The silenced manifesto an autoethnography of living with Schizoaffective Disorder

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THE SILENCED MANIFESTO

AN AUTOETHNOGRAPHY OF LIVING WITH

SCHIZOAFFECTIVE DISORDER

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Doctor of Philosophy
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I never dreamed that I would be writing this thesis. As I have mentioned many many times in the writing forthwith, I fundamentally believe that I am lacking, that I am a sub-citizen, a sub-human and a social misfit. The people that I acknowledge here are my heroes. My mentors. My loved ones. They have held me, carried me, believed in me, and stood by me. They have been all so wonderful and supportive, putting up with my desperate and constant need for reassurance and validation – a persistent part of my schizoaffective disorder. And for that I am forever grateful.

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Let us see what a sub-citizen, sub-human, social misfit can do!
I dedicate this autoethnography to my darling sister, Kate McMahon.

November 2, 1977 - April 4, 2019

Stop all the clocks, cut off the telephone,
Prevent the dog from barking with a juicy bone,
Silence the pianos and with muffled drum
Bring out the coffin, let the mourners come.

The stars are not wanted now; put out everyone,
   Pack up the moon and dismantle the sun,
Pour away the ocean and sweep up the wood;
For nothing now can ever come to any good

‘Funeral Blues’

W.H. Auden
SYNOPSIS

SILENCED MANIFESTO: AN AUTOETHNOGRAPHY OF LIVING WITH SCHIZOAFFECTIVE DISORDER

7 LESIONS: 7 VOICES: 7 DRUGS: 7 STORIES: 7 CONCLUSIONS

I have been living with schizoaffective disorder for over twenty years. In that time, I have had periods of relative wellness and relative illness. I fight each battle as it comes. I am trying to win my latest battle through my Doctor of Philosophy studies.

This thesis takes the form of an anthropological study of mental health. Specifically, an autoethnography of living with schizoaffective disorder, looking at the ways I have been labelled as a lesser human, and understanding that labelling is part of the culture which encompasses it. While the thesis devolves from my unique viewpoint, the autoethnographic methodology that underpins its hypothesis, research, analysis and conclusions bear witness to the common experience of the mental health community.

I have seven lesions in my brain. It is ironic because these lesions have no function or purpose. This disappoints me to no end. According to my neurologist, they are useless and do not affect
or cause the schizoaffective disorder that has plagued me for so long. My neurologist states that the lesions would not have been discovered if not for a continuing growing medical culture of measurement, which seems to justify an ethos which disempowers those with a major psychotic illness.

By coincidence, I hear seven voices; often discordant voices. As a person living with schizoaffective disorder, I am aware of at least seven voices in my own head, all which conflict with the person I am now and the person I want to be. In this thesis, I extend my study of the poly vocal world of my disorder, to position myself within an extension of the multiple voices of the health and medical systems that now control my life.

In homage to this accidental theme, other chapters follow the ‘seven’ edicts. I take seven drugs that deal with the side effects of the other three therapeutic drugs. I have also included a chapter of seven stories, as artefacts, furthering my autoethnography of what life is like living with schizoaffective disorder. To finish, the conclusion of the thesis is written in seven subsections, following on and expanding from statements posed in the thesis introduction.

My autoethnography of living with a major psychotic illness is a journey through diagnosis, institutionalisation and attempts at reintegration. Ultimately, it is a story of transformation in a profoundly negative sense of the word; how my life has been stripped bare by my illness and the institutions which now control it. I explore how the biomedical lens of psychiatry views me and how it positions what I can and cannot do and be. I explore the experience of being tested and measured. I explore how biomedicine has the capacity to stigmatises and de-humanise people
with mental health conditions, but also how difficult it is to resist the definitions and labels imposed upon me. In a sense biomedicine tries to measure the unmeasurable, and use crafted measurements to define and confine subjects, as in the mentally ill, often inappropriately and over-zealously.

By looking at the ways I have been labelled, and by understanding that labelling as a function of the scientific culture that crafts it and the social culture that validates it, I examine this hypothesis: that psychiatric science rests on a self-vindicating ethos of clinical measurement and consequent labelling which perpetuates mental illness. From this, this thesis sets out to break through the glass ceiling and straight jacket of the labelling, to enable the silenced to be heard, better understood and empowered. This is here called the Silenced Manifesto.
CHAPTER ONE

INTRODUCTION TO THESIS

7 LESIONS: 7 VOICES: 7 DRUGS: 7 STORIES: 7 CONCLUSIONS

“I am now convinced I am disabled. I am coming to believe that I am all the labels people
are bestowing on me. I am lacking. I am stupid. I am powerless. I am silenced.” (Field
notes 24th March 2012)

In this chapter I will be hypothesising my thesis.

I have seven lesions on my brain. Apparently, they are there but they do not do anything, nor
have done anything in the past. The neurologist calls the condition ‘functional neurological
symptoms’. I get spasms, mostly in my arms and legs. I especially have trouble standing up and
getting out of cars. I have a 30% chance of developing multiple sclerosis with my condition.
This upsets me somewhat because I was hoping to have an answer and gain some relief from my
mental health prison.

I hear about seven voices. They are both male and female, all ages, different tones. The voices,
or ‘noises’ as I call them, are quiet when I am well, and not so when I am unwell. When I am
unwell, they shout at me. They say things like, “You are so bloody stupid!”; “You are hopeless
and worthless!”; “No one will ever like you and definitely never love you!”; “I hate you!”; “Die
bitch die!”; “You good for nothing sap on society!”; “I will find the slowest way to kill you…bitch!”; “You mother fucking waste of space!”; “You’re not even worth the energy that I am spending to talk to you…. Fuck you…!!”

The seven stories, to be detailed at the end of the thesis, describe seven experiences I have had in recent times. They are all harrowing accounts of my life with schizoaffective disorder. It seems that the label of schizoaffective disorder, like other mental health conditions, cannot be shaken. The culture I am embedded in has perpetuated and endorsed my labelling. I find that I am in fact, lacking.

I have adopted an anthropological study of mental health. Specifically, an autoethnography of my living with schizoaffective disorder, looking at the ways I have been labelled as a lesser human, and understanding that labelling is part of the culture which encompasses it.

There are five statements underpinning this thesis:

1. I live with schizoaffective disorder. I am labelled as such, as per medical science. I have been measured to affirm this label.

2. I am defined by Westernised biomedical and psychiatric values, and indeed the values of the broader community who have faith in science, perpetuating my labelling.

3. This labelling and culture perpetuating defines me as a sub-human, sub-citizen, and/or social misfit. I am stigmatised.

4. I will always be lacking… in the context of the disempowered and perpetual role of (post)colonialism.
5. There is the need to put together a strong theoretical framework to move forward. Critical theory will be explored, to destabilise the dominant biomedical model.

Schizoaffective disorder is basically having schizophrenia with an additional affective side. That is, having issues with reality and perceptions of reality, including hearing things such as voices, with a dash of depression and anxiety.

**Being Crazy**

Throughout this thesis, I banter with the term ‘crazy’. I also use the terms ‘madness’ and ‘sick’ interchangeably, and in jest. The reason why I rely on terms, particularly ‘craziness’, is to introduce and provoke and request another level of understanding of what it is like living with a major psychotic disorder. By encouraging a different and another level of understanding, through jest and a black sense of humour, I hope to relate to others, both the sane and insane. The liberty of using poetic licence through humour, as permitted with the methodology of autoethnography, provides a more complex and multifaceted understanding of the experience of living with schizoaffective disorder. Indeed, by using the term ‘crazy’, I am also challenging the labelling of the mentally ill with the terms sub-human, sub-citizen and social misfit.

