sandra thought that it would make a difference insofar as: “*actually having a person who could make contact with people*, get them out of the house ... Because I think in all these diet and lifestyle coaching things and a personal trainer approach, they work because you have to be accountable to another person, you’ve got an *enthusiastic*, kind of bouncy person encouraging you to come along with them.”

Another potential solution was to shift more responsibility to GPs. When I asked of the role of the GP here, Adam said,

We want to believe that patients have GPs, that when we’re not here the GPs will pick up the slack, we want to believe that the GPs are confident, and have the skills required to do that. Um, and this *isn’t* always the case. People are scared of psychiatry, people are scared of psychotic illnesses, if they don’t have a lot of exposure to them ... people with psychotic illnesses I guess don’t see GPs *often*

enough for the GPs to feel comfortable or confident ... But, psychiatry itself has kind of shot itself in the foot here. I think as a whole we're not very good at communicating with GPs, we're not very good at sending them back recommendations for what treatment *ought* to be, we're more likely to send back a letter saying 'and I'll see the patient in three months.' Um, rather than letting the GP take *carriage* of what happens next.

Beyond Primary Care options, George also suggested that a referral to a surgeon was also feasible to deal with extra weight gain: "One of the things we don't tend to do, and that's our fault, is that people over 35 of Body Mass Index in this country are eligible [covered by NHS] for bariatric surgery, and we are never referring people to do that, and we will probably have at least 10-15 people who should be referred – why not?" It was difficult to know whether it should be the psychiatrist or the GP that makes these further referrals. In all, it seemed there was a reluctance to pass the buck any further for patients who were already at the 'end of the line' in terms of treatment options.

Part of this reluctance may have been due to lack of consensus about underlying causes of weight gain: schizophrenia, clozapine, social circumstances, or the person and their habits. UK psychiatrist George related to his patients' difficulties in changing habits that were overhauled, to a certain extent by events beyond one's control:

If there's something really complicated in this world, it's to change your diet, we are so embedded in our *habits* of eating ... if there's all of a sudden there's such an enormous imbalance between what you eat and what you spend as – can you imagine you're suddenly actively, floridly psychotic, very unwell, and you're admitted to hospital so your movements are completely restricted, and also instead of sleeping 7 hours per day, 8 hours, you're sleeping 10 hours per day, the imbalance it causes you is absolutely brutal, and you will not change all of a sudden how you eat ... you need to have a very strong *will* to change it.

Before turning to the question of "a very strong *will* to change" a habit, it is important to unpack the matter of 'habit' on its own terms. In the first instance, this could be explained along the lines of habitus, whereby, in this instance, one's reflexive and even sub-conscious bodily dispositions become entwined with what it means to be a clozapine patient.<sup>57</sup> This includes the way of being when attending the clinic itself. Tina noted that even when patients

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<sup>57</sup> 'Habitus' as Bourdieu described it, 'is an infinite capacity for generating products – thoughts, perceptions, expressions and actions – whose limits are set by the historically and socially situated conditions of its production, [such that] the conditioned and conditional freedom it provides is as remote from creation of unpredictable novelty as it is from simple mechanical reproduction of the original conditioning' (in Weiss 2008:229).

complain that they do not want their bloods taken, they simultaneously sit in the blood chair and put their arms out in anticipation, as though their ‘body’ is overriding their ‘mind.’ Further, there was also the cognitive ‘habits’ associated with schizophrenia. For instance, UK patient Tom conceded that, in regard to his “mindfulness” practices (discussed in Chapter Four), “sometimes, [be]cause of the habit, I slip back into the old way of watching the people,” which, would “drain,” “confuse” and “scare” him, triggering “the voices” again.

Patients experimented with their current habits and enabling change through gradual alterations rather than conclusive overhauls. This was partly about appreciating ‘relative’ stability in ways that many people take for granted, and partly about enjoying things that feel good as a key incentive for the behaviour. As Pedwell (2017) argued in critique of ‘nudge’ behavioral economic theory, to *change* one’s habits is more complicated than shifting from something perceived as ‘bad’ in the present to something perceived as ‘good’ for the future. Insofar as ‘freedom and power are to be found in and through the constitution of habits, not through their elimination’ (Sullivan in Pedwell 2011:76) – while ‘docility’ is ‘power to remake old habits, to re-create’ (Dewey in Pedwell 2011:83) – it is the personal experientials of ‘*current* tendencies’ that matter (Pedwell 2011:87). In support of Pedwell’s (2017) suggestions, patients could feel empowered in the short-term sense to change so long as the change was neither absolute in terms of others’ guidance nor a total overhaul of current habits.

Like with regular consumption of clozapine, there were then ‘habits’ around other consumptions taken into the body with familiar associations. For instance, UK patient Kevin, said that he still went through “patches” of losing weight but that he would, ultimately, “always slip back into old habits” – consisting of eating “takeaways, having cream and cheese, having snacks” because when it came down to it, “I don’t wanna change my eating habits.” UK patient Alice recalled to me one day, while looking at the nutrition label on her diet Pepsi bottle, that as a kid playing sport she used to drink a lot of soft drink, but always found coke too strong and preferred diet drinks because they were “more watery.” Arguably, her ongoing desire for diet soft drinks was not just a matter of compromising on her appetite; this had been a part of her appetite since childhood.

As suggested earlier, patients tweaked current behaviours such that there were elements of novelty – but only so long as there was also familiarity. UK patient Martin, 51, said he was

often tempted to sample Belgian beer at the pub, but instead “I try to restrict myself to the draft ales.” However, he continued, “I like to try different ones, [be]cause they have different ones.” When I suggested that he was not, then, “a creature of habit,” he replied, that he did prefer the “same table, usually the same meal – I normally have the burger, I used to have the pie but it’s more wintery I think.” Strategies for changing habits could also align with clozapine clinic efforts to persuade patients to experiment with changes in their habits, as long as they addressed and allowed for patients’ desires.

The clinical suggestion could at least *temporarily* shift some patients’ dietary habits, so long as the process had a personal reward attached. UK patient Holly, 40, was pressed by her parents to lose weight with a promise of taking her out to her favourite restaurant as a reward. Holly recalled Clive’s advice to keep a ‘food diary,’ meaning that she simply just noted down what she was eating. For three weeks, she stopped herself from eating her usual “crisps and chocolate.” She kept drinking soft drink however, so as to not change things up entirely: “All I’ve had, which is okay, I suppose, is diet coke, um... but my parents say, ‘oh you shouldn’t be drinking diet coke!’” Interestingly, Holly did not tell her mother (who had previously gone so far as to confiscate chocolate from her while on a recent family holiday) about any changes that she had made. Moreover, when I commented that her mother must have been pleased, Holly was dismissive and said she did not feel the need to tell her. She had reclaimed the change in such a way that she was personally accountable to herself in terms of how she lost weight. Holly was much keener to tell me how, “me and Dad, we weigh each other at the gym, and I’ve lost something like two kilos, which is great, in the past week!” She was, however, most of all looking forward to indulging in the restaurant dinner promised to her. Holly was willing to change her eating habits in the short term so long as doing so did not interfere with her enduring desires.

There were also habits around energy out-take that patients were proactive about experimenting with. As George said, weight gain is likely “if there’s all of a sudden such an enormous imbalance between what you eat and what you spend.” UK patient Alice said to me the last time I interviewed her that she was “still over-eating, I still find it hard to be disciplined about that ... I’ve got into a pattern ... I’ve got used to eating too much.” When we talked about short-term versus long-term goals when it came to exercising, Alice said that she had thus far, since her diagnosis, only been able to keep up exercise for up to 6 months at a time – “then the bad habits come back.” These habits pertained to being sedentary since her

time in hospital, while upholding her lifelong appetite for diet soft drinks. UK patient Robert also reflected how in hospital: “I used to sit a lot on my own and smoke there and think about things and try and get well.”

On the one hand, the habit of smoking was seen by patients to be straight forward. UK patient Hugo, 25, who had “always smoked since I was about 17,” felt that it was now “just normal, just a habit.” Contrary to other patients, when I asked him if it provided any relief, he replied, “no, just a habit.” UK patient Trevor, who contentedly smoked for a range of reasons, including the notion that cigarettes have “anti-psychotic properties” (Brown & Dennis 2017) said that when it came to viewing smoking as an “addiction” it was more multi-faceted: “there’s more than one aspect of addiction to smoking, it’s not just the drug, it’s the... taste, the action of doing things, getting into the habit of doing it.”

Finally, agency was apparent in a patient’s intentionality to find one’s own meaning for ‘lifestyle’ habits, which may be understood by clinical staff as part of a patient’s ‘personality.’ Australian Nurse Zoya normalised weight gain as “not because of the medication really... it’s because they have a sweet tooth!” She laughed. I asked if she thought the medication had anything to do with the sweet tooth, and she said she did not think so, “because people – because of their habits themselves before initiation of clozapine, they are used to that.” I asked if clozapine amplified current habits and she said “only one person just told me that ‘when I wake up, I feel hungry because I’ve slept so late in the afternoon, I just want to grab something, you know, something sweet ... But other people just have normal meals ... but that will be their personality before the initiation of clozapine.” Moreover, all patients were quick to point out things that they *were* doing, however incrementally, and that relative to previous ‘psychotic’ states or the extent of lifestyle ‘habits’ (many mentioned how much they had cut down smoking or sugar, even if not ‘quit’), that they felt “not too bad” or even “healthy.”

Just like the decision to stay alive, there is an immediate utilisation of finding personal peace within current situations and habits relative to past experiences. I asked Alice if she felt potential to “control” her lifestyle habits, and she replied: “Control? I think it fluctuates sometimes ... I know it probably sounds quite lazy but I’m quite happy just sitting in front of the TV ... I just want a quiet life basically, you know, I’ve been through a lot of drama. It’s like, with my family, it just seems to be one thing after another, you know.” Moreover, the

question of individual motivation had – from a clinical perspective – the most and the least ambiguous accountability.

#### Motivation: “Everyone’s different”

Understanding a combination of individual differences and ‘external’ determinants is critical to affording people their health agency. Allowing for individual differences can at first seem distasteful. As Kowal (2015) suggested in the context of the Australian Indigenous health ‘gaps,’ professional ‘White anti-racist’ health workers can find it difficult to think beyond the structural determinants of health of Australian Indigenous people’s health in fear of implications around ‘victim blaming.’ Kowal (2015:42) observed that, ‘[W]hen a White anti-racist feels uncomfortable about the idea that Indigenous people might smoke despite knowing better than other Australians that it is bad for you, they are uncomfortable that Indigenous agency might play a role in ill health,’ and ‘beliefs about Indigenous people assume instead that Indigenous disadvantage is wholly due to structural factors.’ Herein, Kowal (2015:46) continues, ‘[t]he full spectrum of Indigenous social life cannot be admitted – only the part of it that is congruent with remediable difference.’ Intervention is construed ‘as tinkering with the structural factors that determine health’ in order to avoid notions of ‘social engineering’ (Kowal 2015:46). In the case of clozapine-treated schizophrenia, clozapine and its side effects may be seen to constitute the structural factors, although the biochemical knowledge limitations, along with incomplete knowledge about schizophrenia, give clinical caregivers a certain opening to bring in contradictory rationales about patient health outcomes. Moreover, appreciating different values of health, given all the ambiguities is a useful way of thinking about the extent of individual accountability. The health ‘gaps’ that coincide with clozapine-treated schizophrenia can therefore be interpreted as caused by both, rather than either/or.

Some clinical caregivers without medical school training (phlebotomists, nurses, social workers) took the stance that patients who did not seek to change their lifestyle habits under clozapine might simply be “lazy.” UK phlebotomist Tina reflected, “everyone’s different ... I do motivate them, I say ‘have you tried doing this, have you tried doing that, if you *beat* your laziness you can do it,’ but I’m not a lazy person”. Implicit in this statement is that patients have a choice. Tina also said to me in regard to whether patients listened to advice given about their ‘physical’ health, “it all depends if they take any notice, if they take action,

[be]cause you cannot force them, everything has to be done by them; their own will ... a few of them have been advised and they are going away and *doing* and they'll come back and say, 'I've been going to spinning classes.' She then brought the question back to her own experiences of exercising four to five times per week: "If I don't go to the gym then I'll feel guilty if I eat!" This resonated with UK patient's Joanne's admission mentioned earlier that, "sometimes I do graze and sometimes ... the next couple of days I'll have to watch it."

Arguably, the notion that clozapine patients can have agency in the matter of being psychiatrically stable *and* able to challenge weight gain highlights their 'normalcy' rather than 'madness.' A confluence of 'structural' factors weigh in to yield situations where individuals interpret their situations not so much in terms of a different sort of agency, as Kowal (2015) suggests could be the case for Indigenous Australians, but rather in terms indistinguishable from the general population. Jenkins (2010:9) suggested that possibilities of side effects from antipsychotic drugs that are considered under socio-political renderings of 'choice' to render patients "crazy" or fat, sexless, and genderless' may, in contradiction, exacerbate 'madness' for the patient. Yet Ned, 27, challenged his constant food consumption cravings by explaining, like anybody might,

You just gotta stay away from it, you've gotta think what's best for *you* ... you know, craving a cigarette, and you've gotta think 'I don't really need it,' because you've got other options. There are other options that you can go with. So, you've just gotta choose another healthy option. So, I guess it's like, taking the stairs or walking up the escalator, you know... you've just gotta do it.

Ned was also motivated by financial factors, saying, "it's expensive as well to eat like that, you can't have takeaways all the time." Further, he had developed his own reasoning for countering the appetite he perceived to be caused by clozapine:

Everyone's different, but for me, it's another reason I take my medication before I go to bed, because like I don't wake up feeling hungry, it doesn't make me *want* food during the night or anything, so. It's only if I take it, if I take it a 12 o'clock or something, then yeah, I'll be hungry and I'll wanna eat, so yeah.

The negotiation of clozapine and appetite was indeed partly to do with the time of day that clozapine was consumed. This aligned with clinical rationale, too, at least insofar as other immediately felt side effects were concerned. For instance, UK psychiatrist Kate said, "you

can combat the sedation by taking it all at night, but most people take it in the morning and a larger dose at night.” For patients like Ned, though, personal values were important.

Personal values are a further point at which clozapine-treated schizophrenia patients could be said to not differ from the general population. The ‘new health morality’ (Becker in Conrad 1994:387) that has been promulgated through public discourse about what makes a ‘healthy body,’ can lead to ‘motivation’ insofar as seeking ‘a moral balance between the bad and the good’ (Conrad 1994:394). Yet, as Conrad (1994:397) suggested, ‘independent of the results, merely engaging in wellness activities is a virtuous activity.’ While Conrad noted this to be a phenomenon of the ‘middle class’ Americans in his ethnography, in that ‘wellness-seeking becomes a vehicle for setting oneself among the righteous’ (1994:398), patients in my study make for no exception to different aspirational goals of eating depending on socioeconomic factors – as Australian nurse Tony suggested earlier. Those who did not have family or a job to assist in their everyday living costs were generally not as selective about what they ate as choice was limited. Those who were in paid employment and/or family support tended to be inclined toward particular dietary regimens that could be planned ahead.

As for anybody, values and motivations could also shift. Australian nurse Zoya commented: “The way you want to perceive ‘am I getting fat?’ Everyone is concerned in this society here ... As normal people, everybody wants to watch what they eat ... One thing is that we just keep on, keep on giving the advice, until such time they make up their mind”. The notion that people can “make up their mind” or take time to adjust to the drug, before engaging in regulations of side effects, was suggested by most clinical caregivers. Australian clozapine coordinator Kerry suggested of motivations to “change” habits after stabilising on clozapine, “it can take a year or two ... once this [clozapine] has settled down, they look at themselves and think, well, I better get some clothes, better have a shower, better get my hair cut... for some reason, somewhere along the way, it’s clicked.”

While the present-centred temporalities of clozapine will be discussed in Chapter Four, I note here that the longitudinal impacts of clozapine and the imaginings of time needed before decisions around ‘health’ could be made, weighed into both clinical and patient perceptions of how clozapine worked. For instance, UK patients Tom and Joanne, now in their fifties, both spoke of how the initial weight gain they experienced upon commencing clozapine treatment took much effort to be able to “shift” (as Tom said of his eventual weight loss and

energy gain). Tom, who had also developed Type II diabetes, asked to have his dose reduced, started practicing tai-chi, quit smoking cigarettes and followed a stricter diet. Joanne, while not wanting to reduce her dose to a ‘sub-therapeutic’ range like Tom’s, instead worked at challenging her midnight food cravings, attended a weight watchers program, and started exercising regularly. Both described hitting a particularly miserable stage first. Moreover, Australian psychiatrist Sandra noted of lifestyle changes:

For a couple of patients I’ve seen, it was a couple of years down the track, so they kind of had the chaos of their early years with psychosis, then it’s almost like a period where they grind to a halt. And that might be a number of things, like being on the clozapine initially being a bit more of a *blow* to your system, perhaps the dose being higher than they need it to be. I think there’s also a phenomenon where people go from being *very* psychotic to actually becoming quite *depressed* for a period ... then it’s like they kind of emerge from that ... roughly 2 and 5 years after starting clozapine having this upswing in function? ... Perhaps having your illness controlled for enough time gives you *space* to build, you know.

Other factors such as gender, engagement in workplace, community and recreational activities may also play a role here too. When I asked Sandra about the “physical health” of the “high level public servant,” she replied, “not great!”; “he was overweight, and inactive, he was a cigarette smoker, he drank too much! ... then I’ve had particularly young women do a good job.” Tina said, “the ones I know that work, I don’t see that they’re overweight.” She recalled, nonetheless, a female patient who had recently started working and, “she’s a little bit overweight and sometimes she’s concerned about that.” “But,” Tina continued, “she says she feels *better*, that she’s working, that... I don’t think her weight has changed but maybe it’s because she’s out there, she’s *doing* something for herself ... she’s *acting* ... if you know that you feel *active* then you kind of work around your weight, then you’re happy with what you are.” This reinforced the notion of people finding their ‘happy’ medium. Tina continued, “it all depends on how you are, because any medication, it depends on *your* body and how *you* take it.”

Because the determinants of ‘health’ in the course of clozapine treatment were irreducible to one cause or another, they were ultimately different for each individual. UK patient Christopher described himself as doing “virtuous things,” contingent on what he consumed as supplementary to clozapine to alleviate the voices, which he said could “get stuck on my frequency” unless he kept actively recreating his “coping strategies.” Both clinical caregivers

and patients agreed that the notion of health was intrinsically about ‘doing’ what one wanted to be doing, which other aspects of one’s health could result by proxy of. After all, UK patient Kevin had started exercising upon being discharged from hospital because “it was something to do.”

### Health as a verb

*I like to keep myself busy, and that’s what keeps me sane ... I found it’s better if I keep myself busy, if I’m occupied with things like golf and tennis I’m not so bad; it’s when you’re not doing anything, there’s nothing to distract you, that’s when I struggle, which is, I guess, that’s probably the reason I do so much, you know, it keeps me... well, I guess. – Kevin, UK patient*

*When one is wholly devoted to something and ‘really’ busies oneself with it, one does not do so just alongside the work itself ... A specific kind of forgetting is essential for the temporality that is constitutive for letting something be involved.*

– Heidegger (1962[1927]:H354)

To iterate, I have observed health and agency as interrelated and active rather than fixed states, and clozapine patients drew from their social contexts to exhibit power (Archer 2004; Rapport 2003). UK patient Kevin could only feel one step ahead of his voices while “keeping busy.” Thus, to clinically frame his thoughts in terms of OCD or delusional ideas undermines his ordinary human tendency to keep himself occupied within an awareness of what worked for him. What ‘worked’ was a combination of social influences and personal interpretations. UK patient Geoff described himself as “healthy” because of his “healthy eating, exercise, getting out and meeting people, finding activities to do in the flat – I find, also, I enjoy reading the paper and listening to the radio.” UK patient Bradley, 29, had astutely described health as, most simply, a matter of “being alive.” When I asked him whether there was anything else describing what “healthy” meant, he replied: “Could be anything - healthy relationships, healthy lifestyle, ah, healthy output of life, healthy input of life, healthy thoughts of life, you know healthy could be a range of different forms.” Even when describing healthy as coming in “different forms,” there was an underlying theme of *moving* from one form to another and being absorbed in the process of doing so.

The notion of health through action, does not, once again, stand in opposition to general population ideals about the means rather than the ends of ‘wellness’ and ‘virtuosity’ (Conrad 1994), nor does it stand in absolute opposition to clinical ideas. UK patient Joanne reflected,

I used to think about what the doctor once said to me, the first time, like, ‘a rolling stone gathers no moss’ ... I think if you carry on doing things that gives you positive feedback, into your life, and it might be a bit chaotic, and people might wish you were a bit more laid back sometimes but, that positive feedback of things has a knock-on effect and, I mean it helps you to be healthier.

Like with her blood test swimming ritual (Chapter Two), Joanne acquiesced to a doctor’s remark that “a rolling stone gathers no moss.” UK nurse Narelle resounded the views of many participants (clinical caregivers and patients) when she remarked that the optimal situation for a clozapine patient was “being able to do what you want to do in your life ... people feeling like there’s something they’d like to do and being able to do it.”

The will to keep moving was therefore also about agency, as ‘the capability, the power, to be the source and originator of acts’ (Rapport & Overing 2000:1). UK patient Martin reiterated that health was not only about “the absence of illness” but also about “being *okay* enough to... carry on.” The ongoing process of “carrying on” – like a “rolling stone” – exemplified another way in which patients persisted (rather than resisted, or merely complied with) their situations in order to keep up a sense of agency over their experiences of health (and the metonymical compartments of it that I explore shortly). Like clozapine treatment that required ongoing certifications, patients continually tried to keep themselves ‘on track,’ in conjunction with clozapine keeping them “on the straight and narrow” (as UK patients Martin and Dylan both described). Patients were continually reassessing situations and being wary of the need for new strategies to work in sync with clozapine.

Patients’ knowledge that stable experiences were provisional contributed to their sense of their own input and a will to avoid “not doing anything,” in order to keep feelings of illness at bay. Indeed, as Heidegger (1962[1927]:H354) posited, temporal suspension and self ‘*forgetting*’ happens when one wholly engages in a task at hand. Kevin, who had been taking clozapine for 15 years, said that “a big thing in my life is worrying about people hearing my thoughts” – namely the “strange thoughts, slightly perverse thoughts.” Clinically, these were understood as Obsessive-compulsive symptoms (OCS). Despite clinical attempts with drug augmentations, I did not come across any cases of OCS disappearing entirely. Rather, what seemed to alleviate the feeling of thoughts spontaneously popping in or out, and giving patients a sense of being “well,” were when patients were “occupied with things,” as Kevin

explained.

When I asked Kevin if he felt that I could hear his thoughts during our conversation, he explained, “[be]cause we’re talking and keeping myself busy, I haven’t really got the opportunity to think so, no, you couldn’t hear it, but if were sitting here in silence, I’d have thoughts and you *would* hear them.” While this might have been clinically regarded to be simply as ‘delusional’ rather than OCS, Kevin’s thoughts seemed to be a non-negotiable reality for him and, despite trying alternative medications to alleviate the invasive thoughts and talking to “many therapists” about alternative strategies, “we kind of get stuck there.” The only strategy that helped was based on his *own* experience of having things to do, which yielded further benefits: Kevin said, “I think gym was something to fill that... something to do.”

For Kevin and many patients, having “something to do” that took away “the opportunity to think” was the experience that could be relied upon most to move forward with. Thus, while Jenkins’ ethnographic evidence has highlighted the role of clozapine as the primary perceived agent of ‘control’ that ‘keeps the person stable ... busy and active, out of hospital ... from hearing voices, from being crazy’ (2015:51), my participants suggested that intentionality in ‘keeping’ illness at bay can also surpass the activity of clozapine. As I suggest in Chapter Four, taking clozapine in the more *immediate* sense was more about the countering of activity rather than a triggering of activity.

Arguably, what Myers (2015;2016) suggested as constituting ‘moral agency’ contingent on integration into a wider community can be experienced, to some degree, through more immediate aspects of the treatment regimen in ways that can serve purpose and social connections, too. When I first met UK participant Luke, only a few weeks after he commenced clozapine, he described his clozapine-treated-schizophrenia to me as “a pursuit race,” whereby “getting ahead is about staying ahead.” He explained:

You constantly have on your mind what should I take today, what should I do ... constantly looking after your health, constantly touching base ... constantly thinking could I do that better ... who could I meet who would be better for me ... it’s all about eking out an existence, isn’t it?<sup>58</sup>

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<sup>58</sup> Part of this quote is cited in Brown (2018:161).

This was synonymous with a moral notion of “recovery,” which he said involved “constantly thinking ‘could I do that better?’” The process of “constantly touching base” and imagining what one “could do better” indicated a process of engaging in the *ongoing* process of navigation towards a better future that could not be quite assured but was nonetheless worth pursuing. Luke was largely isolated; his contact with the clinic and care-workers were his only social contacts. Yet, a certain degree of continuous socio-moral commitment to self-improvement was suggested in his accountability to the clozapine regimen. I observed that people continually combined external directives about ‘betterment,’ both small and larger scale, with what they experienced for themselves as necessary in order to move forward. Returning to how Conrad (1994) constituted ‘wellness’ as means of striving to be ‘virtuous,’ repeating activities that one felt yielded feelings of well-being was critical.

Feelings of health were temporally connected to the activity patients could rely upon, and the subsequent feeling of assurance they felt. Australian patient James, 32, told me that he could tell if he was “well” or not by the ability to “focus” on “reading for prolonged periods of time” and if he could “just keep doing and doing and doing things.” UK patient Alan said to Narelle during a clinical check up one day, “I need to keep busy, otherwise it’ll be like psychiatric rehab, just staring at the wall smoking cigarettes.” Moreover, while ways in which patients kept themselves moving forward differed (some felt that smoking was a way to keep occupied rather than something to prompt further activity), there was a general emphasis on “keeping up” with feelings of health. Keeping ahead of threats of illness meant that patients could only be temporally assured that they had moved away from illness; to stay “not actively ill,” as Joanne put it.

Even planning to do things gave a feeling of control, also fitting Conrad’s (1994) explication for well-being via virtuosity. UK patient Hannah said, “I feel in control when I’m planning things to do, planning my day.” This was because she knew that, “sometimes if I have some time where I don’t have to do anything, that can make me on edge.” She added that the meaning of health was “about being at your best.” For Hannah, this was when she was “active and helpful, calm and organised - I think it helps to do things to keep you healthy, to exercise, do something creative, do some relaxation.”

Once patients knew what activities they could return to, it was a matter of keeping going with

them. Having particular activities that patients could rely upon to feel level while doing was important, as would be the case for anyone. UK patient Ian, 40, posited that being “busy” and “happy” were not mutually exclusive states: “The reason I’m busy, the reason I’m happy, is [be]cause I’m busy, you see; I get happy [be]cause I’m busy.” As well as eating (described above), Ian kept himself busy by playing the piano and reading books. The notion of keeping busy to distract oneself from uncomfortable interferences seemed to be more about avoiding self- concerns than engaging in self-concerned things.

Although keeping oneself busy suggests a consuming of time such that it is not consciously accounted for, keeping oneself busy seemed to primarily keep patients afloat and distracted, rather than detaching from concerns as one might when actively ‘letting go’ and allowing the self to not only remain stable but to find peace (as I elaborate in Chapter Four). This was perhaps most clear in the case of UK patient Trevor, who would often tell me how “busy” and “energetic” he was.<sup>59</sup> In regard to his schizophrenia Trevor said, “well it’s amazing how the mind can be disrupted and how it can recover and come back to normal isn’t it? It’s absolutely amazing ... you can’t tell me from any normal person now, can you?” His only recurrent symptom or clozapine side-effect, he felt, was “maybe worrying; I’m a bit obsessive – double-checking things”. Further, “I carry on smoking,” he said, not only because “it helps me deal with my symptoms of schizophrenia,” “it’s a way of killing time as well, isn’t it?” Another UK patient, Josh, smoked also because, “it feels quite good and it’s something to do.” Trevor reported smoking, “about 40 a day, it depends how busy I am, you know, often I’m very busy and I’ve got to take breaks between smoking and I catch up later then I take breaks again.”

Trevor conceded however that “it’s quite good being busy because it actually cuts my smoking down.” As this contradicted his commitment to smoking for managing his symptoms, I asked him if he would indeed like to cut down, to which he responded, “I enjoy smoking, so, not really, I just want to leave things as they are - it hasn’t seriously damaged my health so far.” In all, Trevor could reassure himself in the sense of day-to-day busy-ness, which involved his go-to strategy of smoking, so long as his health continued as was. Just as he planned to stay on clozapine, Trevor was adamant that, “you don’t want to change things

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<sup>59</sup> Trevor said, “I haven’t any major health problems, nothing’s going seriously wrong with me” - despite a number of clinical concerns that came to my attention otherwise. He said of the clozapine side effects he contended with, “dribbling, low blood pressure possibly, high cholesterol, sugar levels, compulsive repetitive behaviour, umm... and that’s about it I think.”

if what you're on is working... because you don't know with anything else, exactly what's gonna happen." The notion of keeping on with what works was thus also about avoiding tipping points, discussed earlier in this chapter.

Lastly, notions of health as a verb were apparent in patients' ideas about who they knew to be healthy – as being able to give and not merely receive energies. This again taps into Rapport's (2003) supposition of agency through an 'extended homeostasis.' Many responses concerned people who had cared for them – from clinical caregivers in the hospital to parents who were perceived to lead a social life, to spiritual figures who supported them. At a more fundamental level, though, ideals of health tended to concern the capacity for patients to carry out tasks that would have knock-on effects, from carrying the shopping, cooking, to more extensively looking after others. When I asked UK patient Josh, 43, if he could think of anyone in an optimal state of health, he said his friend living below him in his flat, "because, I s'pose, he goes out to town nearly every, nearly every day to buy something, he does." Josh had similarly described clozapine as something that "keeps you fit" – "moving around ... doing more." When I asked him when he felt most in control he said it was while "diving into the pool" and "listening to music." I confirmed what health meant, to which he said, "going swimming" - an embodied action. Connecting the 'mind' and 'body' on one's own terms was critical to patients.

Kevin had told me that the term health "means two things - it means mental health and physical health." By physical health he meant "fitness and endurance," and by mental health he meant, "not being paranoid." Kevin's worries were not continuous: "If I have a good day I don't feel at all that way." He continued, "I guess it's finding that *balance*, I find if I do *too much* then I struggle, if I do *too little* I struggle; it's finding that middle ground, keeps me well – doing enough but not overdo[ing] it." Moreover, "doing enough" to achieve feelings of "*balance*" often involved imageries of shifting between mind and body states.

### Shifting between 'mind' and 'body' states

Building on the notion of health as a verb, patients drew on metonymical dichotomies afforded by clozapine treatment to reallocate and 'negotiate' relationships between separated aspects of their health, and what counted towards a personally constituted 'homeostasis' (Rapport 2003; Brown & Dennis 2017). Notions of mind and body compartmentalisations

were productive for patients to work with, in conjunction with imaginaries of how clozapine was acting on both. As I have suggested, clozapine-treated schizophrenia patients were not heavily confined by their circumstances and clinical subjectification involving multiple somatic levels of attention. Rather, these biomedical narratives were reworked both within and beyond the neoliberal guise of ‘choosing’ for, and acting *on*, oneself – in the terms of Rose & Abi-Rached (2013). Indeed, some of Lucas’ (2004:150) ethnographic participants with schizophrenia ‘sought to measure bodily “vibrations,” monitor “hormones,” or manipulate sensory and physical inputs’. The potential to attend to bodily processes, whether perceived to be part of the self or externally inflicted, therefore needs more consideration in the context of clinical monitoring and the pathologically validated unhinging of physiological processes. Despite biomedical provisions that subject patients to multiple aspects of their ‘bodily’ being, people can understand themselves, however inconsistently, as more *partially* embodied, as Lyon and Barbalet (1994:56) assert in their notion of the ‘social body’ that is ‘inter-communicative and active.’ Just as blood imagery and clinical circuitries described in Chapter Two reflected literal and metaphorical meanings regarding blockages and flow, so, too, was it important for interconnections between mind and body to be continually enacted.

I began my fieldwork exposed to the idea that a tight focusing of present attention to the unseen or habitually unattended regions or actions of the body, and its ostensible divisions into ‘physical’ and ‘mental’ experiences, might raise self-awareness of one’s own bodily systems and parts of the body. Sass (2004:313) had observed that, in regard to specific body ‘parts’ holding attention in schizophrenia,

[O]ne would expect profound transformations in the felt quality of the affective life. Rather than serving as an attitude *toward* the world, certain emotional configurations would instead be experienced at a subjective distance, almost as objects in themselves, while others might simply fail to coalesce at all...such a person is likely to hold herself back – thereby to become aware of, and, at the same time, detached from habits of bodily being and affective response as well as cognitive framework assumptions that might otherwise function invisibly.

Sass suggested that this can result in ‘radical scrutiny and remaking’ of the body as object (2004:319). Having to attend to a dominant biological presence of the body has also been suggested to constitute a form of agency for other medical patients (Braidotti 2007; Lundin 1999). Lundin (1999) suggested that the opportunity to attend to the workings of the body and its ‘physical’ processes can elicit feelings of agentic potential rather than weakening. For

organ transplant recipients in Lundin's ethnography (1999), paying reflexive attention to the present body could result in feelings of personal ownership over the replaced organs and unfamiliar biological responses to them.

Of course, the notion of foreign contents in the body could indeed be felt by patients experiencing delusions, but it was also, arguably, tied into the feeling of constipation as well as personally existing fears. UK patient Geoff, who had been taking clozapine for nearly eight years, once experienced the feeling of a snake inside his stomach, at which time he admitted himself to hospital. He explained, "I thought I had a snake in my stomach, so I went into hospital and ended up on a... on the psychiatric ward ... it's just very frightening ... I think it was just stuck inside, yeah... I think I was a bit paranoid about having snakes in the garden... umm... and having snakes in the bedroom, and, yeah!" Geoff was a keen gardener but had only seen a snake at a "Reptile Centre" before. When I naively tried to joke that he probably should not visit Australia, then, his returning laugh was singular, his eyes looking slightly alarmed. I asked what made the snake go away in the end and he replied, "I think going into hospital and *talking* about it." At the clozapine clinic, talking about bodily experiences was normative.

Just as intersubjective assurances between people were important to release fixations and bodily blockages, so, too, were the release of 'mental' and 'physical' blockages via the movement of the body. UK patient Tom "connected" his "mind and body" through self-prescribed "mindfulness" and exercise techniques, whereby he was able to "clean my system out" (Brown & Dennis 2017:375). Through exercise and martial arts, Tom explained that he would "sweat a couple of times a week" to "get the blood flowing" and "get the toxins out." Patient experiences suggested that a 'calmer' disposition could be induced by focusing one's attention from the 'mind' to the 'body,' while 'bodily' commotions could also be conceived as inhibiting the 'mind.'

A number of patients reported anxiety and panic attacks that could be resolved via a negotiation of one's physical positioning. UK patient Robert, quoted in the introduction to this chapter, said his "mental illness" was "taking it out of me, physically and emotionally, *zapping* my emotions". His chest pains also prompted him to keep within the 'physical' realm and lie down, because: "If I sit up and do things, they just get progressively worse." Robert's habit of resting for a few hours each afternoon was one he may have developed from his time

in hospital, where he had appreciated the freedom to “rest” when he wanted to. Another UK patient, Blake, 45, described how he, “used to walk around [the hospital] grounds, and then suddenly [clicking fingers], whoosh! I would think, *wrongly*, about everything, *paranoid*, everything, and I couldn’t cope, and I had to come back and lay on the bed in the [hospital].” Blake left the hospital before he felt ready to, and still experienced this every few weeks or so, and described how, “I’ve gotta rush to get home to try and get rid of it ... if I talk to my mum *long enough* it will... get better.”<sup>60</sup>

While Blake called his mother for assurance, most patients did not have (or desire) such immediate emotional supports, and would instead, like Robert, “lie down” until such feelings of disease passed. Joanne described how if she was at home when “panic” set in, “I take myself over to the bed, to lie down on the bed, and tell myself ‘you’re just a bit tired, let time pass, it’s okay’.” She would repeat this mantra, “and just through breathing, laying myself there on the bed I *knew* that it would pass.” Patients were informed of such techniques by attending to therapeutic information given during the course of their treatments. UK patient Felix described how, when he has a panic attack, he “remember[s] what it says in the ‘mind booklet,’ and ah, I sit and play the keyboard, try, try, and make myself fall asleep.” Felix had thus personalised the technique in regard to playing the keyboard. UK patient Alice, who reported feeling panicked when she walked for exercise, had been told by a social worker that it was “because I was overweight, and sweating”; “they said to me it’s just because you’re fat, I thought it was that, so I’d sort of go on, trying to do faddy diets but they never really worked.” Alice then learnt later from a psychologist that these were “panic attacks,” and subsequently read in an information booklet that bodily “symptoms” of “sweating” and “aches” may have contributed to the panic attacks. She now attended to the triggers – namely, “going to the supermarket” and new social settings. Alice said that “on the way here, I didn’t have a full panic attack, I just felt very breathless, it’s just walking down the road, but they do fluctuate – I think it’s because I’m anxious about taking the medication, but I’m hoping they’ll get better when things settle down a bit.” She was giving herself time to adjust to her new context.

Personalised assurances and adjustment could also be about overcoming a static ‘physical’ state. Tom, for instance, described how he would still occasionally, when walking in public,

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<sup>60</sup> When I asked Blake if he found it “helpful” being back at home with his parents after returning from hospital, he replied, “no, because they kept going out and leaving me on my own in the house and that wasn’t very good for me.”

experience moments of “panic” where he would “freeze and think, if I move one of my legs again, something *evil*’s gonna happen.” But, he elaborated, “now I can just flick it off, you know, if I have it I can just [clicked his fingers]” (Brown & Dennis 2018:375). Blake was, in contrast, less secure in the process of challenging his fears – of falling onto the train tracks once a week when he had to travel to work at a voluntary job he enjoyed. He currently felt he could not work more often, “because sometimes when I get up, I don’t feel so well, you know, I just feel a bit weird sometimes when I wake up ... I get worried about when I have to step off the train, with the *gap*, you know.” Blake spoke of having to negotiate feelings of having a “numb head” following recent medication reduction. On the one hand, this was attributed to bodily adjustment beyond his direct control: “Once the body gets used to the lower dose of these ones then I’m sure it’ll *level out*, in the end.” On the other hand, when I asked Blake, “how did your *body* feel throughout this?” He replied, “well, I used to lean on the table and *not* get a numb head, and when I went like that [demonstrating pulling his body upright] it was numb head.” I queried, “so lying down would help?” and he replied, with a firm “yes, yeah it did.”

The experiences of both clozapine and other enactments in the external world could also work to rebalance mind and body. UK patient Ian, 40, said that the main benefit of clozapine was that “it stops... it alleviates pain in experience.” This meant, “clozapine stopped headaches” and the “stinging pain along my backside”, which “was similar to needles.” Ian could not, however, be sure of the role of clozapine. At other times, he explained to me that the pain, “went away by chance,” or that playing the piano “stops me [being] upset ... about physical pain, the past ... like I was saying, the needles.” The action of interacting with the external environment could relieve his pain. What is more, the capacities that make up the experiences of being a mind inside a body inside a world, with self-experienced intakes and outtakes, point to an intentionality toward finding ‘essence’ in one’s ‘extended homeostasis’ (Rapport 2003).