A premise of this autoethnography is that it is a reappropriation. A reappropriation is the cultural process by which a group reclaims terms or artefacts that were previously used in a way disparaging of that group. (*Reappropriation* n.d.) Reappropriation is assumed throughout this thesis. With a deconstruction of schizoaffective disorder, along my autoethnographic journey, I
have developed a unique insight and profound understanding into the strange alternate world of
the ‘crazy’, as labelled by me.

I must emphasise the significance of my fragmented writing. It is a style that is a side effect, as it were, of my chaotic and broken and divided mind. It is difficult enough to describe a reality coherently in a single language, yet I am translating the realities of seven noises yelling at me. My fragmented writing reflects my craziness. There is not one filter siphoning my thought processes. My mind does not operate unilaterally. It operates multilaterally, a multiplicity that screams at me, assaulting my mind at the same time. And this fragmentation is not always explained well by me. In order to reduce confusion, both for my readers and for myself, I try and take small steps in my explanations, trying to unpack as I go, carefully, to try and make my thought processes clear for everyone. Without these attempts of clarity, this thesis would be an untranscribable mess. All I can hope for is the readers’ patience with my transcribing. The existence of fragmentation in this autoethnography is data in itself. It is a method of thinking, an expression, a logic. Fragmented writing is an expression of a fragmented mind. It is a reflection of trying to understand a way of thinking that can give a voice to the silenced. Let this be called a paradigmatic method for which to better understand my crazy head.

Whilst in psychiatric wards, I’ve known a man in his 50s claiming to be seven months pregnant with Jesus Christ. There was also a senior officer in the armed forces cowering behind a cubby house he built out of a coffee table, magazines, dolls and teddies, claiming to be a king in the kingdom he built, and the dolls and teddies were his minions. Though what really broke my heart was when I was in hospital the first time. My brother and his wife were trying to get me to hold their new baby. All I could do was hide behind chairs in the corner of the room, sobbing,
uncontrollably. I wish I could have held the dear little one and expressed my love. I really regret that. I was powerless from the psychosis. It is times like this that I hate my illness; times which starve me of the love I have for my friends and family. The process of reappropriation unpacked in this autoethnography empowers me to be heard; empowers the birth of the language of the Silenced Manifesto.

I have written an autoethnography

Central and pivotal to this thesis is its methodology. I have written an autoethnography. The fundamental story and reflection of my lived experience is depicted in the details of what it is like to see what I see and to hear what I hear. What I must tell is vital in the understanding of living with a major psychotic illness. Developing an autoethnography brings together the worlds of science, culture, art and emotion. Not a melting pot, or an act of assimilation, rather an autoethnography tries to make commensurable what has previously and possibly been incommensurable. I bring together language and discourse to be transferable and translatable. I attempt to cut through the powerful colonial hegemony and empower the silenced.

Exploring theoretical underpinnings – critical theory and (post)colonialism

The term (post)colonialism is phrased as such, with parenthesis, because some theorists question whether there has been an end to colonialism the first time around. Aboriginal activist Bobbi Sykes asked at an academic conference on (post)colonialism, “What? (Post)colonialism? Have
they left” (Smith 1999: 25)? As such, in this thesis, postcolonialism will be termed (post)colonialism (Smith 1999).

Science may be a tool of colonialism, and the concept of mental illness can be likened to (post)colonialism. It is directly related to my experience of living with a major psychotic illness. I am controlled, defined and silenced by the politics of the colonisers, in this case and for example the realm of biomedical science. Thus, the Silenced Manifesto.

The Silenced Manifesto is a fluid cultural concept. Using the method of autoethnography, culture is essentially a malleable tool for defining and understanding the self, and the self in comparison to the Other. The fluidity of culture allows for the production of knowledge in a world where there is no absolute truth. The fluidity of culture disallows the traditionalist older view of a static culture which is limited by boundedness, timelessness, and homogeneity – such a static view of culture is quickly adopted by hegemony, which of course is a tool of colonialism (Abu-Lughod 1991: 143)

Cultural interpretation and understanding are the fundamental purpose of anthropology. Culture depicts a certain sense of identity construct which is constantly under definitional duress. This duress becomes the fight of the Silenced Manifesto, where culture and identity are forever changing; forever negotiating; forever struggling to find a voice, a voice that can be heard.

It is at this early point in my study that I need to identify and position myself definitionally; in an intellectual position and how this relates to my own socialisation. I need to answer the
question, “Who am I?”, especially “Who am I, despite my mental illness?”. I go into detail about my life history and life before craziness in chapters four and five, but here I can say that, drawing on feminist theory and queer theory, and the poetic and artistic cues that such critical theory allows, I can situate myself within an identity and history. I am from English/Irish Catholic descent – from the third fleet to Australia in 1791. I had a Catholic education, was one of seven children, from a single income family where my father earnt the family’s wage. I have a commitment to social justice issues, thus my valuing human rights and the essential importance of cultural wealth. Although I have a family history of association with Australia’s first colonisers, I feel as if I have been colonised myself.

I feel like I have been disempowered by the colonising government where my voice is not heard despite my yelling and screaming. I am silenced. So when I am describing the Silenced Manifesto throughout this thesis, I am not only influenced by the cultural power play of living with schizoaffective disorder, I am also situated within the creation and dynamics of other cultures I am socialised into, for example, from being a cis woman, Caucasian, 46 years of age, post graduate anthropology student, Catholic, heterosexual, and monolingual. My experience of living with schizoaffective disorder can be better placed with an understanding of these sub/cultures I am socialised into.

I am a part of the Silenced Manifesto; defined by and hidden behind a dominant and discriminating discourse. The discourse is punitive as it does not allow for the language or expression of those living with a psychotic illness. The discourse disallows and disempowers agency for the marginalised, supporting a form of punitive discourse that promotes the subjugation of the sub-humans, sub-citizens and social misfits, and promotes inequality, both overtly and covertly.
The term, ‘subaltern’, considered by Spivak (1988) to be the colonised, can be likened to the culturally crafted identities of sub-human, sub-citizen and social misfit discussed in this thesis. The subaltern has been colonised and suffocated by the colonisers’ dominant ideologies. (Post)colonialism is strongly represented in this thesis as a theoretical tool of analysis because, as part of critical theory, it significantly represents the space of the marginalised group.

Within a space for commensurability comes a message from the marginalised, those living with mental illness; where there is a site of creativity and power; where the mentally ill recover; where we meet in solidarity to erase the categories of colonized/colonizer. As hooks (1990: 152) states, “Marginality is the space [site] of resistance. Enter that space. Let us meet there. Enter that space. We greet you as liberators”. Forms of possible disempowerment for the colonised subordinated subject is to give up their knowledge for the use of the Western academic. Forms of possible empowerment and remittance for the colonised include using the coloniser's tools of language and discourse (hooks 1984).

*Labels perpetuated by culture*

I aim in this thesis, firstly, to unpack my experience of living with schizoaffective disorder. I will pull apart, excruciate, examine, study, analyse, extrapolate and compile my experience of living with schizoaffective disorder, and how my being labelled within the science of mental health defines me and confines me.
When considering the cultural identities of sub-human, sub-citizen and social misfit, I cannot ignore the importance of labelling theory. Durkheim was the first social theorist to discuss labelling theory in *Suicide* (1897). Labelling theory came into its own in the 1960s and 1970s, around the same time that critical theory (including (post)colonisation) became more significant in the social science vernacular. Goffman (1963) also contributed to labelling theory in his discussion of stigma. Scheff introduced labelling theory to the construct of mental illness in 1966. Scheff (1974) also discussed the stigma of the mentally ill and how identifying as mentally ill is a self-fulfilling prophecy. If you are labelled as lacking, you will be treated as lacking, and identify yourself as lacking, and become lacking.