When ‘health’ was described along the lines of compartments of “physical” and “mental,” it was about continually reconciling these. UK patient Tom, 54, posited, “if you haven’t got the motivation, the energy, the awareness, the compassion, the drive in your mind, you’re not gonna have it in your body, ‘cause mind and body are connected ... I can’t ignore my body” (Brown & Dennis 2017:375-376). Tom’s experience of panic as making him “freeze” thus manifested in a ‘physical’ paralysis, that he then negotiated with his ‘mind,’ just as Trent had

to negotiate with his “voice” to be able to do things. As Lyon (1997:96) noted, ‘particular respiratory patterns are part of the embodiment of emotion’ and ‘bodily aspects of emotion cannot be separated out from social action more generally because they particularly constitute that action, and this action is part of what constitutes emotion’ (Lyon 1997:96). From panic attacks to chest pains prompting patients to lie their bodies down and rest to experiences of physical ‘paralysis,’ the point was that people wanted to do something about it, to regulate their eating or their breathing or their exercise or their smoking for themselves, drawing on the imaginary of mind and body (and other) as separate parts to be reckoned with.

The agentic feelings patients experienced were in regard to inhibition or energies that they could level out or move from one compartment to the other. Resonating with UK patient Kevin, Australian patient James, 32, remarked that in regard to his “auditory hallucinations,” “when I do exercise ... I’m able to just *push* that aside ... exercise is probably *the* most important factor for me, exercise and healthy eating” (Brown & Dennis 2017:376). Australian patient Donna also said that exercise was “the best thing for my mood – remember how I told you I wake up feeling awful? – Going for a walk *always* makes me feel better.” I asked how she motivated herself when she was tired and she said, “I just eventually get up and go!” She had faith in what worked for her. Further, James commented that if he does not “use” the “energy” then “it just whirls around upstairs” (Brown & Dennis 2017:377).

Patients could also draw on their imaginations to evoke the impact of shifting energies between mind and body. Joanne described how, while swimming, “kicking my legs I just *imagine* that it’s helping my ligaments, muscles, making them stronger.”<sup>61</sup> Joanne’s swimming regimen also helped her to reallocate her “emotional” energies when “tired”: “Even if you’re tired, you go swimming, you come out ... and now you’ve got the physical tiredness ... Your muscles are kind of relaxed and that sort of goes with a relaxed mind somehow, or a relaxed way of thinking and seeing things.” She continued,

It’s difficult to get yourself *above*, the worried level, sometimes, and I find that even if you’re tired you go swimming, you come out, and yes, you’re tired but you’ve, you’ve made the step and look at yourself and you’ve become physically tired and that is, has a good feedback ... now you’ve got the physical tiredness.

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<sup>61</sup> When I said that another patient had attributed a feeling of “muscle weakness” to clozapine, Joanne agreed: “yeah, I can relate to that.” She was thus working to mitigate this as much as reallocate her energies.

Joanne was, like James, able to redirect her ‘mental’ energies into ‘physical’ energies.

Such projects ultimately acquiesced as much as personalised how energies circulated inside one’s body and intermittently impacted patients sense of health agency. During a consultation in the Australian clinic, when psychiatrist Adam asked 27-year-old patient Ned to clarify whether he knew that he had an “illness,” Ned nodded agreeably. Adam asked what he thought caused the illness and Ned said, “changes in my brain chemistry” and “a dopamine overload.” Ned effectively utilised the ‘pharmaceutical imaginary’ (Jenkins 2010) that would ensure an unproblematic clozapine review, although added his own interpretations in a way that complemented clinical ambiguities.<sup>62</sup> Like how other patients selectively ate sugar, Ned told us that he could avoid feelings of fatigue attributed to clozapine by exercising immediately after consumption (by walking or doing push-ups). Ned also suspected, though, that the fatigue could be due to “the pH in my stomach” or “foods” he consumed in addition to clozapine. Adam assured Ned that this was a common experience of clozapine, although it was not clear whether he was just referring to the fatigue, as Adam did not comment on Ned’s alternative explanations for it. Either way, Ned asserted both his clinical ‘know-how’ (Petryna 2004) and his own personal interpretation and resolving of the issue. It could not be determined whether clozapine, or his stomach environment, or his food choice caused the fatigue. This ambiguity gave Ned a sense of being able to try to counteract it by his own means of exercising after taking clozapine, paralleling with Joanne and Hannah’s actions around blood work results (Chapter Two).

On the face of it, the biomedical emphasis on eradicating *all* ostensibly mind-based symptoms can resound in patient ideas of recovery and cloud interpretations of any “acceptable” mind-associated experiences that happen in between. For instance, Adam suggested that when it came to clozapine treatment, “as a best-case scenario you can expect complete remission of psychotic symptoms with some actually developing true insight into the fact that they’ve had a psychotic illness.” A quantitative study I wrote up with researchers at the UK clinic suggested that, when symptoms of schizophrenia and side effects of clozapine are compared by patients in regard to what predicts their subjective well-being

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<sup>62</sup> Chatting to Adam on another occasion when he had just returned from a home visit on a “suicidal” patient, Adam commented how mental health workers can, when focusing on behaviour as the symptom, see “suicidal” behaviour as sign of non-compliance to medication and deliberate action against doctors, “rather than seeing it as part of the illness, i.e., why do we treat mental illness!” He said that a caseworker had asked him, on the way back from the home visit, “why aren’t they on medication?” Adam lamented that suicide is not so predictable or controllable, especially in regard to medication. Moreover, Ned’s adoption of ‘biochemical imbalance’ clinical imaginaries (Jenkins 2010) still allowed room for dual explanations so long as the baseline of him being treated for an “illness” could be agreed upon.

(using a clinical scale), it was the ‘positive symptoms’ (hallucinations and delusions) that were found to be statistically significant (Brown, Mezquida & Fernandez-Egea 2016). This finding also correlated with some comments I received from patients in my own study. For instance, Kevin said when I asked him if the voices he still heard were all negative: “I guess some are okay, yeah, some are acceptable... but just *having* a thought, just the fact that someone can hear you having a thought, whether it’s positive or negative is a bad thing.” UK patient Tom had also stated that, “mind is the main health” (Brown & Dennis 2017:375).

The assumption that a more ‘motivated’ mind will result in improved ‘bodily’ health is incomplete, though. Another study conducted at the UK clinic found that, contrary to clinical expectations, reduced ‘negative symptoms’ (blunted affect and motivation levels) correlated with higher Body Mass Index – weight gain was found to be more likely in patients exhibiting more emotion and motivation (Mezquida et al. 2017). In light of some of my ethnographic findings, this was less surprising. The degree to which one symptom becomes manageable is not the same as the degree to which one symptom or side effect determines another. While patients like Kevin and Tom at first conceptualised their experiences of health in this way, the more I spoke with them and other patients about when they actually *experienced* health, it became a matter of active engagements with things that elicit or shift energy states. In the manner of ‘precarity,’ rather than ‘vulnerability,’ when understanding lived experiences of mental illness (Jenkins 2015:14), experiences and compartmentalisations of illness and wellness become *usefully* insecure. The precariousness of wellness, just like blood counts, can be creatively harnessed to bring livelihoods otherwise taken for granted if one’s exposure to ‘mental’ instability is mitigated. Moreover, patients could rework the mind-body dichotomies by utilising consumption tools available to them as well as potential bodily outputs of energy in order to experientially ‘level out’ their own clozapine levels.

## Conclusion

This chapter has argued that clozapine patients actively rework imaginaries of clozapine, the mind, and the body, with energy inputs and outputs, to find a personalised homeostasis that resound their health agency. This health agency is enabled through the ambiguities of clinical knowledge in regard to clozapine that leave plenty of room for personal construing of clozapine’s effects and what individuals can do themselves to enact or deactivate these effects. Clozapine treatments may be positioned somewhere between what Rapport (2003)

described as ‘democratic violence’ and ‘nihilistic violence,’ tilting mostly toward the former, and patients had to work with the everyday logics and experiences to find meaning and control. Different explanations were drawn on at different times by different individuals, alleviating responsibility for clinical caregivers at the same time as leaving interpretations more open for patients to work with. There is no clear tipping point when it comes to prescribing or consumption effects, and thus the degree of accountability in terms of how clozapine interacts with individuals, and what can be done about side effects, problematises who and what is to blame when patients are experiencing a clinically questionable quality of life.

In light of incomplete medical knowledge, as well as evidence of some patients being able to overcome biochemical limitations and symptoms in ways that are not separable from general population experiences, there was plenty for patients to reclaim for themselves. When people with co-morbidities are given a host of information about risk-ridden consumption habits, these habits can become very rational under context-specific health priorities. Patients nonetheless worked to find energy stasis through consuming substances that balance out the sedative impact of clozapine, and also engaged in at least one personal ‘health’ ritual, such as a specific food believed to protect them or counter-act ‘unhealthy’ consumptions (Warin 2010). Moreover, quantitative findings that suggest people taking clozapine might put on weight in conjunction with appearing more enthusiastic toward their lives (as opposed to appearing detached or nihilistic) (Mezuida et al. 2016) make sense if we attend to the ways in which patients continue to consume clozapine *and* other consumables in order to harness embodied energy potentialities. There was always a sense that more could be done, that ‘health’ was in sight if not already felt. Patients cared and health was a moving project, requiring continual regulation and upkeep by patients themselves. I now turn to the temporal frameworks of clozapine treatment that patients worked with.

## Chapter Four: Clozapine Temporalities and The Focused, Insatiable Self

*Kung fu ... feels good, I've done lots of martial arts but kung fu and tai-chi, it gets your whole body moving, gets your joints and your ligaments and your bones, and your muscle structure and your brain and your mind and your soul and your imagination, it just... enables you to focus on discipline, and stillness and emptying yourself of all the madness that... you know, all the worries, not just myself but people in society, with all the anxieties like work and study and bills, and, when I do martial arts, it's like it provides me, just a temporary relief from not just schizophrenia – that aside – just from all the frustrations of life in general, and when I do martial arts it's not there. And when it is there, it just doesn't appeal to me.*

– James, 32, Australian patient

*By taking up a present, I draw together and transform my past, altering its significance, freeing and detaching myself from it. But I do so only by committing myself somewhere else. – Merleau-Ponty 2002[1962]:528)*

Ways in which experiencing what Australian patient James described as an embodied sense of “focus” and “temporary relief” from “frustrations of life in general,” were critical to experiences of self-reclamation for clozapine patients. This mirrors ways in which psychological well-being movements in Western society are now geared toward a will to ‘live in the present’ (Boniwell & Zimbardo 2003). Following my attention to how patients actively work with ambiguities and mind-body imaginaries pertaining to clozapine treatment and other consumptions in Chapter Three, I here turn to temporal experiences of embodied unification and concurrent health agency. James’ description of “your joints and your ligaments and your bones” through to “your imagination” working in synthesis evokes Sartre’s positioning of imagination as constituting a ‘surpassing and nullifying power’ (in Rapport 2000:4). Similar to James’ concerns shifting while doing martial arts, Merleau-Ponty (2002[1962]:528;530) remarked, ‘taking up a present’ temporally frees the agent from their past, and ‘choice and action alone cut us loose from our anchorage.’ As explored in Chapter Three, for the duration in which one is ‘doing something,’ a sense of health and proactivity is felt.

This chapter argues that patients express health agency by formulating their own present-centred rituals, complementing the clozapine regimen, to enable them to deal with stress and uncertainty about their past at the same time as keeping their futures open. The strategies that patients deploy to focus on the present include clozapine, routines, and meditative pursuits

that allow temporal focus and freedoms. Part of this story is about clozapine as a drug that slows people down, and part of it is about what patients do in conjunction with the temporalities brought on by treatment, their medical conditions, and their personal drives to move through – and suspend – linear time. Whereas phenomenological explications of schizophrenia emphasise how patients suffer from ‘disturbances in feeling self-present and feeling anchored in the world among others’ (Stephenson & Parnas 2017), I suggest that clozapine-treated patients can, even in spite of persistent clinical symptoms, experience embodied or ‘enminded’ subjectivity that anchors them both temporally and socially.

In beginning my argument about how agents optimise their well-being vis-à-vis keeping present-focused potentiality ahead of undesirable pasts and futures, the first section of this chapter explicates the temporalities induced by clozapine treatment. Patients experience these situations at a minimum, setting the pace for managing day-to-day and longer-term concerns. The relief and self ‘re-setting’ provided by sleep, as a baseline, will be a theme running throughout this chapter. Many patients look toward ‘doing things’ to keep well and occupy their time in between the solace of sleep. Whereas in Chapter Three I suggested that health itself pertained to activity, here I discuss how harnessing attention and finding ‘focus’ in present-time allowed patients to detach from existential ambiguities and to temporally transcend fear and uncertainty. As Simone de Beauvoir (2000[1948]:157) described of experiences of managing self-doubt, we feel ‘certitude’ only through our ‘drive’ to do things, and in this way become temporally self-assured. As psychiatric stability is largely defined by being able to doubt rather than fixate on ideas about how things are (Rhodes & Gipps 2008), I explore how for patients, tentatively stable on clozapine, temporal drives can lead to attainable, self-driven levels of productivity and imagined futures beyond being a clozapine-treated schizophrenia patient.

I explore how achieving present-state awareness translates to states of well-being comparable to pursuits of meditation and ‘mindfulness’ to overcome trauma. I consider emotion and stress management, and how ‘flow’ experiences (Csikszentmihalyi 1990) may be applicable to clozapine patients’ experiences. I suggest how patients – both deliberately and by proxy of focusing on the present – were able to develop rituals for themselves, informing their sense of health agency. I build on the notion of ‘flow’ to consider how patients express self-growth beyond self-fragmentation. I return to Rapport’s (2003) notion of ‘self-intensity’ and ‘essence,’ to explain how temporal self-reclamation was achieved through engaging in

attention absorbing activities that are challenging and ‘novel.’ I then expand on how temporal creativities and potentialities enabled through concentration and activity contradict more fixed clinical perceptions. Ultimately, patient experiences cannot be differentiated from phenomenological notions of existential freedom or Heideggerian ‘dwelling’ or ‘ecstatic temporality’ (Heidegger 1962[1927]). Further, I explore how clinical observations of ‘negative symptoms,’ ‘attention deficits’ and ‘working memory’ are highly contextual and often heightened in clinic interactions with a clinical focus and time demands.

### Clozapine as a provisional “shield”

*Clozapine is somehow keeping me alive ... like an exoskeleton frame, and it feels like this frame might all collapse on me if I stop taking it. – Mark, 52, UK patient*

Clozapine supplies patients with a basic structure and potential future, with increased agency over their health. Consumption and monitoring enters patients into a mode of provisional adjourning of concerns, bringing either feelings of solace or limitation, depending on whether patients feel they have been able to navigate the effects. For most patients in my study, clozapine provided “a shield” of sorts – as Australian patient Keith, 55, put it. UK patient Mark, 52, said that clozapine treatment was “like an exoskeleton frame” because it “feels like it’s holding me together in some way.” This distinctive ‘pharmaceutical imaginary’ (Jenkins 2010) was temporal. Mark said he experienced a feeling of being “a bit woolly ... you feel clouded,” but that one of the “main benefits” of taking clozapine was that it made him feel “subdued, a bit numb.” This stood in contrast to “a great deal of anxiety and confusion” he had experienced in the lead up to starting clozapine 25 years earlier. Similarly, UK patient Geoff, 53, explained, “when I was initially put on clozapine it was as though it psychologically ... conquered me ... I was less able to think.” I clarified, “and has it helped?” To which he responded, “I think it has, yeah ... staying well, um, not being too anxious or frightened ... yeah, being able to live a near-normal life.” Clozapine provided temporal protections from dose-to-dose.

Respite from consuming clozapine in the immediate sense of swallowing the tablet meant a temporal “stopping” of discomforts. Australian patient Angus, 38, said that clozapine simply “turns things off.” UK patient Kevin, 34, had supplemented clozapine with other activities but said that he “would love for my thoughts to stop, you know, all of them” (Chapter Three). The experience of clozapine tended to involve at the very least a sense that “time slows,” if

not “stopping” discomfort in its track (or eliciting feelings of “thought suppression” as UK patient Nathaniel, 36, reported). These experiences were in stark contrast to how “everything happens so quickly” during psychosis – as UK patient Gordon, 39, explained. UK patient Dylan, 34, iterated that, since taking clozapine, “I’ve *really* slowed down.” Present-time stability was prioritised over potential future concerns.

Clozapine was described by many patients as a provisional protection that, in conjunction with what had come before, could give rise to feelings of survival. Australian patient Liam, 38, with recurrent psychotic symptoms said, “sometimes I feel like I’ve lost track of time, I feel like I’ve been on the toilet for three days.” Liam feared going to the toilet due to “panic attacks” (more below), but clozapine helped to alleviate these at times. I asked him what the benefits of clozapine were and he replied, “it works fast; I’ve done really well.” He felt that clozapine was one of four “magic pills” that had worked in conjunction with his prayers to God. Whereas he felt he “was just getting poisoned” on illicit substances, he viewed pharmaceutical drugs differently. He said, “sometimes when I’m so desperate I just take my meds at 5[pm] instead of 9[pm].” Liam would also “pray” during this time that just one would work initially, as to not quite send him to sleep yet, “then the rest will kick in at 9pm, to send me to sleep.” Liam thus felt an agency over the biochemical process. When I asked Liam what “wellness” meant, he said, “when I feel 100 per cent.” When I asked him when he last felt this way, he said, “this morning.”

The experience of taking clozapine seemed to be about how the restful pause facilitated in a predictable fashion by clozapine suited patients’ desires for more agency. It especially suited patients who were more cognisant of, and exhausted by, more recent psychotic episodes – often pertaining to trauma, whereby ‘the intentional structure [of the self] collapses immediately’ as opposed to ‘at will’ (Ataria 2018:52). Being on the clozapine regimen and having additional caregivers like parents around in between clinical care (not common but more likely for younger patients) facilitated the temporal respite to keep specific agendas out of the picture.

Patients could find their own ways of ‘re-setting’ their lives with clozapine, and it often took time, often years, to adjust to clozapine. As stated in Chapter Three, Australian psychiatrist Sandra suggested that, “perhaps having your illness controlled for enough time gives you *space* to build,” while UK patient Alice who had recently started taking clozapine

commented, “I just want a quiet life basically, you know, I’ve been through a lot of drama.” Australian patient Charlie, 35, recently put on clozapine but exhibiting what clinicians would call the ‘negative symptom’ of ‘anhedonia,’ was relieved to be feeling care-free since taking clozapine. He went so far as to tell me that after all he had been through, “now I wouldn’t care if I died” (Brown 2018:159). He elaborated, “I’ve had no sexual idea or pleasure or anything for four or five years now, just too much suicide compulsions – that’s what did it.” I asked,

JB: So, you just feel... *spent*?

Charlie: Yeah, I’m all spent ... it’s like being in a war. You know, have you seen the Deer Hunter? With Robert Di Niro? He comes back from war and he gets into bed and says ‘Goodnight’ and goes to sleep. You know, they don’t think like that anymore, they’ve been too badly traumatized by what’s happened to them ... What happened to me with that suicide compulsion was it was like being in a war. Every day I thought I was gonna *die*, for sure ... [now] I’m happy the way I am though. I don’t have sex as a behaviour anymore, that’s all that happened. I’m not sexual anymore. I still have other behaviours. ... It’s taken a lot to get to this point but things are pretty good as they are.