The essence of labelling theory is that individuals are crafted by society and given identity by society. This is done via the labels that individuals are given by society. Some labels result in harmful effects, such as the conformity of deviance and the reappropriation and perpetuation of stigma. These labels are enabled, empowered and perpetuated by society. The negative effects of labelling, the naming and assumptions, are internalised by the individual so that they adopt the negative influence of the labelling. Importantly, in this case, the individuals self-actualise and learn to accept and identify as a sub-human, sub-citizen, social misfit.

In this autoethnography, I will explore what it is like to be labelled and categorised and stigmatised as sub-human, sub-citizen and/or a social misfit, culturally crafted identities which have been applied to the mentally ill. These terms are very close in definition and should be understood as supporting each other. And they need to be defined first. Sub-humans are defined as those not granted full human status in society in that they are deemed to lack the capacity to participate in society. Aristotle claimed that to be human is to be social (Colaner 2012). Indeed, Scheff (1974) claimed that mental health is a social construct. To be sub-human negates the
fundamental social nature of humankind. They display behaviour that is going against what is
the norm of social and cultural behaviour (Scheff 1974).

“Human beings are social creatures. We are social not just in the trivial sense that we like
company, and not just in the obvious sense that we each depend on others. We are social in
a more elemental way: simply to exist as a normal human being requires interaction with
other people”.

Atul Gawande (2014)

Sub-citizens, very similar to subhumans, do not participate fully as citizens of the state, not from
their own choice. For example, sub-citizens do not fully contribute to society, politically or
economically. Sub-citizens do not always vote or play an active role in the governance of society.
Nor does the sub-citizen participate in the economy, by having a job or actively seeking work.
The concept of sub-citizen is in relation to the State or nation (Matute 2018).

A social misfit is a person who does not fit into society. There is no room for them. They do not
adhere to the public values and behaviour of the socially kept and powerful. They are rejected
and not tolerated. Their behaviour is labelled as anti-social. They are outcasts of society (Allman
2013). It is not uncommon that people living with a mental illness with their anti-social behaviour
are homeless – and in being so rather public. Those who do not want to have their space
infiltrated by anti-social behaviour do not want to see the mentally ill homeless person in their
public space. They label such people as social misfits, and commonly the social misfits are
admitted to psychiatric wards. They are silenced and hidden by the mental health system. Where
else are they to go?
Measurement is a tool that labels. In considering measurement and diagnosis as cultural phenomena, and considering measurement as a labelling tool, one asks, what do these measurements represent and how does measurement act to label mental illness? There is a magic of representation displayed in measurement – and at the same time a violence of writing, and a violence of measurement (Said 1978; Smith 1999). As such, mental health measurements perpetuate a culture which ultimately leads to a crisis of representation (Smith 1999).

Measurement can be both liberating and/or disempowering. Measurement, for me, has defined and confined me, for example, through my diagnosis. What are the tools of diagnosis, the tools that measure sanity? And what are the broader significance of these measurements? I have found
myself, through measurement, being associated with a certain type of categorisation. Some perspectives on these are addressed in my medical notes (see chapters five through nine).

Diagnoses via scientific magical evaluation (Lea 2008) may be defined as and perpetuated by the culture/s of madness, and/or vice versa. An analysis of diagnosis is somewhat legitimised by the banter and negotiation between the mentally ill and mental health professionals. Diagnosis is the ultimate in labelling and categorisation. It is reliant on measurement and categories that perpetuates culture and stigma.

The psychological measurements in these testings have significance to anthropology. According to Lea (2008), they come to life as a series of numbers, cultural artefacts and ‘factoids’. Lea (2008) defines a factoid as a fact negotiated and influenced by the socio-cultural, economic and political context from which it was derived—definably subjective rather than objective. A generator of factoids is rather controversial, not least because researchers treat factoids as if they are objective measures. Some advocates of the psychometric tools explored in this thesis hold great hope of them being a useful measure for representing the needs and possible treatment of the mentally ill (Lea 2008). (See chapter ten.)

Measurement is a cultural phenomenon, including the cultural phenomenon of a somewhat universal application of maths and science, for example, how far one metre is and how many four is. Socially crafted facts are measurements of culture which are used to validate and demonstrate the success of measurable activities, such as sporting events or government elections. And measurements can be essential in evaluating more esoteric phenomena, such as measuring and assessing abstruse cultural activities, such as labelling and identity formation. Measurements
come wrapped up in an enchanting and captivating consequence of numbers. The cultural practice of measurement is quite profound and enticing for those who respect and adhere to an ultimate scientific, measurement mandate – a mandate entwined in the rational, governing society, and its culture (Lea 2008). Ultimately, however, despite the persistence of and respect of science, one is left to ponder, can we really measure the seemingly unmeasurable?

“To some people original thought is a medical condition that leads to migraines”

Rassool Jibrael Snyman (c. 2017)

Culture perpetuating labels

The second part of the thesis focuses on an analysis of the culture/s which perpetuates these aforementioned categories and labels. The significance of stigma and all the issues addressed in this thesis is supported by autoethnographic data. In this way, I will examine the significance of culture, politics and economics. I will investigate cultural analysis and measurement in psychiatry. I will also theorise how measurement relates to the colonisation (or (post)colonisation) of the mentally ill, much like colonialism being associated with racism.

Culture may be defined as the dynamics of values, norms, beliefs, boundaries, meanings, and importantly power negotiations bestowed on a social structure. Within the culture that sets boundaries of values and norms from which structured society is confined, culture defines those with a mental health disorder.
Culture is fundamental to power. In fact, culture is fundamentally about power. Culture tells the story of the most influential and how they became so formidable. Then how they use their strength and effectiveness to keep them in significant positions through which they can continue to dominate others. When the discourses of culture are in the hands of the underdog, the power distribution shifts, even if only briefly (Richard 2008: 1724). It is because of this relationship between culture and power that the sub-humans/sub-citizens/social misfits are excluded, marginalised and rejected because of the part of the robustness of the dominant culture.

Considering the purpose of psychiatry, as a form of medical science, it is to gain a scientific grasp of mental illness and of healing the mentally ill. Psychiatry also plays a cultural role, defining those with mental health disorders as a type of social class, a class that is defined as lacking. Similar treatment was assigned to women, homosexuals and Indigenous peoples, who were hunted and imprisoned and some were killed like vermin (Smith 1999: 28). The psycho-metric assessment tools measuring me are socio-political technology fact-creating tools which aid in the governmentality of the unwell and the social misfits.

Some psycho-metric testing measurements have proven to be highly significant anthropologically, that is, in the cultural context of (dis)empowerment of the mentally ill. Today’s mental health institutions and hospitals are all about measuring and judging and surveillance. The mental health assessment tools and medical observations, cultural tools of modern psychiatry, are all about measuring and judging deviance (Foucault 1961). This measurement leads me to say that I am in servitude to medical science and will be for as long as I am crazy, which will most likely be until I die.
The mentally ill are stigmatised as a form of outcasts. They are not full humans nor full citizens – they are people who don’t belong and are unwanted. This disdain is precipitated and justified by various policies of cultural significances and control, in the name of managing ‘anti-social behaviour’ and with people classed as ‘stigmatised’ (McMahon 2017).

There is an assumed *a priori* knowledge that psychiatric inpatients and/or community patients are lacking or in deficit in some way and need intervention and support. There is currently a political commitment to deal with the ‘mental health issue’ in Australia, more so due to Professor Patrick McGorry, a mental health advocate, being declared Australian of the Year in 2010. McGorry campaigned for the government and community to address complex socio-cultural issues of the mentally ill to lessen the degree of stigma related to this marginalised group. The political issue of mental health is made more perplexing by considering mental health policy and government bureaucracy. Mental health political and bureaucratic infrastructure is complex and bewildering. (ABC News 2010)
The utilisation of measurement results in knowledge production. Measurement tools, for example cognitive functioning tests (discussed at length in later chapters), become an objective instrument of governance, producing practices of knowability and justifying the expenditure for program continuance and policy valuation and implementation. The assessment process creates a space for knowledge production, a formation of political technology where the act of ‘measurement’ forms a type of discovery which has political and governmental significance. Which brings one to question, who owns the knowledge of the crazy?

These cultural spaces in all their facets have affected me, defined me, and labelled me. In this culture I don’t seem to have a choice. As a young woman (when I was diagnosed), it was through the culture of medical science that my identity was set. This identity construct, being defined for me, has disempowered me and brought me great shame as a sub-human.

A cultural space of the State is exemplified by my dependence on the State for the supply of a drug called Clozapine. Clozapine is an anti-psychotic drug that treats to some degree those who have been non-responsive to treatment with other anti-psychotic drugs. To be eligible for Clozapine, I needed to have a diagnosis of schizoaffective disorder or schizophrenia. As part of taking Clozapine, I must consent to being measured and ‘poked and prodded’ monthly. Also, at least every two months, I must see a psychiatrist. Seeing a psychiatrist so often, and more if needed, is free of charge. This is an absolute luxury. Clozapine is very expensive, but the public system covers the cost, for now. The cost of taking Clozapine in addition to all the other medications I must take comes to approximately 12% of my total wages. This is medication alone, not including important services such as primary health care and allied health professionals. If the government decides to stop subsidising Clozapine, I simply could not afford
the treatment. So, ultimately, at the whim of government policy, my health can be taken away at any minute. And it will, so the gossip at the Clozapine clinic tells me.

The alternate to taking Clozapine is frightful. I may still be in the throes of psychosis. I am highly dependent on the drug. I don’t know what I would do without it. The possibility of not taking it due to cost is appalling. There are undercurrents of fear and terribleness in a highly dependent community. Despite the horrific side effects, I am tied, glued, attached and entwined to biomedicine.

*How is my thesis different?*

Mental illness is a highly stigmatised phenomenon. In Australia, as with many developed countries, people may be sectioned, or civilly committed, against their will because an appropriate public servant, medical officer, such as a General Practitioner GP) or senior mental health professional, judges and perceives an individual to be a danger to themselves and/or to others (Testa & West 2010). Although many authors have attempted to explore the world of the mentally ill, their ‘voices’ are external, and in many cases (see Biehl 2005) they struggle to enter the worlds of the people they are working with. In this thesis I am attempting something different. I am presenting an autoethnography of my own mental health experience. This is my own account of the struggles that I have trying to make sense of my world. The experiences of my day-to-day life living with schizoaffective order include negotiating with multiple and conflicting noises, heightened paranoia, disassociation and negotiating with the here and now, extreme anxiety and often a depressed mood.
This thesis explores areas of mental health in a way that no one else has done. Others have authored autoethnographies on aspects of health (Ellis 2004; DiaGiacomo 1999), yet, no one has written an autoethnography before with such insight into the depths as experienced by the person living with schizoaffective disorder. This thesis is unique in that it illustrates life through the eyes of someone with insight. With the gift of insight - that is the ability to be significantly self-reflective - I can give a rare and raw perspective of what it is like to live with a major psychotic illness and be suffocated with the disability it bestows upon me. Perhaps others can relate. Perhaps others can learn and benefit from my study and sharing of this.

My autoethnography is important as it gives a voice to those living with schizoaffective disorder, through the lens of one. Previously, such an insight into the patients’ experience and perspective did not exist. Previously, the only voices being heard in the culture concerning mental health were those employed and engaged with the bio-medical model. The mental health participants/participants are those who are silenced and disempowered. This thesis gives a voice to the silenced, through me. With due diligence, through my inception of the conception of the Silenced Manifesto, I have aided the silenced to now be heard, better understood and empowered.

*Filling in the gaps*

The phenomena of mental illness are categorised. How am I, living with schizoaffective disorder, understood and defined and labelled, by the broader cultural space? How is this explored through the lens of an autoethnographer? This thesis explores the phenomena of living with
schizoaffective disorder and the labels that are bestowed upon me. These are the labels of sub-human, sub-citizen, and social misfit. Labelling theory allows for a greater understanding of how labels are perpetuated by culture.

Other people living with a major psychotic illness could share my experience. As this study is an autoethnography, the sample size is one, me. Through my experiences, I can provide a lens through which to examine and realise the culture that enculturates me. As this is an anthropological study, I will focus on the analysis of the culture/s which perpetuates how it is to live with a major psychotic disorder.

What are the culture/s that perpetuate this labelling? How is the experience of culture negotiated? What are my experiences of the culture/s being perpetuated and negotiated? I have been stuck and oppressed within my diagnosis and the perceived appropriate treatment I need to have, as per mental health professionals’ decree.

The suffocation of my expression, my thoughts, my essence is perhaps the most disabling experience of my life. And I wish I could say that it happened only once. Rather, such stifling and suppression is embedded in psychiatry, for everyone. Further, and a highly significant issue, is the added marginalisation and subjugation that mental health participants receive when they are an already marginalised and subjugated group. To extrapolate, mental ill health is over-represented in the homeless, the social misfits (Sullivan et al 2000).
I delineate the cultural as defining the importance of what is social, and at the same time I would delineate the social as structuring what is cultural. Only a systemic analysis can come to terms with this quality of culture that escapes the individual’s control (Hacking 1999: 15). I am interested in the exercise of power within culture and the social body (Foucault 1982; Kleinman 1988: 25)

*Outline of thesis*

This thesis begins with a synopsis. Then this introduction, chapter one. Here I begin by depicting a hypothesis and address for the thesis in the form of five statements. Chapter two sets the approach of the thesis which aligns the methodological and theoretical scene. I also explain why I chose the methodological tool of autoethnography, and how this tool best fits a study that places the researcher in the middle of the query. As this thesis relies considerably on Foucauldian concepts, a historical discussion is essential. There are two chapters based on history. Chapter three situates the discussion as part of a history of madness. The fourth chapter concentrates and situates the historical discussion from an individual perspective, my perspective. This chapter, more specifically, displays my own history of madness and my own experience of living with schizoaffective disorder.

Chapters five through nine are five specific autoethnographic chapters. Chapter five focuses on my life up until the first of the three psychiatric ward admissions – ‘Life before’. The three admissions focussed on here are dated from 2012 to 2014. Chapter six gives an autoethnographic account of when I became acutely unwell and was admitted into the first ward out of three, Ward
A (public)— in 2012. Chapter seven gives an autoethnographic account of my admission and stay in Ward B (public)— in 2013. Chapter eight gives an autoethnographic account of my admission and stay in Ward C (private)— in 2014. Chapter nine, ‘Life after’, unpacks how I now manage my mental health, utilising skills and techniques I have picked up over the twenty plus years of living with a major psychotic illness.

The analysis chapters are in three parts. The first, chapter ten, concentrates on measurement. It describes how psychiatry, and consequent psychiatric diagnoses can be legitimised through the art of measurement. Chapter eleven describes and emphasises the stigmatised position that I continue to face; the irony and injustice of trying to live a normal life in a culture that labels me as sub-human and a sub-citizen, as seemingly incompetent and not fitting in the hegemonic ‘sane’ world. Chapter twelve follows on with an analysis of labelling and the culture that perpetuates it. This involves a study of stigma, history, governmentality and theory. Here the concept of the Silenced Manifesto, a concept I discovered, continues to be discussed and examined.