The feeling of being “happy the way I am,” by way of relating one’s experiences to a wider social discourse (ideas in the film *Deer Hunter*) reiterated Charlie’s sense of how, “you just feel normal” on clozapine. While Charlie at first said to me, “I haven’t really achieved much in my life,” he later said, “I’ve just done everything I’ve wanted to do,” and then added that he had aspirations to pursue his interests in writing and making music. Thus, while life on clozapine, like life with schizophrenia, might be analytically construed as a phenomenological minimising of ‘sudden changes’ or creating a ‘substitute of inner continuity’ (Fuchs 2007:234), patients also reclaimed experiences as relative *renewals* of life, and as-yet unwritten futures. There is a temporal orderliness implicit in clozapine treatment, focusing on immediate concerns only.

The intended remedial aspect of clozapine does not include confrontations with patients’ pasts nor specific plans beyond the imminent future. For some, including older patients, clozapine kept emotional life within bounds – as UK patient Martin, 51, said, “it keeps me on the straight and narrow ... the main thing is stability.” Martin told me that no health professional he had seen throughout his treatment had talked to him about his past; “it’s more focused on *current*, current needs.” When I asked him if he thought this helped, he said he was “not sure,” because: “I’m a bit *sceptical* about these people you see, psychiatrists, getting

them to relive their childhood *traumas* ... you are who you are anyway, and you've got to make the most of it." As discussed in the Introduction to this thesis, Martin, like many patients, revealed to me very casually in conversation several events in his life that sounded traumatic to me but he dismissed as not significant.<sup>63</sup> I observed a relationship between participants' attitudes to traumatic past experiences and their gender. Seven out of eight female patient participants had told me about how they had sought various kinds of counselling, leading to a clearer narrative about how past family relationships had affected their experiences.<sup>64</sup> Nevertheless, the need for present-time stability was particularly important when it came to addressing uncomfortable experiences either side of consuming clozapine.

The routine of taking clozapine was a central part of a patient's day. For instance, UK patient Peter, 54, told me that he could only face each day after taking clozapine, having a cup of tea and smoking a cigarette (see Brown 2018:161). When I asked UK patient Geoff, 52, how he kept himself "well," he said:

I have routines, in the morning and night time ... In the morning, I get up, I take my medication, feed the cat, wash, dress, have breakfast and then... in the past I've been napping in the morning after breakfast but I'm trying not to do that, I'm trying to change that... [in the evening] I lock the front door, take medication, change into my pyjamas, brush my teeth, check the appliances in the flat and then go to bed.

While these behaviours were clinically regarded to be Obsessive-Compulsive, they were also critical to maintaining a sense of orderliness from day-to-day.

As suggested in Chapter One and Two, the truncated time concerns of clozapine were also observed by clinical caregivers. Just like each dose of clozapine bought 12-24 hours for patients, each clinic appointment suspended concerns that might stretch beyond the clinic time window. In terms of treatment monitoring concerns, UK nurse Narelle explained that each appointment presented her with a momentary "opportunity" to try to "connect" health concerns more "holistically." Clinical prioritising, however, was inevitable due to the

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<sup>63</sup> Namely, his older brother committing suicide when Martin was a child, his parent's divorce and subsequent re-marrying, adding step-family, his mother dying of Alzheimer's Disease and not remembering him at a time when he was failing university course and having employment difficulties.

<sup>64</sup> This can also be understood as a form of 'autobiographical power' (Myers & Ziv 2016). As noted in Chapter One, a discussion about gender differences is not within the scope of this thesis and in any case not central to patients' experiences of health agency in relation to temporality.

“curtailed” appointment times from government “cuts” to resources (across all services). Regardless of how much she could fit in during the time allocated, and between her wider community health work and her two days at the clozapine clinic, she felt she “could fill a week with *this* clinic work, *easily*.” She surmised, “you live with a different level of-, you know, it’s *always* the case that you go home and something will pop into your mind ... but the *kinds* of things that pop into your mind now, make me gasp a bit!” It was “just really a bare fact,” that “somebody will pop into your mind [after work hours, and] ... It’s all *risk* stuff, all risk.”<sup>65</sup>

The phenomenon of particular “kinds” of worrisome thoughts coming and going was a large part of patient experiences, too, notwithstanding the effects of clozapine. As UK patient Kevin posited in Chapter Three about how the feeling of being “*occupied*” soon recedes again such that “perverse thoughts,” which “pop into my head” as soon as “there’s nothing to distract you.” For some patients, this served as a reminder of otherwise dormant illness. UK patient Joanne said, “it’s hard to describe when you don’t feel at all ill, and something will happen and you’ll think ‘oh, yes, I have schizophrenia’.” Similar to sets of ocean waves, whatever was missed during time spent riding a present wave did not necessarily stay missing from subsequent waves of experience.

Insofar as filling present-time frames could only conditionally keep out future concerns that might “pop” back into clinical caregivers’ and patients’ minds later, experiences of clozapine being able to “stop” and “slow” linear time sequences were again impermanent. Although UK patient Dylan, 33, had said to me that when he first took clozapine – “it took away all my thoughts, and I was like, *wow*, this is brilliant!” – the feeling was conditional. When I asked what kinds of thoughts he meant he responded, quietly, “just... weird thoughts” and “mistakes”, from when he was “younger.” Clozapine’s temporal assurance needed to be replenished, and this could create a feeling of what UK patient Peter described as a “*need* for it ... [be]cause I never wanna go back to how I felt when I was without it.” Again, the solace of sleep as another temporal stopping and slowing was critical to patient experiences.

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<sup>65</sup> Narelle was looking to formally integrate her psychotherapy skills when performing ‘physical’ check-ups with patients, which, depending on supervisory approval and funding, would also give her more time with patients to think beyond immediate ‘risk’ management.

## Temporal orders

Depending on whether we are sleeping or awake ‘and whether the body had approximately the right amount of time in the previous mode’ (sleep or waking life), we experience different ‘tempo’ or temporal orders (Jowsey 2016:1097). Most patients were grateful for being able to sleep better since taking clozapine, as it was both an opportunity for restoration and an escape from discomforts. UK patient Tom, explained, “if you’ve got schizophrenia it’s not very good to have nights where you can’t sleep [be]cause it brings out the... psychotic things.” UK patient Luke said, “I do sleep as much as I can,” because “it helps me to relax, to get positive thoughts in my head,” and – drawing on medical imagery – “I achieve the alpha state when I’m asleep ... that’s what I look forward to.” UK patient Alex, 48, told me that his hallucinatory presence of the “Suey people” (Chapter One) “don’t hurt me when I’m asleep.” Australian patient Keith elaborated that, “it’s [taking clozapine] like having a couple of bongos, not on the same level, but it’s good, it is - puts me to sleep.”<sup>66</sup> Having recently started taking clozapine, Keith noted that he liked “going to sleep early, you know, having a good sleep.”<sup>67</sup> UK patient Martin also appreciated clozapine’s “effect of tiring me ... I take advantage of this – I work in the afternoons; get up a bit later than most people.”

The provisional time of clozapine was also associated with self-prescribed temporal orders. The regularity of taking clozapine at certain times as well as time spent sleeping, speaks to both the temporal structures of ‘clocked time’ and ‘inner time and rhythms’ (based on experiential, bodily cycles) associated with general chronic illness experiences (Jowsey 2016). While clozapine needs to be consumed at particular times such that a restraint on freedoms to do other things at those times might be assumed, I did not find that patients needed to negotiate tensions between ‘clock time’ and experiential ‘inner time and rhythms’ (Jowsey 2016:1098). This was largely because patients felt able to ensure that the effects of clozapine consumption suited their personal interests, particularly around sleep. Once adjusted to how clozapine worked for personal preferences, there was also the knock-on effect of building momentum toward the future. As UK patient Blake, 45, who only took clozapine in the evenings, said, “you have to give it about 45 minutes before you stop thinking funny.” Blake reported relatively high feelings of well-being (an “eight” out of ten)

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<sup>66</sup> Keith continued to smoke marijuana, too, to assist him in getting to sleep, but could not single out whether it was clozapine or marijuana that was most critical in this process. Again, implementing complementary strategies were important to exerting agency.

<sup>67</sup> A critical point I will return to in the last section of this chapter is that many participants did not mind going to sleep early if they had “nothing else to do.”

because he “went to bed early, got up early, came here,” which had become his reliable strategy for having a good day. UK patient Luke said of recently starting clozapine that he felt, “less stressed... I enjoy sleeping ... but there’s more things to do isn’t there! You’ve gotta kind of keep organised, and keep focused, and optimistic and... push on.” This suggested an intentionality to keep protecting himself in the present.

Sleep as a suspension of time and conscious concerns sometimes needed to be reconciled with waking life, and this prompted reflection. For instance, Australian patient Myles remarked how, “when I am asleep, you can’t wake me up ... but I can’t work out howda’ ... deal with, the side effects of this drug, I mean you go to sleep, you wake up in the mornin,’ the whole pillow’s covered in drool, saliva from - it makes you drool all night.”<sup>68</sup> The pockets of time that were suspended from other realities either through clozapine “numbing,” sleep or activities (discussed below) was an underlying theme for patients. While clozapine itself could be seen as providing a ‘knowing presence’ or ‘arbiter of reality’ (Jenkins 2015:60) – such as how Myles described: “It’s sorta like it’s someone in me head that talks to this person, so I don’t have to” – the experiences of unaccounted for time were also powerful because they were short-lived but familiar enough to provide a common thread through patient experiences.

Over time, the shorter-term temporal bearings associated with clozapine treatment could provide enough security for patients to build upon. UK patient Felix, 45, said he had “been continually making progress since 1998” (when he started clozapine). When I asked him of the changes he had experienced he said, “I don’t know really, it’s just that... I always take it, you know, morning and night – sometimes I take the night time dose a bit early, if I feel panicky.” As Felix had suggested of his cigarette smoking habit, which he said, “helps me with panic attacks,” feelings of “making progress” could be grounded more in maintaining present stability rather than in clear changes from the point at which patients found their reliable sources of stability.<sup>69</sup> Moreover, the temporal cost is also present, with the knowledge of both positive and negative immediate futures suggested through the personalised management of threats to stability.

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<sup>68</sup> Myles also chose to continue smoking marijuana as well as taking clozapine because “it actually solves my mental problems” and “makes me sleep”; facilitating temporal alleviations.

<sup>69</sup> Felix felt that ceasing smoking would be “a problem either way because if you do give up the withdrawal symptoms will give you a panic attack”.

## Temporal upkeep

Arguably, clozapine facilitated ‘Fordist’ aspirations of ‘regularity, task-specific duties, and mechanical rhythms’ (Ferzacca 2000:35). As Adam (2008:113) suggested, ‘the more intensely progress is pursued, the less the future becomes predictable.’ Australian patient Liam identified that it was important to him to be able to follow routines, as this helped to establish some measures of predictability in his immediate future. Yet this predictability was a double-edged sword when it signalled unfavourable futures. For example, the process of showering, as well as going to the toilet, tended to bring on “panic attacks” because “I might get the routine wrong.”<sup>70</sup> Liam explained, “I don’t know if I should tell you this but I have a curse – straight after the shower, I wet myself.” Clinically, Liam’s experiences could be interpreted as the clozapine side effects of incontinence and/or Obsessive-compulsive symptoms (his superstitious rituals of prayer and particular routines). Liam nonetheless suggested a willingness to persist and strive for experiences of feeling “100 per cent” and to maximise a sense of control over time.

There was space to fit in new possibilities for health alongside the provisions of clozapine, in line with how people in modern society take ‘the future to be subject to our own will’ (Adam 2008:113). UK patient Christopher, 39, understood his experiences in terms of “neuroplasticity,” which he described in relation to time: “The paint hasn’t dried.” He felt himself to be “waking up” and negotiating with the “negative” voices he still heard. Christopher continued, “what I say about schizophrenia is it’s like the light goes on and you’re blinded by it but, yeah, after a *while* ... my eyes are slowly adjusting.” Many patients who had been on clozapine for a longer time described a process of adjustment and acceptance before they could think beyond their current appreciation for mere stability.

Of course, the years spent in liminal time appreciating stability, to not do anything in particular yet, could be highly consequential to patients’ longer-term prospects at social integration. Patients might not ever ‘catch up’ with their expectant life stage had they not been diagnosed with schizophrenia. UK phlebotomist Sam commented to me one day that

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<sup>70</sup> This routine consisted of “rinse off, shampoo, lathering for five or ten minutes, rinse.” Panic attacks also prevented him from going to the toilet: “sometimes when I have a bad panic attack I dread the thought of going to the toilet. I go eventually but I wait a while.” He also suggested, “When I get home I need to brush my teeth. I haven’t brushed my teeth in weeks, I’ve been too slack” – this did not relate specifically to the panic attacks but Liam mentioned it in the context of them. Critically, Liam was determined to keep trying: “I was going to have a shower yesterday but then a panic attack came on and I couldn’t do it, so I’m going to have a shower again tomorrow, have another attempt.” Many patients told me about ‘tomorrow’ aspirations.

patients were now able to enjoy their lives without having to take responsibility yet, particularly younger patients in their thirties who were “catching up on what they missed in their twenties,” or even earlier. Sam had observed how patients enjoyed “sitting around together eating pizza and playing video games,” like they might have done a decade or two earlier. A number of patients in my research who became unwell toward the end of their schooling or university years were retaking school or university subjects again, often telling me how ‘studying’ textbooks had become a part of their daily routine, albeit toward no particular end-point. Clozapine was helping to keep their futures open.

It may seem that clozapine enters patients into an all pervasive ‘provisional time’ whereby patients cannot escape a parental regime imposed on them because they are not afforded time without the impacts of clozapine. One could say that clozapine treatment enters patients into situations of ‘chronic time,’ wherein ‘chronic time is an intruder who forces life into a kind of lock-down that interferes with improvising temporality’ (Morris 2008:415). Clozapine patients, however, could effectively escape this ‘chronic time’ using strategies to temporally evade existential uncertainties that come with illness or otherwise. Heidegger (1962[1927]) suggested that our sense of ‘Being’ is fluid and ultimately ‘to-Be.’ It is simultaneously available and unavailable, ‘throwing’ and ‘projecting’ us toward what is contextually meaningful. He described such temporality as ‘ecstatic’ in the sense that it stands, ‘outside-of-itself’ and ‘in and for itself’, whereby there are continually opening horizons of ‘ecstases’: The ‘having been;’ ‘the Present;’ and the indeterminable future (Heidegger 1962[1927]:H329). Thus, while our lives might be retrospectively pieced together along pinpoints of *time*, while time is ‘happening’ we improvise our way through a multiple, non-linear and ‘ecstatic temporality’ that is behind, alongside and ahead of itself (Heidegger 1962[1927]). Taking the case of children with Type I diabetes, David Morris (2008:419) argued that to suit the conditional demands of bodily functions and monitoring, ‘the future is already eaten up by the next dosage, the next test, the next thing to eat,’ yielding only ‘chronic time’ – and no ecstatic temporality.

Social norms, conventions, habits and practices driven by our individual circumstances are the sources of domestic and bodily regimes that provide an underlying beat to our lives. For clozapine patients, ‘chronic time’ strengthens this beat through patients continual and vital engagement with their medication regimens. Yet, as the locus of these provisions, the body also becomes the platform for possible feelings of freedom (Morris 2008:417). Morris

(2008:419;418) observed that when diabetic children do not concord with their insulin regimen, they were grasping for the only means of ecstatic temporality, otherwise granted in adulthood, that they might ever experience. Herein, Morris (2008:419) posited, these children have not yet had any time *to be* themselves (“I have not even had time to be me”). The existential framework of rebelling against chronic time and reclaiming ecstatic temporality via any openings for non-concordance is worth considering in the case of adult, clozapine-treated schizophrenia patients.

Ways in which patients resolved to carrying out tasks one at a time suggested that they did not take their personal experiences of focusing on these tasks for granted. In overcoming initial stress one day when she had had to change her plans because she had woken up to a leaking roof requiring a workman to come around when she was hoping to be somewhere else, Joanne said to me, resolutely, “you can only focus on what you can do.” Joanne said of her schizophrenia, “I have to be a bit more focused than another person who’s doing little jobs through the house, who perhaps do it with the radio on while they’re singing or something – I mean I could do that as well but otherwise I’m focusing on doing this, then I’m going to do that.”

The veneer of feeling “too busy” to take on more was common amongst patients and suggested a kind of buffering of time to deal with uncertainties. For instance, UK patient Felix, who worked in a voluntary job twice a week, felt “busy” and reflected that, “on the one hand, I kind of think it would be good to be in a full-time job, on the other hand if I was then... I wouldn’t be able to sort out other things like having the electrician come around and fix the light, on the balcony, or...answer the phone.” Being able to do these tasks may be indicative of Felix’s fears about what it might mean to trade his time spent doing “not very much.” It also resonated with the impression that most patients gave me, that although most knew that they did not have a huge array of commitments they *felt* busy, and thus they were reluctant to take the risk of adding in more activities, partly in fear of relapse, partly in not wanting to plan too far into the future, and partly in keeping “in control” and focusing in present time.

Picking up on my previous point, the future was kept open for clozapine patients in regard to present time options being continually savoured. UK phlebotomist Sam remarked that patients have “some dreams, but they don’t really know yet ‘what I want to do’,” especially if

there is no sense of “urgency,” or “when parents are still taking care of things for them.” The latter scenario could apply to UK patient Holly, whose ‘impulsive’ behaviours (clinically defined) along with her cautious experimentations with rebellious consumptions (trying alcohol for the first time at age 40 by drinking one bottle of cider, and then trying cigarettes by vaping an e-cigarette), could be viewed differently had she been a child or adolescent and not highly pre-occupied by her parents (dis-)approval of her. On the one hand, the decelerating of time in terms of curtailed expectations toward self-reliance might render her as not being able to fulfil long term independence from others (Morris 2008). The majority of patients were not as financially supported by their families as Holly was, and prospects for gaining independent housing arrangements and the stretching of time in between was critical. UK nurse Narelle remarked:

They come out of hospital and think, you know, “I just want my own flat,” and don’t we all want that, isn’t it *good* to aspire to that? But people are told “well, yes, but that’s down the line. Before you can have that, you have to do this and this ... because that’s the process to get to there, that *we* say! And of course, when they get in the first place, once they’re in there ... they’ll wait two years for a vacancy in the next one, I mean, people’s *twenties* are taken up by that kind of decision.

On the other hand, while being largely dependent on parents or an inefficient social welfare system can exacerbate the slowing of time while on clozapine, attention to present-centred concerns seemed to suit patients who did not have intimately therapeutic relationships available to safely attend to their past or future.

Patients appreciated the ‘provisional time’ in part because it was still flexible. Living in the present meant utilising clozapine to provide restful pause when it was wanted. Although the half-life effects of the drug seemed to facilitate an energy to “do things” beyond being ‘sedated’ by the drug, the sedentary effects upon first consuming clozapine were of course welcomed before bedtime. UK patient Steve, 21, who had been on clozapine for “probably two years,” which felt like a “long time” to him, liked to make music and socialise with friends later in the day, and felt that clozapine was “alright” now that he could predict and work around its sedentary effects. He elaborated, “every time I take it, it knocks me out for about 12 hours.” Steve said that if he had to get up early, “I’ll only take half a dose, [be]cause otherwise I won’t be able to do anything.” UK patient Alan, 43, said that once the clozapine “wears off ... I perk back up again a bit, so I’m alright.”