The conclusion, chapter thirteen, summarises and reviews the findings of my autoethnography, as completely as such a thing can be done.

The glossary, chapter fourteen, concludes the autoethnography.

These fourteen chapters (plus the synopsis) represent for me both an intellectual searching and a critical time of personal exploration. There are illustrations throughout developed by Bridget
Rauch. The use of Rauch’s drawings represents my intention here is to change society not just interpret or write about it. Only an autoethnographic methodology can assist me with this.

Yet always, why is there monitoring, measuring and medicating? Always. (Biel 2005)
CHAPTER TWO

SETTING THE SCENE – METHODOLOGY AND THEORY

“Honest autoethnographic exploration generates a lot of fears and self-doubt and emotional pain. Just when you think you can't stand the pain anymore that's when the real work begins. Then there is the vulnerability of revealing yourself, not being able to take back what you 've written or having any control over how readers interpret your story.”

Carolyn Ellis (2004)

When considering autoethnography, there is a sample size of one. One subject to explore, explain, extrapolate, and to exhaust. One subject to unpack and repack, deconstruct and reconstruct, and to understand and be confused by. Through the one the many are understood; as through an autoethnography a culture is enlightened. Neither a simple narrative nor an autobiography, the one ethnographer, who has been immersed in a culture, illuminates the socio-cultural phenomena in all its complicated complexities and seemly simplicities (Ellis 2004).

I am sitting in my room, freezing, even though it is summer in my hometown, staring at my surrounds, begging for inspiration. I have arranged over sixty books and countless articles in
piles on my floor, trying to devise some sense of intellectual order, so I at least have some hope of ordering the chaos that is inside my head. It took me days to arrange the piles, first in chronological order, then order by methodologies, and finally in order of topic: a process that was complicated by my persistent psychotic madness and the shifting multiple realities that plague me. My favourite books include Tess Lea’s *Bureaucracies and Bleeding Hearts* (2008), because I think it is a shrewd account of how public health policy, as an entity, empowers itself by developing and utilising tools. These tools are called cultural artefacts, and they measure and then validate the policy makers and service provider’s existence, as well as their inherent power. Other books range from Fanon’s *Black Skin White Masks* (1952) to a couple of astute books from LaTour, one of which is *We Have Never Been Modern*. I also have the obligatory texts for anthropology students such as Geertz (1973) and Said (1978). Then there are the texts which are deemed necessary and very topical reading in critical theory, such as Smith’s *Decolonising Methodologies* (1999). Some topics have larger piles on the floor than their neighbours. For instance, various social theorists make up four large piles, anthropology of emotion has a substantial pile, whilst specific studies and analyses of the anthropology of madness have a lowly twelve books in their pile. (Moyer & Nguyen: 2014) This represents not a lack of desire to engage with such material, but a substantial gap in the anthropological lexicon (Hale 1975).

Well-known Australian based academics who have experience in mental health research include Foster, who has worked in and has experience from being a child of a parent with mental illness (2012; 2016). Another academic, Broadbent completed an ethnography about triaging people with a mental illness in the emergency department (Marynowski-Tracyk, & Broadbent 2011). Then there is Muir-Cochrane, who is a consumer advocate and qualitative researcher. Salvador-Carulla, from the Centre for Mental Health Research at the Australian National University has
also been involved in much research in mental health in Australia including the topics of lived experience and mental health policy. Senior (2006; 2009) has also influenced this body of research with her support of the autoethnography method used in this thesis.

In addition to the lack of studies on madness, there is a poverty of anthropological studies on self-experience, or autoethnographic analysis, of madness. I have read autobiographic works such as Sylvia Plath’s *The Bell Jar* (1963) and Janet Frame’s *An Angel at My Table* (1984). Although amazing pieces of writing, with excruciating and discomforting detail, they still left some questions unanswered for me. Firstly, these narratives do not show how the individual experiences their illness within the context of their public historic-socio-cultural order, that has structured, engulfed and created the definition of the phenomena of what is today called ‘mental illness’. The public historic-socio-cultural order which bounds ‘mental illness’ in this thesis is today’s modern Australian culture. (As per the development and formation of autoethnography, modern Australian culture ranges from the 1960s till the present.) Secondly, these narratives lack a comprehensive description and analysis of the individual’s experience of having a mental illness, more specifically, that of having a major psychotic illness. Thirdly, how does the psychotic individual experience the phenomena of hospitalisation, both voluntary and involuntary, and what does this means for both the individual and the social context from which it was developed.

Following on from Plath and Frame, and according to Neumann (1996) an autoethnography is “text [that] democratises the representational sphere of culture by locating the particular experiences of individuals in a tension with dominant expressions of discursive power.” The
description and analysis of the lived experience of the mentally ill individual seen as within the structure of the mental health system in this instance, contributes to an alternate view, perhaps postmodernist or poststructuralist in form, which unpacks and reveals the multiplicity and kaleidoscopic phenomena which is mental health. To expand, poststructuralism, closely aligned to postmodernism, but perhaps also reactive to it by negating the importance of all social theorising, not limiting social analysis just to multiple truths. In reaction to exploring and negating, the nature of structuralism is known by deconstructing it. There are no macro-universal truths, nor micro nor nano truths. Social power play is rife, which brings to light the nuances of the social in practice and the social in theory, if there is an actual difference between the two. For a short time, Foucault claimed to be a poststructuralist (Foucault in O’Farrell 2007) (Note: to some theorists, postmodernism is much of a muchness with poststructuralism. See glossary chapter for definitions of postmodernism and poststructuralism).

I intend to use this dialogue – to explore and analyse through the lens of my mental health experience, that which includes an analysis of the biomedical labelling of schizoaffective disorder. It is of interest to note that the social labelling of schizoaffective disorder is not necessarily at odds with the biomedical labelling of such. From this focus flows my personal story and an exploration of the societal issues of mental health labelling. This autoethnography is about understanding the mental health culture that I belong to, seen through my lens, telling my enculturated stories.

The reason why I focus on a Euro-Western-centric account is because it is the culture which situates my autoethnographic perspective. This includes the colonisational account that is the
foundation of my understanding of Australian social science, Australian psychiatry, and the histories of such. I am also able to situate my personal enculturation into the mental health system, namely an understanding of the empowerment and disempowerment what it is like to live with schizoaffective disorder.

A significant theme evidenced in this analysis is measurement. How am I measured? What tools are used? What artefacts are employed, that is which measurement tools used have cultural meaning (Lea 2008)? The different types of measurement may turn out to (mis)represent the subject being measured, thus measuring the unmeasurable, or perhaps measuring nothing in fact. Of significance to measurement is the realm of diagnosis – measurement is often seen as an end, serving only to legitimise the diagnosis process, and the role of the mental health professionals involved. As well, legitimising diagnostic power can be seen through the art of measurement. The power of measurements and consequent numbers and pie graphs are quite profound (Lea 2008). The purpose of this chapter is to define and build upon the knowledge produced by the chosen methodology of this thesis, that is autoethnography.

I hope this dialogue scrutinises an account of how evidence is manufactured and negotiated, by the policies perpetuated by public health and bureaucracy. There is a visible gap in the literature, thus the need to add this thesis to the scholarship of medical anthropology and/or socialised medicine (Moyer & Nguyen: 2014). Tess Lea’s Bureaucracies and Bleeding Hearts (2008) asks the pertinent questions: what are the power dynamics involved in evaluation, measurement and accountability? What are the social constructions of facts – ’factoids’, and the cultural/statistical artefacts geared to justify reproduction of cultural institutions/phenomena, such as bureaucracies? Then there are the phenomena of silenced reports on shelves. where the (political)
voices and discourse of the marginalised are suffocated and muffled by those in power, the ‘colonisers’ as such of knowledge.