Critically, clozapine regimens did not quite reflect ‘chronic time’ because once domesticated, time could be re-ordered. When UK patient Tom, 54, started clozapine treatment ten years ago, he entered a cycle of taking clozapine, feeling “drowsy,” having “nightmares” throughout the day and night, and “chain smoking” to “relax” in between clozapine doses. His appetite increased, and, being sedentary, he put on 29kg (40 percent of his initial body weight). Before long he was diagnosed with Type II diabetes, prompting him to quit smoking. But the nightmares persisted and continued to torment him, so, five and a half years into his treatment, he asked for his clozapine dose to be reduced. As suggested in Chapter Three, when I met Tom (in 2015), he was down to one seventh of his original dose, had lost weight, reversed his diabetes, his “energy” had returned, and he was practicing tai-chi at least once a day to “focus.” Tom smiled softly, “at least I know [that] it’s not the *end* for people with schizophrenia.” When I returned to the UK the following year, however, Tom was no longer attending the clozapine clinic. Staff told me that Tom’s cat had died, causing him much distress. Subsequently, he stopped taking his clozapine altogether. He quickly became psychotic again, and was readmitted to hospital. He agreed to go back on clozapine, provided he could move away to another the town, to start again, and attend a different clozapine clinic. The temporal respite brought on by clozapine was a central ingredient in finding order, but patients saw themselves as individuals negotiating the ‘chronic time’ of clozapine for themselves.

Often feelings of cognitive sharpness were experienced with a lower, sub-therapeutic dose of clozapine, as recent clinical evidence also suggests (Mezquida et al. 2018). UK patient Christopher, who had been working with his psychiatrist to lower his clozapine dose over the last five years (reducing from 600 to 475 milligrams so far), but declined supplementary medications for ongoing ‘psychotic’ symptoms, said, “some people get dragged into it, the mind-numbing cycle, and before you know it you can’t change yourself.” UK patient Nathaniel, who actively smoked while taking the clozapine to try to combat “a general feeling of *weakness*,” found that in coming off clozapine treatment (Chapter Two) his experience of “consciousness” returned such that he felt “more coherent”, at least initially.

While progress in terms of ongoing ‘stability’ could be appreciated, the emphasis was more on continuing to seek out activities and assurances that could maintain a sense of security. UK patient, Trevor, described himself to be “in a good state of well-being at the moment ... I’ve been out of hospital a very long time; I’ve been stable a very long time.” He wanted to

“leave things as they are,” which meant “to enjoy life really, forgetting about the past, coping with the current situation ... minimising stress – I don’t want to put myself in very stressful situations because, you know, it’ll make me ill;” “I need to feel secure.” As Christopher pointed out, feeling secure was part of what he recognised as “Maslow’s Pyramid of needs”:<sup>71</sup>

So, you’ve got to have your food, you’ve got to have your clothes, you’ve got to have your shelter... it’s difficult, because I worry about things like losing my job, and if I lose that... If I lost everything and bombed out, it would... poverty, being locked in poverty; you’ve got to do things.

This resonates with previous ethnographic evidence about the significance of basic housing and financial support on outcomes for schizophrenia patients across cultures (Luhmann & Marrow 2016).

Unfortunately for patients in public housing, feeling secure was difficult, yet they compensated by implementing their own sense of order and predictability in their lives. For instance, Australian patient Daniel said that finding a “focused frame of mind” did not always feel “feasible” due to his public housing situation. His neighbours were frequently “climbing up” over his balcony to access the apartments above, and there were continual break-ins. Thankfully, clozapine allowed Daniel to “keep a constant sleep, [be]cause otherwise I’ll just try and keep myself up for ages,” “trying to be hyper-vigilant ... not wanting to sleep ... ‘cause you’re worried about people breaking in your door.”

When patients could find safety in their surroundings and minimise stress triggers, on the other hand, the difference was significant enough to not be able to distinguish between the impact of clozapine and the changed surroundings. UK patient Kevin said, “my mind’s a bit calmer... I think I’m less paranoid,” but that he was not sure whether this was because he no longer exposed himself to “clubs and pubs” or because of clozapine: “I’m definitely better but I don’t know why ... am I just in situations that don’t stress me out as much?” He conceded, however, that, “clozapine *dulls* down your feelings”, and that he was reluctant to reduce his dose because “I don’t wanna end up *back* where I was ten years ago.” “I try to live in the present, I don’t like looking too far back or too far forward,” UK patient Alice

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<sup>71</sup> Maslows’s Hierarchy of Needs is an established psychological theory that prioritises human needs in the following order (highest to lowest): Physiological, safety, social, self-esteem, self-actualisation (see Block 2011).

stated. Furthermore, having a sense of provisional security and temporal order could bring patients to a place of “focusing” in and on present time. This could also reflect a return to the rhythms of sleep and wakefulness that characterise a desirable present, keeping the past and future at bay. Together, these everyday rhythms constituted a present worth having.

### Focusing in time; suspending uncertainty

*Tom: I think there are people out there who are... fairly focused, should we say, and they don't suffer from schizophrenia, yet, and maybe they never will, if they're lucky, but they might have marital problems, relationship problems, work problems... you don't suffer from schizophrenia, Dr [George] doesn't, are you 100 per cent happy?!*

*JB: Well, no, I don't think there's-, this is why I'm interested in exploring it, but not even just happiness-*

*Tom: Health?*

*JB: This idea of health, yeah, what does it really mean?*

*Tom: Yeah, I'll go back to what I was saying about connecting with your body and mind, working on that, that's all anyone can do – yoga, tai-chi, meditation, ballet or whatever, anything ... that's gonna get you so you can FO-CUS*

Patients engaged in activities that provided immediate embodied connection and concentration; activities were not pursued for the longer-term reward. Post-modern analysts have rendered this inclination to focus on the present a reflection of ‘late capitalism,’ such that schizophrenia patients can be understood as ‘the product of a schizoid culture which seems to aspire to the collapse of linear meaning into the compressed time of a perpetual present’ (Currie in Woods 2011:196). In this context, the schizophrenia patient is somewhat constituted as ‘disembodied and deprived of agency ... a spectre of depthlessness that perhaps says more about the pessimism of cultural theory’ (Woods 2011:199). Further, while Fuchs (2007:234;235) has suggested that ‘the outward similarity of succeeding moments creates something like a substitute of inner continuity, an artificial steadiness of one’s experience’ – such that ‘schizophrenic patients try to avoid sudden changes as far as possible’ and ‘in its extreme the immobilization or ‘freezing of time’ may lead to catatonic stupor’ – I found patient experiences to align with a wider means of managing existential anxiety in Western culture. For clozapine patients, being able to “focus” enough to ground oneself in present awareness was, as Tom suggested, tied into a connection with the world. Feeling “focused” and “doing things,” yielded a temporal sense of self-efficacy in the world.

Several patients reported knowing they were well if they could focus enough to read. When I asked Australian patient James whether there was anything other than eating fresh fruits that he did to keep his health on track, he responded, “reading, that’s pretty much how I evaluate am I sick or well, am I well or unwell, regarding mental illness, is can I focus on reading, for prolonged periods of time.” He furthered, “If I’m really well, I can sit there for 5 hours and read a book; if I’m unwell, I can probably read for about 5 minutes and then be distracted.” This qualified his ability to move through other activities.

Patients found ways to divert their focus when faced with undesirable possibilities within their present time commitments. For instance, Martin explained that he did puzzles at work to “distract” himself from “work appraisals” and “add-on things” that “coincide with my lack of self-esteem issues.” In regard to how he occupied himself in times that he would otherwise be alone, he always had a book “on the go” to read in bed, after watching television, and in regard to the hours between work and late-night hours, he said, with a shy but cheerful laugh,

I guess I’ve got, what with the croquet, and... snooker, backgammon and the bridge, I’ve got... some of my colleagues will say, ‘oh you’ve got this, oh you’re a social butterfly, you’re always doing something,’ and I’ll say ‘well you’ve got a husband or a wife and when you go home they welcome you in and they chat with you, and I haven’t got that, so I need to, I need to *go out*.’

Martin preferred his own company if he was engaged in an activity, or planning for one that would involve other people. He said that he enjoyed “getting through” the process of organising croquet tournaments or helping customers at work. Moreover, as well as ‘health mentors’ pertaining to people that were able to “do things” (particularly in the realm of caring for others), some patients also mentioned caregivers (clinical and informal) who simply had it “together.” UK patient Garry, 29, told me that his Dad represented “health” because “he seems quite well all the time, like *with it* ... focused.” Feeling focused tied into being occupied enough to suspend other concerns.

Arguably, clozapine patients, while facing treatment provisions subjecting them to ‘chronic time’ (Morris 2008), are domesticated enough by the regimen to experience a more ordinary freedom – and to reclaim themselves in focusing on an open future. We might assume that the more extensive the health provisions, the more one’s ability to improvise toward imagined freedoms might stall. However, the health agency described in the previous

chapters along with the ongoing non-compliance to health advice during clozapine treatment (at the same time as complying with taking tablets and have bloods taken) suggests a *persistence* of ecstatic temporality that may be critical to self-efficacy and pursuits of phenomenological authenticity.

Existential and phenomenological theories emphasise the human capacity to find ephemeral freedoms from uncertainties and doubts that may surface when one reflects extensively on the meaning of one's experiences. Ontological insecurities are thought to be a large part of schizophrenia (Fuchs 2007; Sass & Parnas 2003), and psychotic 'delusions' are thought to involve a switch into inflexible 'certainty,' whereupon alternative perceptions appear unreasonable (Rhodes & Gipps 2008). When acute psychotic symptoms are alleviated on clozapine, I observed that the experience of greater ontological *security* to deal with both ordinary and extreme uncertainties opens up.<sup>72</sup> This could be ordinary in the sense that, as Merleau-Ponty (2002[1962]:401) wrote, '[t]he percept is and remains, despite all critical education, on the hither side of doubt and demonstration.' That is, everything is still yet to be proven. As suggested in Chapter Three, part of being a clozapine patient is about continual management of uncertainties, and this happens within the predictable stability provided by the medication regimen.

Finding focus to fulfil present time and suspend doubt was not taken for granted. When I asked Steve, 21, whether he remembered what it felt like to be "well" before getting his diagnosis, he said, after a long pause, "I had more concentration, I could focus on something." Australian patient Trent, 24, also felt that his illness was indeed largely a matter of resolving his concentration - but this was something that was he was still negotiating with his female presence/voice, called Bon Chance. When I asked Trent what part of his treatment had helped him the most he said that it was when his doctor had agreed with him and Bon Chance that his concentration was "the main issue ... holding me back in my life":

He [Trent's doctor] established that the concentration was actually part of my illness and that was important to me because, um, to me, that's true as well, it's quite an accurate distinction ... But Bon Chance says she'll leave having fixed that, and we can fix that, but it's a social thing ... Bonnie says that she'll resolve my

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<sup>72</sup> This may or may not be linked to Obsessive-compulsive symptoms; it is beyond the scope of this thesis to comment but I note that UK psychiatrist George suggested to me that he would hypothesise that part of the reason patients experience OCS is due to patients not wanting to let go of delusions and hence becoming obsessively superstitious is another 'cognitive' avenue for their concerns (my paraphrasing).

concentration before she leaves, and if I take enough clozapine she'll leave altogether ... I'm hopefully on a good trend, really.

Trent wished to find freedom to focus so long as it was with both clozapine and Bon Chance's support. He told me he would miss her if she disappeared entirely, thus creating ambivalence about her leaving altogether. As Lavis (2013:48) has described in the case of her ethnographic informants' 'friendship' with anorexia, there is a 'dialectical engagement between – and multiple temporalities of – processually reproducing something that you already have, whilst knowing that it too produces and constrains you in ways both valued and unwanted.' Trent said that Bon Chance "says ridiculous things that make me laugh, like every day." "She won't let me do anything except for a couple of things a day" – "she'll let me go on a long walk, and she'll let me play games and play music" – "but she won't let me do anything, like, *hard*." I highlight the importance of having challenging activities for 'optimal' well-being later in the chapter, but here I note the importance of finding focus by being able to engage with basic activities for enjoyment – as Trent perceived Bonnie to be helping him to do, as a first step.

The baseline experience that was not taken for granted was the capacity to move through present engagements without losing concentration. Finding activities to focus on in the present alleviated external pressures often experienced in the past. UK patient Dylan, 33, had observed that, "if I'm going fishing or watching a film or something like that, I'll concentrate." When I asked him about when he could not concentrate he replied, "well, I went to college, I found it *hard*, especially when you don't understand something." Dylan said that teachers were not sympathetic and this exacerbated his difficulties. This was something that resonated with other patients' experiences. Thankfully, attending the clinic was something patients could focus on doing as a socially affirmed competence. When I asked patients how they were feeling (0-10; 0 being the worst they have felt; 10 being the best) during our interviews at the clinic, the answer tended to be on the higher end of the scale. The listed contributors to this subjective scoring usually concerned simply getting up and making it into the clinic.

Even when things were not perceived to be going that well, patients were still able to find solace in living from day-to-day rather than letting themselves be limited by linear timeline

concerns such as the potential consequences of clozapine and other consumables. For instance, Australian patient Angus, 38, said of managing his appetite:

It's like, everything's against you and you're trying to battle up a wall, and you can't get over... it's nice just to live every day. I used to look forward to pension day [be]cause it's the time I had the most money, but, no, it's good just to live every day, and enjoy every day ... Otherwise I'm just stuck here in this time, this perceived timeline and, history.

Not getting “stuck” meant finding focus with present-time concerns and a will to extend present time as much as possible. Health agency was experienced as a process by which temporal freedoms are lived in present potentialities, no matter the future unknown consequence. Further, abilities to find agentic freedoms through temporal focus that suspend uncertainties suggested an ordinary human capacity.

How patients dealt with uncertainties by occupying themselves with meaningful activities and finding personal rituals for coping with residual symptoms are part of what it means to be human. As de Beauvoir (2000[1948]:156-157) remarked of how we surpass uncertainty when feeling ontologically insecure:

One does not exist without doing something ... Regardless of the staggering dimensions of the world about us, the density of our ignorance, the risks of catastrophes to come, and our individual weakness within the immense collectivity, the fact remains that we are absolutely free today if we choose to will our existence in its finiteness, a finiteness which is open on the infinite. And in fact, any man who has known real loves, real revolts, real desires, and real will knows quite well that he has no need of any outside guarantee to be sure of his goals; their certitude comes from his own drive.

Two points in de Beauvoir's statement resonate with lived experiences of clozapine-treated schizophrenia. First, there is the observation that existence involves ‘doing something.’ As discussed, this seemed to be a post-psychosis freedom that clozapine patients did not take for granted. Faint recollections of psychosis were mostly described along the lines of sudden, frantic feelings out of one's control – “I couldn't concentrate” (Steve, 21); “a very confusing time” (Mark, 52); “thinking such God-awful things ... I came to a complete full stop in a psychosis, but I was still in a psychosis” (Alan, 43); “my life just kind of stopped” (Kevin, 34); “it was kind of a beautiful thing but it kind of snapped *on* [finger click]” (Christopher, 39); and “everything just flies off sideways and goes onto a different track” (UK nurse

Narelle observed of her patients). Whereas psychosis could be described as chaotic happenings and halts, once patients were on the clozapine ‘track,’ experiences were more about coherently ‘doing something.’ What is more, ‘we are absolutely free today if we choose to will our existence’ (de Beauvoir 2000[1948]:157). Clozapine-treated schizophrenia patients pursued life with at least some sense of potentiality to overcome unknowns.

Second, de Beauvoir’s (2000[1948]:157) assertion that the ‘finiteness’ of living (and doing) ‘is open on the infinite’ wherein man’s ‘certitude comes from his own drive,’ was critical to patients appending their existential fears and doubts. That is, moments of certitude were not tangible and taking hold like they would in psychosis, but instead were part of a temporal uptake of self-efficaciousness towards a not-yet-known future. In Chapter Three, I considered how patients efficaciously work between compartmentalisations of health, utilising imaginaries of consumption intakes and expenditures to embolden their active remaking of their health. As Tom suggested, in the opening quote to this section, working on embodied “connections” and “focus,” wherein all psychic and bodily energy was temporally integrated, allowed agentic investments in present-centred potentialities. Of course, these ephemeral certainties and suspensions of uncertainties mirrored the underlying premises of clozapine treatment itself: to keep patients alive.

The personal resourcefulness of patients to keep on with life was critical to their livelihoods. Larson (2004:462) suggested that Levi-Strauss’ notion of ‘bricolage’ not only describes the ‘constant (re-)negotiation in a situation of existential crisis’ for people recovering from psychotic illness, but also the ‘attribute of human creativity in life and a proof of individual analytic and theory-generating capabilities.’<sup>73</sup> While Larson’s (2004:466) ethnographic study concerned how patients made sense of their situations in the wake of first-episode psychosis, rather than chronic schizophrenia, his emphasis on ongoing ‘conceptual work to appropriate and combine different explanations’ can be carried over into the ongoing, creative salvaging of selfhood and personal drives experienced by clozapine-treated schizophrenia patients.

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<sup>73</sup> Levi-Strauss (1966:24) described ‘bricolage’ as evident in human problem solving insofar as: ‘The choice of one solution involves a modification of the result to which another solution would have led, and the observer is in effect presented with general picture of these permutations at the same time as the particular solution offered. He is thereby transformed into an active participant without even being aware of it. Merely by contemplating it he is, as it were, put in possession of other possible forms of the same work; and in a confused way, he feels himself to be their creator.’

As explored throughout this thesis, what it means to live as a clozapine patient is hinged on both biological and social factors that patients reclaim their sense of self through. UK patient Bradley distilled the term ‘health’ to mean, at a minimum, “being alive.” Given the plethora of unknowns when it comes to the embodied interactions of clozapine, the blood work and checking for ‘vital signs’ during treatment monitoring provisioned against imminent threats to life, may indeed render one, at least relatively and clinically, “healthy.” Further, the very experience of breathing, Lyon (1997:92) illustrated, is a process that is both autonomic and open to subjective regulation, and also communicative of ‘feeling states.’ Similarly, Fuchs (2012:154) pointed to ‘the homeodynamic regulation between brain and body,’ hinging on two relations. First, there are experiences of ‘vitality’ (‘mood’ and ‘attunement’), which are most verifiable in the absences of harmonious bodily states (Fuchs 2012:153).

Second, there is ‘conation’ – experiencing ‘drive, instinct or urge’ to interact with the environment (Fuchs 2012:156). Fuchs (2012:163) summarised that a ‘continuous ‘resonance’ between the brain, the nervous system and the entire organism is the precondition for conscious experience,’ reminding us, then, that the ‘*living body is necessarily subjective.*’ The body ‘is a self because it constantly transcends itself through its boundaries and relates to the environment by assigning meaning to it’ (Fuchs 2012:163). The phenomenological trope that we cannot separate bodily experiences from consciousness (Merleau-Ponty 2002[1962]; Csordas 1994), along with findings that experiences of self can both usefully and more problematically dissolve under certain circumstances, thus brings me to consider health agency in regard to meditative pursuits.