“Where there is power, there is resistance.”

Michel Foucault (1976)

Diagnosis and prognosis

I was 23 when I was first hospitalised into a psychiatric unit. I was there for 39 days inclusive, from April until May 1997, as per my medical notes. It wasn’t until the end of my stay that I received a diagnosis of bipolar disorder – which type I do not know. Seeing as diagnoses are complex and multifaceted, it is not surprising that my actual diagnosis wasn’t discovered for many years after that first hospital visit. I don’t know whether this absence of a full diagnosis is because the medical professionals involved didn’t know, didn’t think it is important or that they wanted to protect me - all reasons I declare to be unsatisfactory. This shows that psychiatry is an inexact science, much is unknown, and how medical professionals try to paternalistically protect me and others. Protection, an inappropriate and well-intentioned means to a misappropriated end. The need to diagnose is interesting: to define and confine, to measure and to label apparently improves and guides treatment. For those scientists and mental health professionals for whom it matters, psychiatry is a science where treatment can be calculated, determined and evaluated. The science behind diagnosis is also important to some people living
with mental illness. It gives them somewhat of a tangential explanation of their position, no matter how oblique (Szasz 2008).

So, I am diagnosed with schizoaffective disorder. Schizoaffective disorder can affect anyone, but generally more women than men suffer from the disorder. Schizoaffective disorder often begins in late adolescence or early adulthood, with a typical age of onset of between 16 and 30 years of age (De Hert et al 2011). Schizoaffective disorder is a condition that many people have never heard of, and yet it affects as many as one in every two hundred people, that’s 0.5% of the population. The mental health experience for those living with schizoaffective disorder is little known, and this is not surprisingly due to its complex and multifaceted components. (Benabarre et al 2001)

Let me discuss the currently accepted definition of schizoaffective disorder. "Schizoaffective disorder can easily be confused with bipolar disorder and schizophrenia because the symptoms are very similar. Someone living with schizoaffective disorder will generally experience the hallucinations and delusions that are commonly associated with schizophrenia at the same time as, or within a few days of, experiencing the mood disturbances of and depression that are usually associated with bipolar disorder" (Daniel 2011: 19; DSM V 2013). There are a couple of different types of schizoaffective disorder - bipolar type and depressive type. I do not know which type I am. Thus, is the chaos of mental health care. This definition is directed by the fifth diagnostic and statistical manual of mental disorders – DSM V. The DSM V is the bible for psychiatric diagnosis, mostly used in the colonial West. People diagnosed with bipolar disorder can also experience psychosis. The main difference between the two, is that people with schizoaffective
disorder will experience the psychotic symptoms outside of the mood episode as well as during the mood episode, whereas someone with bipolar disorder will experience hallucinations and delusions only during a mood episode. Schizoaffective disorder affective/mood symptoms include hypomania, mania, depression and mixed states. Affective symptoms can simply be described as symptoms with an emotional component (Daniel 2011: 20). Psychotic symptoms of schizoaffective disorder include paranoia, hallucinations, delusions, all showing a diminished capacity to decipher what is real and what is not real. My main psychotic symptoms are caused by anxiety.

I find anxiety a massive cross to bear. It is always with me in varying degrees. I am disabled by it. Anxiety limits freedom, agency and autonomy. It suffocates me. Yet, anxiety is a normal human feeling that is linked to the sensation of fear that people experience when they are faced with situations that are either threatening or difficult. Anxiety, therefore, can be a positive experience because it is designed to protect people from danger. Anxiety is connected to the famous ‘fight or flight’ response (Daniel 2011: 62-3). However, feelings of massive anxiety have been diagnosed as panic attacks. Some of the symptoms of the attacks as I feel them, include: a desperate gasping for air, rapid short breaths, fast pulse from my heart crushing the inside of my chest, numbness and loss of control of my limbs; and being plagued by sweat, terror and panic. I have panic attacks often. In these days of relative wellness, I have about one panic attack every second day.

Depression is also part of the experience of people with schizoaffective disorder however, it does not plague me as much as anxiety. I do experience depression, chronically, but I feel most affected by the complications of anxiety. After living with schizoaffective disorder for all these
years, the powerful underlying anxiety has become a major contributor to my major psychotic disorder. Many mental health professionals have said that my anxiety is a cause of my psychotic symptoms. That may not have been the case years ago, but it is now (Kaplan 2003: 509). My disorder needs to be managed well. To emphasise, anxiety causes psychosis and psychosis causes a loss of cognitive functioning and poor cognitive functioning causes poor quality of life.

There is much emphasis put on the diagnosis of a mental illness. As mentioned before, the universal and ultimate publication defining mental illnesses is the DSM V. Mental health professionals depend on this resource to diagnose and prescribe the most appropriate treatment. It is a cultural artefact in mental health service delivery, attempting to describe and confine the biomedical phenomena of the elusive obscurity of mental health. Developing an exact diagnosis is a very subjective and difficult thing to do. Both clinicians and health participants argue for and against a diagnostic determination. Again, even many mental health professionals believe that diagnosing someone with a mental illness limits and marginalises them too much. A diagnosis can be disempowering for the individual as it categorises and assumes an *a priori* assumption of identity. Once categorised, many prescribed, expected and somewhat predicative behaviours are assumed, or can be, regardless of the actuality of the individual and their experiences. Yet at the same time, some people find that they are empowered by diagnostic labelling because they can research and come to understand better the nature of their illness (DiGiacomo in Elliot & Ray 2002).

Despite the plethora of mental health professionals I have dealt with over the last 23 years, not one has said what the prognosis is for me having schizoaffective disorder. I suppose I have just
assumed that my life will be shorter than the average healthy person. What with the numerous co-morbidities that come with mental health disorders, such as alcohol and drug misuse, diabetes and obesity and thyroid disease (my hypothyroidism was brought on by years of taking Quilonum. Quilonum is a mood stabiliser commonly called Lithium and is commonly prescribed for people with bipolar disorder.) I have taken for granted that I will just not live as long as the ‘average Jo’. Between 30% and 40% of people with schizoaffective disorder attempt suicide at some point during the disorder. Approximately ten percent of this number will succeed in their attempt (De Hert et al 2011)

*Disability and mental illness*

Those living with a mental health disability can access a poor wage from the Australian Government, called the disability support pension (DSP). It is extremely arduous to apply for the DSP. I remember applying for it and feeling disabled by the process. The bureaucracy had disabled me and disempowered me. The DSP, however, was my only option to gain monies to live. I was dependent on the government to live my own life. Although it wasn’t my own life that I was living. I was tied down, economically too. I was hidden and silenced, having to talk the talk and walk the walk of the State. I had become part of the Silenced Manifesto.

The type of disability commonly associated with mental illness is called ‘psychosocial disability’. It is a term used to describe what is often the outcome for a person with a mental health condition attempting to interact with a social environment that presents barriers to their equality with others (NDIS 2020a). Psychosocial disability can be understood as a socialised phenomenon, and
medical science is also branching out within the realms of the social sciences. So, mental health disability is called a psychosocial disability which fundamentally defines sociality as imperative to disability (NDIS 2020a). This is my position as an anthropologist.

When comparing mental illness with other forms of disability, a few questions come to light. Can mental illness be compared equally with physical illnesses? The World Health Organization (WHO) estimated in 2012 that about a quarter of all time lost to disability was due to mental illness (WHO & Calouste Gulbenkian Foundation 2014). According to the National Disability Insurance Scheme (NDIS), we have some idea around racism, there are a lot of surveys looking at racism and racist attitudes, sexism too. But we don’t really know that about disability. We must know what we’re actually dealing with. What are the misconceptions? What are the myths (NDIS 2020a)? Another query, are the mentally ill underestimated? We know, though it would seem likely that some people living with a mental illness disability do not identify as such, possible due to stigma.