### Meditative pursuits

*What this guy, Aristotle, said is that the mark of a educated mind is to entertain a thought without accepting it. So, Mindfulness does that a little bit, and the peaceful thing kind of does that as well ... Nothing’s perfect, it doesn’t work all the time ... When I do these things, it’s kind of like a magic spell or something like that ... I don’t want to call it casting spells because I don’t believe in witchcraft or anything like that, but that’s the best way to explain it ... It’s like, ‘right, you’re in the present moment now, don’t judge that, just let it happen’ ... you cast these spells that discredit the voices, and things like that ... If you can hold that meditation, and hold it for a while, then the voices are less there ... you’re quieting the mind down, really. And some of the spiritual things like having peace. Meditating on peace would do the same thing, but the link between them is the breath, because in Mindfulness, the breath is the anchor of bringing it back. – Christopher, 39, UK patient*

Agency over well-being was also available through meditative pursuits that dissolve linear time and past and future experiences of ‘self.’ Recent ethnographic evidence suggests that it is important to distinguish between experiences of ‘self’ during trauma and during meditative states. On the one hand, ‘mindfulness meditation’ can result in a ‘loss of agency’ because, as one of Ataria’s (2018:49) ethnographic participants suggested, they “didn’t need a controller, I wasn’t in charge.” On the other hand, during trauma agency can be lost because ‘one loses the ability to control one’s actions’ (Ataria 2018:49). Ataria (2018:50-51) underscored how both experiences result in experiencing a loss of time, along with Damasio’s notion of ‘the autobiographical self’ (1999), and feelings of ‘deadness.’ Sensory ‘deprivation/low arousal’ during meditation and ‘overload/hyper arousal’ during trauma ‘can result in similar experiences’ insofar as ‘the subject-object structure ... may collapse’ (Ataria 2018:51). The critical differences, however, come down to experiences of ‘will’; ‘guidance’; and that during trauma, ‘the intentional structure collapses immediately,’ such that people meditating feel ‘protected,’ while those experiencing trauma feel ‘helplessness’ (Atarai 2018:52). Although ‘the relationship between dissociation and psychosis has now become one the most vexed questions in the study of psychosis and spirituality’ (Luhrmann 2016:9-10), ‘mindfulness-based interventions’ have gained little traction in schizophrenia research (Tabak, Horan & Green 2015), and meditation more generally is considered dangerous. None of these techniques were part of the clinical tool kit in the clozapine clinics where I was based.

Despite formal meditation classes often excluding people with psychotic illnesses, a number of patients in my research adopted strategies that aligned with meditative practices. I reiterate that clozapine-treated schizophrenia patients actively repurpose knowledge and experiences to express their health agency. UK patient Christopher first adopted “mindfulness” techniques during a course at ‘recovery college.’<sup>74</sup> He initially just “used” these “around sundown time, to relax for the evening,” and also to “help” him “in a shopping queue in Tesco and it’s all busy-busy, and you’re stressed, so you can kind of take a few breaths there.” Christopher lived with his mother but said that he found it hard when “she has the TV on all the time” (his mother knew this: “She’ll say ‘you’re getting fed up with me, aren’t you?’ So, she’ll go and stay with my brother”). He clarified, “when I’m in my own space, I

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<sup>74</sup> In contrast to ‘mindlessness’ – when action feels automated and ‘the perception of control is not possible’ – ‘mindfulness’, by formal definition, refers to the attentional ‘process of drawing novel distinctions’ that yield ‘a heightened sense of involvement and wakefulness or being in the present’ (Langer & Moldoveanu 2000: 1-2).

feel quite better” because “I’m able to do more mindfulness things, and I’m able to study the Bible more.” For Christopher, his religious spirituality was, in his words, the “constitution” in which he built his life around, and he incorporated concepts of mindfulness into this.

The notion of things being impermanent gave him “hope.” He was at first self-conscious about what I might think about his use of the description “magic spells,” laughing at himself at one point for using the term. Ultimately, though, Christopher’s meditative pursuits were tied into a desire for societal change that transcended beyond himself:

Conversations I’m having with you, sometimes, if I talk to regular people they can use it as a knife and turn it around and stab me with it ... If I was saying ‘oh, the system’s fucked up’ and this that and the other, there are certain people out there that they say, ‘oh we’ve got a *brilliant* system’ ... It’s like, I can’t, I can’t... it’s hard to talk to ... Hopefully this will help your anthropology thing.

Sometimes our conversations led to contemplations about how he might indeed start to talk about his experiences with mindfulness and spirituality more often: “I’ve got a lot more words and I’ve got a lot of context and I’ve got a lot of spells now, so I’m thinking that if I came off my medicine I might have a chance to make it through – when you do get these heightened senses of realities and things like that... I think that’s the place where you can actually make the most change, but it’s never a permanent thing.”

This impermanence was just as much about him being able to assert changes over the process of his mindfulness as it was about making it more “compatible” with his “spirituality.” A year after we had first met, Christopher clarified that in regard to his mindfulness techniques:

I’ve *modified* it now. It’s, you know, it’s coming back to breath. But I’ve added the fact... it’s like labelling thoughts and things that are going on in your head. So, you have this mindfulness, which has a structure for the names of the words, for the things that are going on... breathing, paying attention in the moment, and stuff like that ... Basically, I do a mindful meditation, but I’ve changed the words that kind of maybe mean the same thing but they’re compatible with my spirituality

He conceded, “I’m still in a lot of pain, but spiritual type pain ... but you can’t do anything else but move on.” Previous ethnographic evidence suggests that practices of meditation can transform pain because the process of being present with pain, which often defies language, allows an ‘exposure’ to it that, ‘is accomplished through silence and relies on one’s own

ability to accept their experience alone' (Myers, Lewis & Dutton 2015:499;500). Christopher was one of four participants in my research who had explicitly drawn on and tailored 'mindfulness' strategies. UK patient Hannah was the only patient in my research that linked her experiences of mindfulness to clozapine: "I'm trying a mindfulness course and that kind of helps with the voices – I don't know if the clozapine helps in the same way or if it just takes the edge off the... makes sure you don't have suicidal thoughts, or too much stress building and making your mood low, and these kind of crisis things."

For the other patients who mentioned it, mindfulness had become an add-on to taking clozapine. Before coming off his sub-therapeutic dose of clozapine following the death of his pet cat, UK patient Tom had re-purposed non-clinical knowledge that he could now articulate after reading a book he had recently bought himself, titled 'Mindfulness' (which he had pulled out from his bag to show me). On days when he found himself "getting all confused" at home, he now had vocabulary for how attending to his pet cat would bring him "back to the world." While walking the streets, he tried to focus on his natural surroundings, describing to me with much enthusiasm the birds he now admired and felt connected to: "you're going along and *they're* going along and you *connect* with them; you watch them, it's *brilliant*." To supplement the temporal stability that a sub-therapeutic dose of clozapine, tai-chi and the calming presence of his cat granted him, Tom actively pursued "mindfulness" techniques he had read about, to "centre" himself in the present and "flick off" the voices he experienced (Brown & Dennis 2017:375). Tom reasoned that, "we're conditioned ... by suggestions in our culture and society, and our brain accepts them and believes them, and then that's where the voices start, with a commentary through our lives ... [but] now I know they are just thoughts, and they are meaningless."

Personalised meditation rituals were adapted from cultural exposures patients had had. When I last met with Australian patient James, quoted at the opening of this Chapter, I asked him whether there was something that helped him to "focus" best (to see how the answer compared to notions of feeling "in control"), he responded,

I meditate. I enjoy meditating ... I don't know if I do anything in particular, I sit in a *Shinto's* stance – Japanese kneeling position ... and another one where I sit in this kind of Chinese, Kung fu *Buddhist* position, that's my two ... I allow my mind to *run*, in whatever way it wants to run, through meditation I try to, figure out which is which... bring things *together*, rather than being... thinking this, this, this and this,

bring it all together and sort it out ... I like meditating at the beach, I really enjoy that ... meditation when you're outdoors ... it's *so cool*, you know, *it feels good*.

Despite the fact that his diagnosis had excluded him from participating in formal lessons on how to meditate, James had pursued his own practice of it instead, enabling him to “bring things *together*” and “sort it out.” This happened to reflect my own experience after participating in a formal Transcendental Meditation course, where I had signed a form to certify the only condition of entry: that I did not have a psychotic disorder. The only tangible difference between James and my experiences of meditation beyond the ‘training’ aspect was the frequency in which we did it – while James practiced martial arts three to four times per week, he was proud to meditate “*at least once a week*.” I was told that I should meditate twice a day (like James, however, I do what suits me, which is once a day at most).

While most patients did not conceive of their tendency toward engaging in temporal pause as ‘mindfulness’ or ‘meditation,’ as Tom, Christopher and James had come to do, they suggested (even more) informal means of achieving similar states of embodied awareness. Echoing the words of patients, Myers, Lewis and Dutton (2015:492) posited, ‘meditation is an exercise in temporality: learning to stay in the present moment.’ Myers, Lewis and Dutton (2015:488;489) conducted ethnographic research with ‘American women who use meditation-based contemplative practice as a therapeutic for trauma,’ exploring Pagis’ notion of ‘somatic reflexivity’ and how meditation can even substitute for psychotherapy in so far as there is ‘a feedback loop between one’s self and one’s body, and a strong or repeated stimulus and response.’ They argued that meditation can be deployed ‘to silently – and very privately – accept a self they often perceived as a source of danger, pain, and disappointment’ (2015:503). Indeed, Tom had found that with this newfound “awareness,” “I’m experiencing my *emotions* a little bit more,” and he felt more “conscious of the sadness in the world.” “People are suffering *needlessly*, especially in Western society ... I don’t want to listen to that voice in my head,” and if, “in another culture and that voice is saying *nice* things ... they’re probably gonna be *conscious* of it.” Moreover, the concept of ‘mindfulness’ in its bridging of Eastern and Western ideas of the self and self-transcendence, potentially provides scope for psychotherapeutic interventions that might challenge the ‘self-disorder’ part of schizophrenia rather than dealing with possibilities of multiple selves (Kirmayer 2007).

Personalised practices of meditation may be not only more effective in assisting patients in their sense of asserting agency, but also further still by allowing the ‘self’ to be involved elsewhere. Like Christopher, who partook in several extracurricular community-building activities and volunteered regularly at his local church, Australian patient Donna, 40, was concerned with making bigger changes beyond her own self-management. Donna, had become unwell while studying at university. She had now returned to university, as a postgraduate student, and was finding a balance between her passions and what culminated in a schizophrenia diagnosis. Of the time she became unwell, she remarked, “I felt like the whole weight of the world was on my shoulders ... just looking at the devastation that humans have brought on this planet, and feeling like... nobody’s doing anything about it and I have to, kind of like.... Why doesn’t everyone care about it the way I do?” I asked Donna if she still felt like this, and she replied:

I do, yeah... I often wake up now, feeling like Humanity’s on a knife edge, that we’re in dangerous waters, in terms of our future and the future of life on earth ... climate change, pollution, resource depletion ... keeping Aboriginal people out of the criminal justice system.

Donna said that her “dream job” would be to work for “The Australia Institute; a green think tank.” She was also one of the few Australian patients in my study doing voluntary work, which she said she was “getting satisfaction” from.

As we saw in Chapter Two and Chapter Three, well-being is partly about experiencing “novelty,” as Australian patient Daniel called it, or insatiable and multiple “appetites,” as Christopher put it. Christopher hypothesised that his “coping strategies,” paralleling with “mindfulness,” still “fizzle away ... maybe because I become complacent.” There was thus a need to keep developing strategies for oneself. As I elaborate below, these experiences of chasing novelty and challenging oneself also speak to the notion of ‘flow’ (Csikszentmihalyi 1990). When I asked James how he was currently feeling in regard to being able to ‘focus’ on reading, he responded, “pretty good” because “everything’s on track, I’m reading, writing, I play chess as well - part of a chess club as well.”

It is not that patients were not cognisant of potentially undesirable consequences of primarily focusing on present preoccupations; patients actively chose to utilise this focus. A number of patients played or listened to music. For instance, UK patient Alan described how integral

listening to and playing music was – “I’ve always listened to music, you know, I – that’s what got me through it all, was ah, music lessons, music appreciation.” Alan similarly also commented of his theatre improvisation workshops:

You know once I can disengage from talking to myself, to *engage* in concentrating in the drama group, I think will get that, that sense of achievement that I’ve been lacking ... the actual piece of theatre itself was improvisation ... then you sit back when you’re not in the scene and watch it and you think ‘ow this is really good.’ And the spin-off is, I watch TV out of the wall again now.

Alan’s pursuits had led him to engage in other activities that he once felt “paranoid” about doing.

Patients absorbed themselves in activities to connect with worldly phenomena and reaffirm their abilities. According to Heidegger (1962[1927]: H354), ‘the Self must forget itself if, lost in the world of equipment, it is to be able to ‘actually’ go to work and manipulate something.’ This may now also be referred to as ‘immersion’ (Snodgrass et al 2011) or ‘absorption’ – ‘the profound narrowing or concentration of attention and focused deployment of cognitive resources; the absorbed individual becomes unaware of the external environment, self-awareness and critical thought are suspended and time perception may become distorted’ (Seligman and Kirmayer in Snodgrass et al. 2011:29). Further, as anthropologists have explored in the contexts of ‘trance’ rituals, the experience of ‘dissociation’ can be deeply healing – if it is controlled and anticipated – or profoundly traumatic if the experience is not sought out (Snodgrass et al. 2011; Ataria 2018).

People, generally, also immerse themselves in activities wherein they became ‘enminded’, as opposed to embodied. In regard to everyday practices of regulating ‘mental’ attention, Snodgrass and colleagues (2011:31;44) explored the ‘absorption-dissociation’ states of people who play computer games, whereby the self is transferred to videogame characters and worlds such that, ‘individuals forsake real-life roles and obligations, rather than confronting them directly,’ finding ‘positive therapeutics of online gaming, which function through a combined promoting of relaxation alternating with mildly stress-inducing flow states.’ As Heidegger (1962[1927]) said, when immersing themselves in tasks-at-hand, people transcend their sense of self (otherwise fragile) and are able to put their energies into something else. Heidegger (1962[1927]:H410) also remarked that, ‘[b]usily losing *himself* in

the object of his concern, he *loses his time* in it too ... the temporality of resoluteness has, with relation to its Present, the character of a *moment of vision*.' Further, '[o]ne's existence in the moment of vision temporalizes itself as something that has been stretched along in a way which is fatefully whole in the sense of the authentic historical *constancy* of the Self' (Heidegger 1962[1927]:H410). Thus, while the self 'forgets itself' during the activity, the feeling of 'resoluteness' and 'vision' stands for a holistic and creative reclamation.

Arguably, the 'moment of vision' Heidegger described aligns with the psychological concept of 'flow' (Csikszentmihalyi 1990). The feeling of 'flow' is described as the 'optimal state of wellbeing,' marked by an engagement in an activity that does not have a clear temporal end. The 'soporific' or 'heaviness' effects of clozapine are temporally forgotten during activities whereby one can engage all energies and attention. Critically, experiences of '[f]low helps to integrate the self because in that state of deep concentration consciousness is unusually well ordered' (Csikszentmihalyi 1990:41). 'Paradoxically, it is when we act freely, for the sake of the action itself rather than for ulterior motives, that we learn to become more than what we were ... once we have tasted this joy, we will redouble our efforts to taste it again' and '[t]his is how the self grows', posited Csikszentmihalyi (1990:42). What is more, 'by far the overwhelming proportion of optimal experiences are reported to occur within sequences of activities that are goal-directed and bounded by rules,' such as reading and playing games (Csikszentmihalyi 1990:49).

Many patients spent time engaged in such 'flow' activities. As mentioned above, UK patient Martin enjoyed reading and playing croquet, which allowed him to challenge himself within both safe and uncertain confines. In describing a recent book he had read, he said to me, "there was this fantasy, fantasy type world, there were dream-makers, shadows... it was all a bit weird, you're not sure how those two worlds meshed... it wasn't really clear by the end of the book to be honest," but, he laughed cheerfully, "I loved it because, yeah, it wasn't normal in any way." He said of his croquet, "I care too *much*, so when I'm on the verge of winning ... I throw it all; I think 'oh I can win'!"

Having a sense of working on something accomplishable were important to achieving states of flow. Living in his own flat and being able to take things "slowly," Luke described in detail how he was able to assemble a new bed over a period of "six to eight weeks," in the end getting bricks to prop things up while he worked on various parts. He said that it was a

matter of “having the energy to have a go at it”, and overcoming his feeling of being too “nervous” about how to do it. I asked him whether there was a time in which he felt “most in control” and he said, “when I put my bed together, or when I put my chair together!” He added, “I had to feel more positive, and I had to, feel like it was a *surmountable* problem, a problem I could deal with.”

Csikszentmihalyi (1990:84) noted that due to the negative symptoms of schizophrenia, there is a ‘stimulus overinclusion’ whereby ‘schizophrenics are condemned to notice irrelevant stimuli, to process information whether they like it or not ... Unable to concentrate, attending indiscriminately to everything patients who suffer from this disease not surprisingly end up unable to enjoy themselves,’ which ‘probably has to do with innate genetic causes’ because ‘[s]ome people are just temperamentally less able to concentrate their psychic energy than others.’ ‘When a person cannot control psychic energy, neither learning nor true enjoyment is possible,’ Csikszentmihalyi (1990:84) concluded. To the contrary, I observed that even patients with intermittent (but clinically static) negative symptoms, could find means of enjoyment – whether or not these might be sometimes regarded as obsessive compulsions, or else clinically unaccounted for as such activities never make it into clinical conversations.

While finding states of ‘flow’ is a personal matter for patients, there are more formal engagements around the fringes of clinical treatments that might help. For example, there is evidence to suggest that when schizophrenia patients participate in ‘Dance and Movement Therapy’ or ‘Body Psychotherapy,’ they can significantly lower negative symptoms (Martin et al. 2016). Moreover, the benefits of being immersed in an embodied activity was relatable to clinical caregivers themselves. For instance, Australian psychiatrist Adam spoke to me of his need to engage himself on a particular activity when facing stress. Whenever a patient he knew took their own life, he put himself to task to make a piece of furniture. It was his way of refocusing himself, channelling grief, and challenging himself to make something new rather than dwelling on things he could not control.

While UK patient Christopher, 39, said to me, “I wonder if there’ll come a time where I don’t have to struggle along,” he was also continually “searching for something” and “striving for everyone to be on the same page” (Chapter One), and spoke to me of eliciting “coping strategies” that needed to be renewed. He described a “tug-of-war” between “bottomless appetites,” which he worked to “cast spells” over. “You’ve got to keep doing the positive

thing and re-plugging these connections so they don't disappear." Christopher, like a few patients (such as Tom), was cynical about the ways society pervaded his consciousness. He gave me an example of "bottomless appetites that are less desirable for him: "You watch TV and you see a Man[chester] United t-shirt, and you think, right, I want this Man-United t-shirt ... that will wear away, and you've got buy a new one," and then "the subscription to your mobile phone will wear away, you've got to buy a new one, so it's... I feel a lot of people are being kept *hungry*, to keep them, to keep them travelling on." I suggested, in supporting his attention to contradictions (Chapter One):

JB: Well, maybe that's the contradiction isn't it, we've kind of got to feel like we're searching for things all the time?

Christopher: Yeah

JB: [Be]cause maybe to be on the same page, it's not enough... I don't know?

Christopher: There is *contentment*, it's, yeah... there are-, there will be-, there are ways ... I'm just hoping I can keep it together and keep on the right track. Because if some, if negative coping strategies are with the bottomless pit, then the positive ones are climbing the mountains.

Further, what Christopher had also described as a "bottomless appetite," to keep up with and continually strive to resolve, feeling that 'there is *contentment*' available, parallels with notions of 'flow.' I asked Christopher,

JB: I'm wondering whether it's ever satiable, if there's ever a feeling of being... at peace?

Christopher: Well, you've got some of these guys ... yogis in India ... I'd like to keep that thought that it *can happen*, like utopia, searching for utopia – if you say, 'right I'm not never gonna get there' and you don't walk down a path you're not gonna get closer to it really, so that's one of my things.

Patients were able to not only 'be present,' they suggested to me experiences aligning with Fuchs's (2012:155-156) notion 'conation': The 'energetic' parts of lived experience, pertaining to 'spontaneity, activity, affective directedness and tenacious pursuit of goals'; a "being-after-something" that is directed toward the environment.' While clinical expectations were that patient concerns were largely part of their illness, I saw efficacy in their present-focused activities that were otherwise overlooked because of the associations with illness.