Furthermore, according to WHO, and speaking from an international perspective, mental health is primarily focussed on social health. Mental health and many common mental disorders are shaped to a great extent by the social, economic, and physical environments in which people live, while social inequalities are associated with increased risk of many common mental disorders. WHO & Calouste Gulbenkian Foundation. (2014).
Disability and Otherhood

Because of my diagnosis and my resultant labelling and categorisation, I am immediately placed in the position of sub-citizen, subhuman, and/or social misfit. The function of the mentally ill in the stratification of society is that of the 'Other'. ‘Otherness’ can also be likened to the status of Indigenous people, LGBTIQA+, women, the disabled, the colonised, and any other marginalised group of people who do not fit in with the social norm.

Australian women first won the vote in South Australia in 1895. Australian Indigenous peoples only won citizenship right across Australia in 1965 (Australian Electoral Commission 2020). LGBTIQA+ people are still often seen as social misfits, only recently awarded the right to marry in Australia. The disabled are not classed as being in full control of their capacities, in other words the disabled are classed as subhuman. People living with a mental illness who are known to the police during times of being unwell, are commonly referred to as social misfits. It is not uncommon for Indigenous peoples to be labelled as social misfits, especially if they also have a mental illness (National Strategic Framework for Aboriginal and Torres Strait Islander Peoples’ Mental Health and Social and Emotional Wellbeing c. 2017: 2017). This social misfit identity of the mentally ill is significant, on par with criminals, and classed as outsiders and unwanted in general society; a.k.a. Othered.

The disability movement has been central in reminding us that there is a long history of people living with illness or disability, who are already Othered by society. As Said (1978) argued, Othering means turning the person into an object of some sort, such as a stereotype. Those whom
we study are ‘not us’. The expert on the lived experience of disability or illness is not the clinician, but the person experiencing disability (Richards 2008: 1717).

I am an Other, a lesser human, a deviant and a misfit. Living with a mental illness I have discovered that the mental health professionals are the powerful Us and the mentally ill are the Other. The Other are an identity I belong to and have insight into the ramifications of this identity, part of a fundamental and phenomenal assumption of lacking. The prevailing Us is defined in opposition to Other. The two are hierarchised with Us being commanding. This leads to the need to unpack the politics of the medical realism. Here the relationship between psychiatry and colonisation is introduced.

The disabled are squashed into a medicalised narrative. People living with disabilities or illnesses are objects of study and not agents of study. There seems to be an underlying assumption that such people need to be talked about but should themselves remain silent as if they do not have anything useful to contribute. “Even if I cannot speak, it does not mean I have nothing to say” (Interviewee with an intellectual disability in a “European Union for Fundamental Rights – FRA study. The WHO (2011) attempts to treat these issues in its Disability Report.

They are also frequently the recipients of other people’s expertise not contributors. Disability seems, often, to exist beyond the barriers of thinking, leaving disabled people in silence and obscurity (McDougall, Swartz & Van der Merve 2006: ix). Not all disabilities and illnesses are apparent to observers and not all perceived disabilities are disabilities to the people experiencing
them (Richards 2008: 1719). If disabilities are generalised too far, they can dehumanise the subjects, and then because of being labelled people turn into patients (Richards 2008: 1720).

This is the case historically, however these days the vernacular is spreading to give those living with a disability a louder voice, or at least some voice. With the NDIS (2016) being implemented in Australia, the power dynamic is changing, aiming to empower the ‘disabled’ as the main player in the dialogue. Here is the government’s intent to relocate the focus of care to the grass roots, and to empower the individual. The NDIS is about empowering the individual living with a disability, that is, those living with a disability will decide how their care will be delivered. In Australia, it will take some time for this policy change to settle and for the ramifications to resolve. There is no doubt that for now, those living with a disability remain social misfit and deranged, and that a change in mindset could take decades.

**Social sciences and health**

There is a rift between the social sciences and health, in this case, mental health. Medical scientists place all their faith in science. Social scientists place all their faith in the social sciences. The Silenced Manifesto can help to explain the social science/mental health rift. Social science, in this case through the gaze of critical theory (see chapter one), significantly represents (or misrepresents) the space of the marginalised group. Here, the marginalised group is the mentally ill - the sub-citizens, subhumans and social misfits. There exists the hidden, the silenced voices of the sub-citizens, subhumans and social misfits. As an anthropologist, abiding by critical theory, there is no single truth, no knowledge absolute or independent, and all
knowledge is socially constructed. Herein lies tension. Social scientists’ value most highly social phenomena, such as power dynamics and culture. In comparison, medical scientists’ value most highly clinical settings empowered and epitomised by raw natural and biological science.

**Stigma**

There is always an element of risk in defining something so ambiguous and hazy as a major psychotic disorder. As I have found, labelling someone and defining them as having schizoaffective disorder can pathologise them and limit them to a constrictive medical identity. It affects what could be a healthy sense of self and contributes with an assumed identity of less than human, as unable to contribute equally to society, and enforce a belittling construction of social identity. Defining a major psychotic disorder goes hand in hand with precipitating and endorsing stigma.

Erving Goffman (1959) suggested there are socially agreed upon behaviours that are appropriate to certain people as they engage with the context of Otherhood. According to Goffman (1959), life is scripted; our interactions with others are highly routinised. An individual’s social performance, then, is judged by others to be either in line or out of line with culturally expected behaviour (Goffman 1967). Goffman (1959) argues that people behave in ritualised ways in public contexts. There is scripted behaviour that occurs in social interaction with others because people who deviate from expected social performance face stigmatisation, or the spoiling of their identity. Here issues of stigma, identity and power play come into effect. Having a mental illness, is like living with a socially outed skin colour: you are totally defined by a single
characteristic, in this case of mental health, a biomedical label (1987: 319). It is a stigma, an attitude borne from society that reduces the afflicted person “in our minds from a whole and usual person to a tainted, discounted one” (Goffman 1963: 3). Stigma brings in the whole range of social deviance, social injustice and political corruption.

In this thesis I intend to look at the theories of Goffman in relation to my own experiences by way of a person living with a disability in my society, an individual that has been biomedically labelled. I start from the premise that I agree with Goffman. Goffman’s theories go a substantial way to explain my situation. I would like to explore the relationship between self and society regarding experiencing a major psychotic illness, and how self relates to society on a micro versus macro level. I will also explore the interrelationships of power play between self and society.

There is not a linear relationship between self and society. As Bourdieu (1991; 1998) and Bourdieu & Wacquant (1992) stated, the self and its relationship to society is fragmented. Society emerges from and is constituted by the interaction of selves. The self and society are crafted and defined by social interconnectedness. In a constant state of flux, the self and society are mutually intertwined to the extent that the boundaries of each are blurred into one.

I hope that my insight into schizoaffective disorder can analyse, assess and appraise the phenomena of the pathologised psychotic experience. It seems paradoxical to try and describe the labelling of schizoaffective disorder when I hate to be labelled. I resent how my day-to-day experiences are scrutinised by the medical profession, trying to understand my experiences of
the day to day world, so they know what perspectives of mine need to be mediated and medicated; to
define which of my realities are objective realities. I believe that I can add substantial value to the
current body of work around the lived experience having schizoaffective disorder. I hope to fill the gap with an understanding and insight of what it is like to live on the fringe of medicine and society. I must state, however, that close medical monitoring over my illness has saved my sanity many times, in many ways. It’s a double-edged sword. I hate what I need. Ironic.