## Potentiality and symptom evasion

As with everything else, finding one's 'extended homeostasis' (Rapport 2003) was an ephemeral experience, but enough to surpass symptoms and give hope for further resolve into the future. Just as UK patient Joanne had described herself as "not actively ill," Felix, despite having ongoing symptoms unlike Joanne, said to me, "I'm passed the point of having schizophrenia but I'm still on the medication." Patients, however transiently, were able to feel free of their symptoms, even while acknowledging that clozapine was part of this feeling.

As described above, patients were able to temporally manage their anxiety, which is associated with both schizophrenia and a side effect of clozapine, as they lived through many irresolvable pasts and future trepidations. The apparent flatness of emotion in schizophrenia, often associated with trauma, has been the hardest 'symptom' to treat under biomedical paradigms. Scheper-Hughes and Lock (1987:28-29) posited that emotions are the "missing link' capable of bridging mind and body, individual, society, and body politic.' In then considering medical implications for Mauss' 'techniques of the body,' which problematised the notion that the 'mind' does not simply determine bodily action, but rather bodily actions become 'ensembles' to be ordered socially, Lyon (1997:90) asserted that '[a]ctive bodies are emotional bodies.' Meanwhile, previous ethnographic research on present-centered 'meditative' practices amongst people in Western culture suggest benefits equivalent to that of interpersonal psychotherapy to heal trauma and establish 'somatic awareness' (Myers, Lewis & Dutton 2015). Centring oneself in the present through activities or meditative states could also temporally awaken emotional states - as UK patient Tom said of feeling his "emotions a little bit more" since practicing mindfulness techniques.

Patients who were clinically described as having 'blunted affect' and working memory difficulties were able to transcend these states given some inter-personal freedom to do so. I frequently observed patients change in apparent levels of concentration, coherence and motivation right before my eyes when our conversations turned to non-clinical matters that occupied their time around clozapine treatment. This opening up of the self may also accord with Rapport's (2003) notion of embodied 'self-intensity.' Likewise, Merleau-Ponty (2002[1962]:529) posited:

It is by being unrestrictedly and unreservedly what I am at present that I have a chance of moving forward; it is by living my time that I am able to understand other

times, by plunging into the present and the world, by taking on deliberately what I am fortuitously, by willing what I will and doing what I do, that I can go further.

The tendency to fixate on details or try to solve problems gave patients a sense of livelihood and connection to the world. As discussed, there was an intentionality to minimise ambivalence by continually restoring poise through action in the present, if not through ‘mindful’ or ‘meditative’ pursuits. Indeed, the phenomenological notion of intentionality encompasses an ‘operative intentionality ... which produces the natural and antepredicative unity of the world and of our life, being apparent in our desires, our evaluations and in the landscape we see, more clearly than in objective knowledge’ (Merleau-Ponty 2002[1962]:xx).<sup>75</sup> At the same time as drawing on clinical imagery in regard to alleviating uncomfortable thoughts, keeping busy allowed patients to distract themselves enough to at least *begin* to transcend self-dominated concerns or insecurities residual to clozapine’s workings or their experiences of illness.

Due to contradictions in experience, patients were not always aware of their abilities to transcend the side effects of clozapine. When I first interviewed UK patient Luke, he had just commenced clozapine and was still adjusting to the side effects. By the time I met him again the following year, despite seeming to me more able to stick to the same thread of conversation, he commented that since taking clozapine, “my attention span has reduced, I find that I can’t focus on a thought for more than 30 seconds ... my concentration’s gone.”<sup>76</sup> This phenomenon was not dissimilar from other patients who described how clozapine dulled their sense of control too much. Yet, Luke, like many patients, seemed able to concentrate for extensive periods if the topic of conversation or a task-at-hand was engaging enough and the pressure was taken off (like building furniture at his own pace). The realities of his patienthood were not otherwise easily worked through, however.

Even if symptoms were only temporally evaded, the sense of self-overcoming (Rapport 2003) was powerful. Luke described in detail, with a trembling and abashed voice, a recent

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<sup>75</sup> This quote is from the Preface to Merleau-Ponty’s (2002[1962]) *Phenomenology and Perception* – hence the page number being in Roman Numerals.

<sup>76</sup> When I first met Luke, he was much more erratic in conversation thread. Even two weeks after treatment commencement, he seemed to be more coherent and able to engage - he spent the first half of our second interview telling me about various social issues he had been hearing about on the radio, and he generally seemed more able to concentrate during our conversation and engage. By the time I interviewed him the following year, although putting on significant weight around his middle, he was much the same in terms of coherence.

experience of “a problem” he had where, “I had to go out and get some food, and that was tough,” particularly knowing which type of check-out to use, working out how to use his bank card, whether or not he was getting the best deals and if he can manage with “carrying it home,” and whether or not he’ll get a sympathetic bus driver (“the older drivers are less fussy”). Nonetheless, he said, “I think I sorted that out.” Narelle, who was Luke’s Community Psychiatric Nurse beyond the clozapine clinic, said that she had been trying to get him to slowly open up and talk, but “he has become detached from his past, because it is so painful, and he therefore finds it difficult to concentrate on the tasks at hand.” Luke showed me the diary Narelle had given him to keep track of appointments, and suggested that having two appointments lined up for that week was stressful for him. He said the anticipation of an appointment kept him awake the night before. Yet, when I asked him how he was feeling he said an “eight” because of “coming here, getting my clozapine, meeting nice people, talking with the nurses, it’s always nice... It’s nice to have human contact, make some friends, I get out the door too fast, I think, that’s my problem, I should be more sociable with people, without being pushy.” Having a consistent schedule (like attending the clozapine clinic) was much more manageable than non-regular commitments – the novelty factor had to belong to time in the present. Further, what worked best for Luke was focusing on simpler tasks at hand, on his own terms, like putting his new bed together.

Context and lack of pressure from others was critical to patients finding enough focus to evade their symptoms and clozapine side effects. UK patient Robert felt most “in control” while “at home, by myself” and “during the mornings, playing chess.” I asked if he found he was able to “focus” while playing chess and watching Jehovah’s Witness videos online (which he reported doing for “four or five hours a day”), to which he replied, “yes I do actually, yeah.” I asked, “Do you find that you feel at all anxious or paranoid while doing them?” He responded, “not too bad, actually.” Robert also had aspirations for the future. Namely, “to be baptised as a Brother” (and, ideally, “to meet one of the Sisters, you know, to have a relationship together with one of the Sisters”), and to “start doing some Witness working.” “If I became a Brother I would probably see the paradise,” he added:

When paradise comes, Julia, there’ll be no more mental illness, no more sickness ... when you go to die you don’t actually go to heaven ... the paradise comes when there’s a true relation, where the government will turn against all the churches – *this is not my paranoia* – a true relation where the UN and the governments turn against

false religion, and after that there's Armageddon ... after Armageddon, that's when paradise comes ... when the earth is cleansed of crime, poverty.

I asked Robert if he could imagine getting baptised, and he replied, "I try to, yeah." When I asked when, he responded: "As soon as I give up smoking ... The only thing stopping me is the smoking, that's the only thing". When describing how he was feeling towards the end of an interview, Robert, said "about an eight" (out of ten) because we were "talking about the Bible, I don't get much chance, so it's great to talk about it!" UK patient, Gordon, 39, also told me he was feeling like a "seven or eight" (out of ten) toward the end of a conversation about his beliefs in Christianity, because: "Considering... all these great ideas and, talking about them, just thinking about the things, helps you to *know* the presence of, presence of the spirit, Holy spirit." During another conversation with Robert when we were not talking about Jehovah, Robert said, "if I talk too much it makes me feel nauseous; I'm not used to talking a lot." Moreover, when attending a Jehovah's Witness Convention, Robert's lethargy "wasn't too bad, no, I was alright ... I felt quite well," although he did still experience dizziness and nausea, along with the chest pains that he attributed to smoking. During our last meeting, I asked Robert about why he did not feel his usual need to lie down (Chapter Three) during the afternoon he was at the Convention, and he replied,

I think the main reason was because I was with all the Brothers and Sisters, you know, everyone's... there's no trouble ... beautiful day ... also when I go to [church] as well, I feel okay, I feel fine, so. Except the last time I was there, on Sunday, I had to come home early. I was feeling a bit rough so... I stayed for an hour and 15 minutes.

There were no certainties that difficulties could be entirely alleviated, but, based on experience and imagination, there was enough potentiality for patients to move forward with. As Gordon commented when I asked him if he felt like he was living the life he wanted to: "Yeah, because... we're not static, I don't think we're static. I think it's possible to *change* your- *change* one's ways ... Christians talk about the *resurrection*, which is a...a great hope really."

There was, of course, a clinical caution expressed about the risk of getting *too* caught up in these potential evasions of symptoms. For instance, Australian patient Donna attended weekly and monthly meetings for a number of different local non-for-profit organisations. She told me, however, that her social worker, Jill, had:

Said I should steer clear of things, like policy areas that make me anxious, so it's a quandary really, whether to, like, remove myself from thinking about things like that, or embracing them, and *sharing* them, and I'm thinking... you know, I always feel better when I've been around people who *care*, and I'm fortunate enough to know a lot of people in a lot of different circles who do care, and they, they *know* me, and they like me, I think, so I feel like the burden's not all mine.

Donna continued, self-consciously, "I enjoy writing about these things, and thinking and doing some research and things, and I so enjoy going to the meetings as well." Donna's previous states of illness had involved paranoid delusions about the very topics that also gave her purpose and connection to others in life. It was thus a delicate balance for her to try to find, but caring about these topics nonetheless gave her momentum and hope in the meantime.

Australian patient Daniel was in a similar situation with his taxi-driving work, which kept him well at the same time as making him vulnerable to psychosis. Daniel's feelings of being watched by others exacerbated when he started driving taxis, just before he was diagnosed. He reasoned, "I've known people who are hackers and can hack and stuff like that and ... because the computers in the cabs are all linked in to the taxi base, I sort of got a little paranoid that someone might have hacked in and that's how they were getting sort of footage of me at work." Daniel liked driving taxis, though, because it made him feel in control when he was "back behind the wheel" *and* it helped him to not sleep in. He said, "I sort of need that imperative to work in order to get up on time." When I asked him at a later date how he had been in the month since I last saw him, he explained that he had worked two shifts, which were, "good – I enjoyed doing them," however, "I'm still sort of worried about these ideations of reference". His paranoia had not yet returned but he was cautious that it might, although this caution was not enough to stop him working altogether; it was something he felt he could potentially overcome.

Once patients got to know the types of strategies that would work to help them move through discomforts and symptoms, they were able to imagine how future activity would keep their discomforts at bay. Feelings of health and self-stability constituted an active process, to keep busy and feel proactive; experiences of what UK patient Luke described as being free from "run-away thoughts." As UK patient Alan said when I asked him about what health meant, "well, when I was well, before the age of 21, I had a lot of freedom and I did rather a lot. I

was a bit limited financially but I was, I was a sales rep, I was playing bass in my mate's rock-band." Arguably, Alan's recent reuptake of playing the guitar had given him a renewed sense of freedom that had begun to open up further potentialities.

Alan, who felt himself to be benefiting from playing the guitar again, participating in a writing group and most recently a mental health drama group, remarked, "once I can disengage from talking to myself, to *engage* in concentrating in the drama group, I think I will get that, that sense of achievement that I've been lacking." He was concerned by "intake not outtake"; "doing things little by little, adding more to routine as I go" (Brown 2018:164). As mentioned in Chapter Three, Alan had replaced cigarettes with electronic cigarettes. He told me that he needed to actively inhale something for "mental preparation" – "to get in the bath and wash my hair"; "before getting on the bus"; "before going to my drama group." Vaping was now giving him new momentum: Alan said to me after one of his drama performances that he had invited me to: "I feel like I'm just getting started!" (Brown 2018:164).<sup>77</sup> He later reflected that, "I was relying on cigarettes to get me through my psychosis," as it was "a bit like slowly disengaging ... but in the long term it had me sitting on the chair getting very unhealthy."

Alan said in our final interview that he felt "busier", but that "it's not so much as not *squandering* my time as getting on with little things that help you along a bit." He had several plans for the future, including that, "in four years' time, I could be free of medication, maybe." Whereas when I first interviewed Alan he had described himself as a "borderline alcoholic" who had not had a drink in "15 years," when I spoke to him the following year he said that, alongside his new vaping habit, he was having "the odd glass of whiskey once or twice a week" because "it's more a case of later in life if I decide to booze a bit I possibly can ... saving it for later." He also had recently got a new job, which he was looking forward to so he could come home afterwards and relax; enjoy the day's accomplishment. Moreover, UK patient Trevor said to me when we last spoke, "I'm doing pretty well aren't I - I'm 56 now, so getting old; in another 20 years, I'll be *really* old." He added, with a gentle smile, "it's a shame we all have to die." He said that he does not like to think about reincarnation, because "I don't think the next life will be as good as this one."

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<sup>77</sup> This was the only occasion that I met with a patient participant outside of the clozapine clinic and I did so because it was at a public theatre, in the presence of Alan's community-run mental health group.

## Conclusion

Clozapine treatment helped patients in my research to ‘live in the present’ and keep an open future, no matter how paradoxical or at times provisional this future was. Once patients were domesticated to the clozapine regimen, they were able to find new ways to focus themselves. While using routines to inform their sense of health agency, these routines needed to be worked upon. Patients recognised the risks and dangers associated with undesirable potential futures, which could compromise their routines that society and the clinic might deem appropriate. Finding a sense of focus allowed a transcendence of self-concerns and linear time. This temporal focus, granted initially by clozapine, allowed patients to reclaim a sense of improvising rather than being tied to their illness chronicity. Patients were temporally able to ‘let go’ of whatever stood outside moments of freedom, if not living *with* the past and present harmoniously. Pursuing present-centred practices and finding connectedness to others synthesized to produce temporal stabilities and agentic freedoms from what were otherwise delimiting circumstances.

Feeling like there was always more to work on gave patients a sense of hope and purpose. Having a sense of purpose from moment-to-moment also contributed to patients’ sense of self efficacy and self-transcendence. This again highlights how patients are active rather than passive participants in their making of their health. Being an active participant also gave scope to autonomy beyond their diagnostic ‘fate’ and clinical expectations. While on the one hand this chapter supports previous ethnographic evidence that has posited ‘instances [where] people struggled to situate themselves existentially within the complex constellation constituted by whether one can control and discipline oneself’ (Jenkins 2015:52), I have also suggested how experiences of clozapine allowed a safe base for patients to move from, and *temporally* free themselves from ‘struggles’ in ways that align with the pursuits of persons without schizophrenia. Personalised meditative pursuits, embodied or ‘enminded,’ also moved beyond merely keeping busy or distracted with tasks at hand. They suggested experiences of ‘flow’; an epitome of well-being. An existential freedom was made available through patients’ drives to keep moving forward while also appreciating the personal power of time in the present to experience symptom evasion and the potentiality for even greater health.

## Conclusion

*Man lives by those propositions whose validity is a function of his belief in them.*

– Bateson (1951 in Rapport 2003:27)

To return to the underpinnings of this thesis, as put forward in the Introduction, I set out to demonstrate how agency and hope play out in the extreme life conditions of clozapine-treated schizophrenia. I sought to show how such agency and hope need not be specific to these conditions, just as these conditions do not preclude agency and hope. I have endeavoured to demonstrate how people express their ‘health agency’ – defined here as one’s means of making and working for their own health out of what is given, consumed and monitored in the clozapine treatment regimen – by exerting personal power and potentiality over one’s otherwise confining illness states. I have suggested that clozapine-treated schizophrenia patients are not operating under an assumption of static illness conditions.

As Bateson observed, we contribute our own imaginations toward our understandings of the world, including that of our own ‘health.’ We live by these imaginings to reclaim the potentiality of our lives. While those with schizophrenia may have remarkable imaginations, resilience and life challenges, their abilities to feel health agency need not be spectacularised, although those of us without schizophrenia can learn a lot from people with schizophrenia (Jenkins & Barrett 2004; Jenkins 2015). Patients illuminated for me – through my making of ‘partial connections’ (Strathern 2005) with participants and ideas through anthropological enquiry – how the process of simply ‘doing things’ in present time can bring powerful feelings of control over and meaning to “being alive” (as UK patient Bradley put it in Chapter Four). This feeling of control-through-doing propelled my participants onward toward an unknown future.

I found that the philosophy of phenomenology came into its own during my field work. Being with my participants opened up my thinking about not only what it means to try to sift through endless questions and contradictions, but also how ephemeral clarities can be enough to spur instinctive self-drive and hopefulness in life. While I am ‘maintaining an acute awareness of the inevitable incompleteness of our theories’ (Biehl & Locke 2010:320), in anthropology or otherwise, it has been critical to approach my data with ‘a view of culture as open and emergent,’ something ‘to be discovered,’ via means that pertain to ‘everyday lives in local worlds of meaning’ (Lucas 2004:148). This is why, I suspect, anthropologists who

have looked at schizophrenia beyond the more mundane clinic activities, such as Jenkins (2004; 2015), highlight the ‘extraordinary’ nature of the disorder. Life-worlds beyond the clinic are bound to be even more elusive. While my clinic-based, ‘episodic fieldwork’ (Dalsgaard & Nielsen 2013) was, comparatively, limited in its cultural scope, it was perhaps by containing my focus in this way that I was able to unpack the most taken for granted aspects of my participants’ experiences. Given previous ethnographic evidence on the detriments of reductionist, biomedical treatments in private mental health clinics in America (Luhrmann 2000; Jenkins 2015), it was interesting to observe how, in the publically funded UK and Australian clozapine clinic worlds I entered, the more impersonal social structures provided by the clinic became useful for patients. Clozapine-treated schizophrenia was not the life sentence it first appeared to be, because the clinic environments created conditions for patients to experience health agency.

I found that the intensive clozapine treatment regimen fed into patients’ sense of health agency because it was part of their active pursuit for an ‘extended homeostasis: the maintenance of a set of life-conditions within which the self continues to flourish and has its objectives met’ (Rapport 2003:225). In Chapter One, I laid out my ethnographic and conceptual frameworks for appreciating health agency as something personal and hopeful, persisting through contradictions and contingent on connectedness to others. In Chapter Two, I showed how physiological clozapine monitoring becomes a productive enterprise for agents to manipulate while becoming part of a wider circulation of care. In Chapter Three, I suggested how clinical caregivers and patients utilise the ambiguities of clozapine and mind-body imaginaries to individualise what they can and cannot control, through personalised health behaviours. In Chapter Four, I examined what clozapine has to do with how people imagine their past, present, and future, demonstrating how the self-efficacy patients experience in focusing their energies in present time complement the treatment premises and provisions of clozapine. In this Conclusion, I consider the implications for my ethnographic findings regarding how schizophrenia and its treatment are conceptualised, then, in terms of patients’ agency, their ability to lead a so-called ‘contributing life’ (Lourey, Holland & Green 2012), and how clinical caregivers help and/or hinder these processes. I also posit future directions for anthropologists and public health policy makers in this field.

## Personal power

*Personally, I feel any method or dialogue I could have with another person, I could confront within myself, and try – to use an old cliché – battle my own demons by trying to ignore them, knowing they are real and exist. But I feel it’s a process I can do, maybe feel more comfortable doing by myself ... To quote the Chuang Tzu, ‘a pheasant in a cage, although it may be treated really well, would still rather be free and without the cage’s luxuries.’ It’s a hard problem to resolve, but if there were a med or therapy that could help me not, or make me not, bothered by ‘the cage,’ I would take it. To change my capacity for, to be able to perform socially.*

– Australian patient Daniel, 33

Like anybody, Daniel felt simultaneously independent of and dependent on external structures in his life. What Daniel did not acknowledge, in his above statement, was the freedom he already exerted in feeling able to work things out for himself and in taking his self-competence seriously – at the same time as accepting he was in some kind of social ‘cage’ with ‘luxuries.’ He desired more fluency in his inter-personal interactions within this cage, consisting of clozapine treatment and ongoing challenges to this health, but he was more comfortable working in what did feel like his own space. Daniel worked for feelings of “novelty” and “control” in his life and exercised this during clozapine clinic check-ups (Chapter Two). This also applied to his consumption habits: Daniel went through “phases” of “discipline” by eating certain foods until the novelty wore off; he smoked cigarettes to “stay awake”; “focus” and “distract” himself, as his “main daily routine,” and felt able to quit if he wanted to (Chapter Three). He did not yet feel “safe and secure” and was negotiating sleeping habits around clozapine, residual delusions and a desire to maintain his taxi driving licence (Chapter Four). He spoke to me of his previous feelings of “suicidality,” but he was – during the time that I knew him for – committed to creating new daily interests for himself. Daniel, moreover, was still figuring things out. He was open to new ideas (or medications or therapies) for change, and was, in the meantime, choosing to live by as many of his own terms as his could. What is more, as Rapport (2003:81) posited, ‘only as a self, active in the world in an ongoing accruing of meaning and identity, does an individual construe otherness and relate, consciously or intentionally, to other things-in-the-world.’ Daniel was looking for ways to most productively *be* in, and connect with, the world and he maintained a sense of personal power.

I observed all of the clozapine patients in my research to hold this personal power, which may also be described as an ‘existential power,’ that they exhibited in their contexts,

influencing those contexts. To recap, Rapport (2003:90) described existential power as a ‘self-intensity’ (*Machtegefühl*); ‘an energy or force originating in and manifested through physical, individual bodies, and by its use individuals may be found pursuing a life-project in an environment that represents an extension of their sensoria, their subjective phenomenologies, beyond their apparent bodily integuments.’ We can substitute ‘life-project’ with ‘health’ and understand ‘environment’ as what patients make for themselves with clozapine treatment – its effects and individualised potentialities. When it came to their health, clozapine patients, like anybody, were ‘not forced into particular meanings or motivations; these remain[ed] a personal preserve’ (Rapport 2003:261). Further, ‘the act of making meaning can transcend and hence willfully alter or subvert any existing limits or conventions surrounding the language or system of which the symbolic forms a part’ (Rapport 2003:57). How patients’ personal power fits into previous theories of schizophrenia and its treatment deserves careful consideration.

First, experiences of clozapine-treated schizophrenia do not merely reflect a ‘self-disorder.’ The ‘self-disorder’ aspect of schizophrenia is generally conceptualised around an experiential ‘collapse’ of the dichotomy between self and other, ‘or the most foundational sense of existing as a distinct subject of experience’ (Sass 2014:8).<sup>78</sup> Insofar as they exhibited their personal power to construe their circumstances, clozapine-treated schizophrenia patients did not seem to be experiencing an unbounded or ‘fragmented’ self, although some temporal disconnections were evident (Laing 1965; Sass 1992; Sass & Parnas 2003; Fuchs 2007). Any temporal disconnections complemented the clinical regimen patients were on – prompting them to ‘live in the present’ (Chapter Four) – and, therefore, patients were resonating with clinical aspirations as much as protecting themselves from painful pasts. Many patients were, in more ordinary ways than not, also ‘body conscious,’ despite ongoing schizophrenia symptoms or attributions to clozapine (Chapter Three). Further, patients – both symptomatic and asymptomatic – found agency and meaning through socially affirmable goals.

Clozapine treatment provided a social world in which patients could engage with the system of which they were a part, ‘in a ‘viable’ manner, a manner that might feasibly become routine and long-term,’ such that ‘one’s experience can be described as self-authored – however

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<sup>78</sup> Notably, ‘feelings of passivity and alienation or fading of self and world’ are found in experiences of ‘depersonalization and introspection as well as schizophrenia,’ and are therefore ‘perhaps not inconsistent with the paradoxical nature of the normal self or subject’ à la Kant’s ‘transcendental ego,’ or Sartre’s framework of subjectivity as ‘nothingness’ (Sass 2014:8).

seemingly oppressive' (Rapport 2003:85). Clozapine patients were also able to exhibit a 'social self' (Aylwin 1985:115). Further, as Merleau-Ponty (2005[1962]:347) said of self-experience, 'I am not concealed from myself because I have a world'. To reiterate the phenomenological theories of Husserl, Merleau-Ponty and Heidegger, Zahavi (2005:167) posited, 'since the structure of this world contains essential references to others, subjectivity cannot be understood except as inhabiting a world that it necessarily shares with others.' Clozapine patients were grounded as individuals in their worlds because they felt themselves to be witnessing and moving toward resolving problems that always involved other people and things external to them – thus reiterating their sense of self and 'other.' What was more, patients' competence and hope in this social world, no matter how defined by 'precarity' (Jenkins 2015), such as what Daniel was reflecting, problematises the notion that patients might live on with a sense of loss when it comes to social power.

As discussed in Chapter One, experiences of clozapine-treated schizophrenia do not suggest social oppression. Although 'psychotic experience and subjectivity take form at the most personal juncture between the subject, his/her biology, and local regimes of normalcy and power' (Biehl, Good & Kleinman 2007:241), the 'local regimes of normalcy and power' in the clozapine clinic lend to a renewed focus on physiological health rather than acute experiences of schizophrenia as a psychiatric condition. Throughout this thesis, I have demonstrated how patients, despite not having psychotherapeutic supports, were able to socially engage in their treatment regimens perhaps in part *because* treatments of this kind were less stigma-inducing. Jenkins and Carpenter-Song (2007) have evidenced the problem of 'stigma despite recovery' in Western society's treatment of schizophrenia. In the clozapine clinics in this thesis, however, we have a situation where stigma persisted when considering some clinical caregivers' views on psychiatric statuses, yet 'recovery' was more contingent on the upkeep of physiological stability. Of course, human potential cannot be entirely realised or dominated by State systems of support (Beihl 2010; Beihl & Locke 2010), and it was perhaps the way in which clozapine treatment gave patients "*space to build*" (Australian psychiatrist Sandra, Chapter Three) that was most critical.

My ethnographic findings thus suggest that 'social defeat' (Luhrmann 2007; Luhrmann & Marrow) – pertaining to 'repeated social interactions in which they [people with schizophrenia] subjectively experience failure' (Luhrmann 2007:152) – may be somewhat alleviated by the clozapine clinic treatment regimen. While social defeat in patients' pasts of

course informed their present identities to some degree, there were also new social assurances available. These assurances were enacted through the clinical regimens of care wherein patients could be of use to clinical caregivers as much as to themselves (Chapter Two); and also through patients being able to work with or reconnect their ‘minds’ and their ‘bodies’ where clinical care could not but could nonetheless appreciate (Chapter Three). Further, the will to ‘live in the present’ (Chapter Four) yielded principles of well-being that stretched well beyond what it means to find ‘health’ while living with schizophrenia. Insofar as the treatment regimen provided patients with temporal and social structures that minimise criticisms of patients’ situations, in part due to the ambiguities and dangers of clozapine, patients could not be described as experiencing ongoing social defeat. After all, patients were no longer suicidal; they had hope and their personal power to keep functioning in ways that socially *contributed to* rather than detracted from their environments.

## Labour

As discussed in my thesis Introduction, schizophrenia was first characterised as a defiance of ‘Western selfhood,’ a ‘resistance to labour’ and ‘a resistance to the labour of self improvement’ (Woods 2011:42-43). I have shown, however, how clozapine patients, while more often than not experiencing ongoing symptoms of schizophrenia and being unemployed and state welfare dependent, still worked hard to secure for themselves what they could in present time. Those who were engaged in paid or voluntary work enjoyed doing so when they were in supportive work environments where hours were flexible. *All* patients, meanwhile, worked creatively with the clozapine treatment regimen and around it to maintain their stability and secure individual freedoms toward the future. These might be described as acts of neoliberal ‘self-labour.’ As UK patient Joanne said of worrying that she could not think for herself, “I *challenged* that ... in order to get stronger ... get more confident in myself” (Chapter One). This was not just about using her imagination, it was about working with external influences too. Patients, like anybody, appreciated having structures in their life and contributed to these as much as allowing for clinical inputs and routines.

Patients appreciated routines. Working with clozapine treatment rhythms was a key manifestation of what Jenkins (2010; 2015) described as ‘pharmaceutical imaginary,’ whereby the cultural confines of expectation and possibilities given membership of a clinical population, shapes subjectivity. As discussed in Chapter Four, clozapine patients enter into

conditions that are highly provisioned by clozapine consumption and monitoring, at the same time as allowing for improvisations that temporally free people from what Morris (2008) described as ‘chronic time.’ Time on clozapine is structured around the present, which patients then work with in terms of “keeping busy” and even achieving optimum well-being states of embodied or enminded ‘flow’ while engaging in activities (Chapter Four). Like anybody, patients work to alleviate stress for themselves by proactively keeping afloat, rather than merely treading water and struggling significantly as they had done in the past. Life on clozapine could be said to complement neoliberal, ‘Fordist’ hopes of ‘regularity, task-specific duties, and mechanical rhythms’ (Ferzacca 2000:35). Yet, as Rapport (2003:68) pointed out, ‘when the routine takes the form of socio-cultural institutions, there is no stability in the latter beyond their ongoing recognition and continuing employment by individual interpreters.’ Patients supported rather than resisted these temporal regimens that enabled their ongoing labour.

Patients also advanced themselves by way of manipulating aspects of the regimen otherwise considered to be out of their reach, through the blood work (Chapter Two), and by way of exploiting the opportunities that come with clinical uncertainties around clozapine (Chapter Three). In regard to blood monitoring, blood flow and blockages also present as a metaphor for fluid self-constitutions, with blood work marking the stop-start nature of these constitutions. As we saw in Chapter Two, patients like Joanne resolved to rearrange plans and buttress their routines when goals were not achieved the first time around. Whereas psychotic experiences are thought to involve experiences of certainty after periods of experiencing extreme doubt (Rhodes & Gipps 2008), clozapine patients managed their recurrent anxiety (clinically framed as either a side effect of clozapine or symptom of schizophrenia) through more ordinary means pertaining to Western culture. As de Beauvoir (2000[1948]:157) described, we all feel a phenomenological ‘certitude’ only through our ‘drive’ to do things, and this becomes a means of temporal self-assurance. Moreover, through enacting a combination of ‘self-labour’ and clozapine, patients found meaning in their lives.

While all patients worked for self-assurance, it was perhaps more available to older patients, in line with general population expectations. As UK patient Trevor, aged 56 by the time we parted ways, told me: “It’s a shame we all have to die” because “I don’t think the next life will be as good as this one” (Chapter Four). Trevor felt himself to be “doing pretty well” but also “getting old.” A recent qualitative study of patients with schizophrenia over the age of

sixty suggested that managing health at this stage of life makes patients feel ‘just like everyone else’ because of lowered employment pressures, normalised chronic health concerns and opportunities for creative pursuits that tend to present themselves during ‘retirement’ (Mushkin, Band-Winterstein & Avieli 2018). While this thesis cannot speak directly to these findings as I was unable to interview people in this demographic, I note that patients in my research did experience newfound freedoms because they felt to have lived more demanding lives prior to clozapine treatment. UK patient Alice, 36, had said, “I just want a quiet life basically, you know, I’ve been through a lot of drama” (Chapter Three). Further, the extent to which patients felt their ways of life to be reflecting *moral* expectations that might relate them to wider society was something that this thesis only begins to touch on.

I suggested in Chapter Three that patients who were otherwise socially isolated with many residual psychiatric symptoms, still looked to ‘better’ themselves in ways that begin to suggest a ‘moral agency’ (Myers 2015; 2016), contingent on integration into a wider social world. I add here that patients such as UK patient Luke – who said that his experiences were about “constantly looking after your health, constantly touching base”; “constantly thinking could I do that better? Who could I meet who would be better for me?” – went further than exhibiting the kind of ‘moral agency’ described by Lovell (2007). While patients such as Alex (Chapter One) said that his life’s “task” had become “fighting” his hallucinatory presences and protecting other children from abuse, thus echoing Lovell’s (2007:335) idea of ‘moral agency’ as ‘project[ing] possible moral worlds,’ Alex was also checking for signs of cancer from his smoking habit, and could thus be seen to be keeping a foot in the clinical world of which he had become a part as well.

While the clinical world of reciprocities might not be quite enough to see patients clearly ‘contributing’ their moral labour to social life beyond it, this sense of participation was still something that patients could begin to feel moral agency through in the sense that they were, in their minds, making socio-moral efforts that could be continually improved upon. The question is to what extent these labours could be acknowledged by a wider society. As Joanne had said of why she benefited from her current relationships, including those at her part-time job and voluntary work, “there’s no kind of *power* dynamic” (Chapter One). Managing oneself and the expectations of others can be contradictory for people with schizophrenia (Lucas 2001), and therefore evidence of the kind of ‘moral agency’ Myers (2015; 2016) spoke of is difficult to affirm here as I did not have access to peoples’ worlds

beyond what they told me in the clinic. I have suggested, however, that clozapine-treated schizophrenia patients exhibit aspects of, and hope for, this kind of moral agency in their endeavours that were more immediately relatable.

### Everyday efficacy

*To improvise is to follow the ways of the world, as they open up, rather than to recover a chain of connections, from an end point to a starting point, on a route already travelled ... Lives are bound up in the tangle, but are not bound by it, since there is no enframing, no external boundary. Thus the self is not fashioned on the rebound but undergoes continual generation along a line of growth.*

– Ingold (2011:216;221).

Clozapine patients were efficacious in their abilities to improvise through life, and ‘along a line of growth’ (Ingold 2011:221). As Ingold (2011) posited, people make their way as they go, recreating their sense of self. As discussed in Chapter Four, patients lived according to temporal frameworks that many ‘ordinary’ people in neoliberal societies might strive toward in terms of achieving ‘well-being.’ In this way, they exhibited the ‘extraordinary’ human qualities that Jenkins (2015) has attached to schizophrenia. Many of these strategies, however, could also be appreciated in their mundanity. Patients navigated stress by keeping themselves occupied and absorbing themselves in activities at hand, like reading books, consuming food or cigarettes, or doing exercise to discharge experiential energies.

The daily rhythms of clozapine, as well as daily activities, contributed to patients having a sense of everyday momentum to keep improvising with. As Kleinman (2006:221) has said of ‘what really matters’ in life, it comes down to ‘simultaneously what is most optimistic and what is most ominous.’ Patients in this thesis were presented with plenty of things to potentially fear, but also plenty of hope, and a relatively functional life to proceed with in the interim. Once patients became acquainted with clozapine, their creativities seemed to keep evolving. Moreover, as some patients suggested of their spiritual beliefs, practicing these beliefs facilitated health agency, hope and daily rituals that superseded symptoms of their illness.

Improvisation and illness remedies extended to clinical care, too. As discussed in Chapter Two, opportunities for reciprocity in the clozapine clinic were taken up by patients in terms of communication control and also blood monitoring activities. I noted that in the Australian

clinic, patients had to work harder to reshape clinical rhythms according to their personal needs. My suggestion that a ‘logic of care’ (Mol 2008) was available to clozapine-treated schizophrenia patients in ways that did not, from my understanding, remarkably differ from what has been described in non-mental health treatment settings further suggests the *everyday* nature of improvisation and health care strategies deployed by patients in this thesis.

I have also suggested that psychiatric symptoms and clozapine side effects are, to some degree, dependent on context and perhaps become more prominent in clinical interactions that do not look for everyday efficacies. As well as the clozapine clinic settings discussed in this thesis de-emphasising the diagnosis of schizophrenia, the clinical setting became a form of what Rapport (2003) described as ‘democratic violence,’ that was on the edge of ‘nihilistic violence.’ So long as clozapine and clinical experiences were predictable enough to improvise with, patients felt interactions to be manageable in everyday ways. As Jenkins (2015:263) noted of ethnographic ‘access’ to these observations, ‘[i]t might be overwhelming, threatening, or simply too taxing for persons in the absence of anthropological sensibilities to suspend judgment to enter into unfamiliar extraordinary terrain.’ Whether or not the more ‘ordinary’ aspects of schizophrenia patients’ everyday efficacies will be observed in future research is yet to be seen.

### Future directions

This thesis, as well as arguing for health agency in a context where it is not expected to be activated, has problematised both biomedical and anthropological approaches to schizophrenia. As discussed above, ways in which I came to understand the experiences of clozapine-treated schizophrenia patients did not add weight to arguments for patients being outstandingly different from anybody else. This view comes with the risk of down-playing the remarkable ways in which people with schizophrenia do suffer, under their conditions and under clinical approaches. I met people in the *aftermath* of acute suffering, and came to see how they made their lives and their ‘health’ workable without merely complying or resisting to the clozapine treatment regimen.

This thesis is not intended to endorse clozapine treatment for schizophrenia. It is intended to shed light on how people undertaking clozapine treatment for chronic schizophrenia make meaning and health out of a combination of clozapine, schizophrenia and their personal

power. It is intended to show that agency persists in lives that have been re-given and confined. It is intended to also show how an anthropological approach to situations like these is useful. Further, my ethnographic experience was that most ‘opposition’ to biomedical approaches were also apparent in the views of clinicians, alongside the rhetoric that peddled firm biomedical rationalisations. My collaborations with a neuropsychiatrist, who was for the first time allowing an anthropologist into what would be described as an otherwise biomedical research domain, was as much a ‘catalyst for change’ (Whitely 2014:506) as the ‘critique’ and ‘context’ (Whitely 2014) evident in my ethnographic data.

In terms of implications for public health policy approaches around inequities and how to better assist patients live a more ‘contributing life,’ in the socioeconomic independence sense, I have suggested that patients are not as far away from this notion as they may seem. Their expressions of health agency are geared toward Western ideals of self-improvement and working on something, in the most basic sense and in ways that are easily overlooked. Drawing on cross-cultural evidence, Luhrmann and Marrow (2016:220;221) suggest that, ‘when people who meet criteria for schizophrenia understand themselves primarily as persons with schizophrenia, they imagine themselves as inherently incompetent and without the capacity to live a normal human life,’ and more favourable outcomes occur when one can ‘identify oneself as someone who can be productive and effective, rather than to identify oneself by a diagnosis.’ Further, the ‘illness trajectory is more benign when a psychiatric model of schizophrenia is not all encompassing, and when sufferers are integrated into family and community ... the way we treat the person may be as important as anything drugs do for that person’s brain’ (Luhrmann & Marrow 2016:222). Contrary to expectations, the biologically reductive and mundanely social and temporal structures of the clozapine treatment regimen went some way in diluting the oppression patients might have felt in the past.

Patients appreciated simple accountabilities and shows of faith. The UK clinic’s appointment system was valued by patients, as it was a show of faith that they could get up early if they had somewhere to be. When I mentioned to Australian nurse Ramesh that patients in the UK would even come in early and queue up at the door, he could not believe this because he doubted their general competence. When I told Australian patient Daniel about the UK appointment system, his face lit up with enthusiasm (“Wow! That sounds good” – Chapter Two). As I have discussed in greater detail elsewhere (Brown 2018), the offering up of

clinical compromises like electronic cigarettes also helped patients to build confidence and socially orientated care. Moreover, just as Jenkins (2004) has encouraged anthropologists to consider the particular areas of the self, emotion and social engagement as central areas of research into schizophrenia, I would add that these areas can be studied within the most seemingly dispassionate of clinical worlds, too. We can find discreet and personal ways in which agency prospers by examining life in the very depths and confines of powerful structures.

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