**Traditional ethnography versus autoethnography**

Inspired by the postmodern ‘crisis of representation’ in the late 1970s/early 1980s, and the poststructuralist paradigm from the same time, the term ‘autoethnography’ was first used by Hayaro in 1979 to describe studies in which the researcher is a member of the group being studied (Ellis & Bochner 2000). Autoethnography has evolved to have many different names and forms, but all have in common the overt inclusion of the self in an investigation, of cultural process albeit with varying emphasis on each component. Autoethnography overtly breaches the traditional separation between researched and researcher challenging and effectively dismissing (along with various other qualitative approaches), the notion of the mutual, objective researcher.

There are many similarities between traditional ethnography and autoethnography. The essential difference is the autoethnography’s sample size of one. With this the autoethnographer is enabled and empowered to analyse utilising less traditional means. Like traditional ethnography, an autoethnography typically depicts a great depth, detail and richness of the subject, as does traditional ethnography. The description of minutiae used in autoethnography enables a better
understanding of the social micro-relations, including micro power relations. An essential and pivotal part of autoethnography (and traditional ethnography) is the analysis of self to the relation to the Other. By focussing on the self, autoethnography, brings out a depth and intensity of data that a traditional ethnography does not so well. It is a textual exploration of the raptness and breadth of individual experience, demonstrating the various facets that make the cultural dynamic setting what it is. An autoethnography is not a single voice but an advocate, amplification, interpreter and vehicle for many (Liamputztong & Ezzy 2005: 33). Note that the relationship between Us and Other is different to the relationship between self and other. In my definition, Us and Other refers to the relationship between the socialised groups of colonised and coloniser. Whereas, also in my definition, self and other refers to how the individual entity is defined by the greater society.

Autoethnography brings in several very sharp foci. It is different from traditional ethnography. Differences include: an autoethnography gives the perspective of culture based on an analysis of the minutia and how it is layered within the broader social structure; the dynamics within micro power relations are studied and their place in macro social power relations; the identity formations and perceived role of the autoethnographer; the involvement in micro-politics and personal contexts; and the functions of personal phenomena in the research process, such as emotions, physical health, and most importantly in this writing, mental health.

Autoethnography
Mental health services have long been influenced within landscapes of power. Autoethnographers are also confronting geographies of power within the acute care experience (Ellis & Bochner 1999). Autoethnography can allow a deeper human investigation and potentially a healing place in mental health care. For example, my insight of living with schizoaffective disorder will address the deep emotional affects that I have carried over the last twenty-three years of my life. These include a great sense of shame and fear. Up to the time of writing I have tried and failed to find a place in mental health care that can be wholly therapeutic for me with no or little luck.

There are many definitions of autoethnography. Autoethnography (auto - told from the first person, and ethno – focused on culture) is grounded loosely between postmodern, poststructuralism, and critical approaches to research. Storytelling is used as a method for obtaining and interpreting emotional and social data and presenting findings to the research audience that evoke a desire to effect change (Ellis 1997; 2004; Ellis & Bochner 2000; 2006). The overt inclusion of emotion is a unique feature of this approach, rendering it particularly relevant for me in the mental health arena (Foster, McAllister & O’Brien 2005; 2006; White 2003). Autoethnography, according to Kidd and Finlayson (2010), focuses primarily on personal and interpersonal interrelations. While Marks (1999 in Richards 2008: 1724) points out that the political is embodied in the personal, and vice versa.

Autoethnography has, as a term, been in circulation for about five decades and is defined as “an autobiographical genre of writing and research that displays multiple layers of consciousness, connecting the personal to the cultural” (Ellis & Bochner 2000: 739). Autoethnography, mostly
written in the first person, comes in a variety of creative, expressive and analytic forms, from art to science – ranging from short stories, poetry, fiction, novels, photographic essays, personal essays, journals, fragmented and layered writing and social science prose. These autoethnographic texts delve into concrete action, dialogue, emotion, embodiment, spirituality and self-consciousness so that the function of the autoethnography is to unearth the stories of the autoethnographer and the stories of science and society as a whole. The stories told in an autoethnography add to the growing mass of descriptive, destabilising, testimonial and emancipatory work associated with the culture at hand, and how these stories are dialectically revealed through actions, feelings, thoughts and language. Here the personal relates to the cultural which relates to the personal (Ellis 1999: 673; Ellis & Bochner 2000: 201, 739; Richards 2008).

According to Richards (2008), there are four types of autoethnography. The first three stemming from Richards are testimony, emancipatory discourse and destabilised narrative. This autoethnography dabbles in all its types. As in a testimony I will explore how my life has been dismembered and damaged. Through an emancipatory discourse, I will describe a multifaceted understanding of disability which recognises the importance of examining interrelationships between embodied subjects, and complex social psychological relationships. Here, autoethnography is a form of emancipatory discourse because those being emancipated are representing themselves, instead of being colonised by others, subjected to their agendas or relegated to the role of second-class citizen. However, there is a continual threat in representing themselves, those writing about themselves could replicate the very structures they seek to destroy, reverting to inauthentic identities that others have bequeathed them (Marks 1999 in Richards 2008: 1724).
With a destabilised narrative, I will describe how I have been interrupted by illness (Richards 2008: 1722-1723), and how I have been disrupted by the dominant bio-medicine paradigm. In short, this study is about unloading my experiences to gain a depth of understanding. This will be done with the help of my insight into my mental health illness and insight into potent individual interrelations. Also, I will use my skills as an anthropologist to explore knowledge of the literature and knowledge of the socio-cultural phenomena which embeds mental health services within it (Liggins, Kearns & Adams 2013: 108).

This autoethnography seeks to explore and analyse the lived experience of a mental health service participant (me). The rich, vigorous and powerful explanation of my experiences will be explored through the culture, politics, economics, and the environment of mental health service delivery. An analysis of my medical notes and mental health policy and bureaucracy will be utilised.

Autoethnography uses all senses of humanity and these are expressed through emotions and intentions. Social life is messy, uncertain, and emotional. If our desire is to research social life, then we must embrace a research method that, to the best of its/our ability, acknowledges and accommodates mess in chaos, uncertainty and emotion (Adams, Jones & Ellis 2015). Autoethnography can be liberating, offering a way to escape the typical form of academic writing.
According to Wall (2008: 39), autoethnography offers a way of giving a voice to personal experience to advance sociological understanding. Brooks (2010: 2) states that autoethnography is academic and artful storytelling that is at once personal and intellectual. It is both method and a text (Reed-Danahay 1997), and it is cultural, introspective, and reflective (Ellis & Bochner 2000). The autoethnographic text delves into the experiences and emotions of the researcher, keeping his or her voice and perspectives on to and through the context of enquiry (de Freitas & Patos 2009: 983). These texts, therefore, convey the interactional textures occurring between self, Other and contexts in ethnographic research (Spry 2001: 708). Not only can we write about ourselves through autoethnography, but we can write about our contextualised interactions with others, mixing those lived moments with what we find in literature, theory, and analytical discussion. Autoethnographic text is an important site for both academic understanding and social connection because we can carve out an intellectual space thick with shared awareness, one that goes far “beyond the self of the author” (Sparkes 2001: 222).

Here lies a comparison between positivism and relativism: the science of medicine versus the individual ‘crazy’ perspective. Science aims to contain via measurement and analysis. As someone living with a major psychotic disorder, I defy the deification of measurement and analysis. I cannot emphasise this enough - psychiatry is an inexact science. There is not a generalised blanket definition of schizoaffective disorder. However, it would be remiss of me not to explore the phenomena of medical science in a description of the disorder.

The autoethnographic way of writing has been critiqued as inappropriately emotional, personal, or therapeutic, at the expense of being academic (Atkinson 1997 in Richards 2008: 1717). It
allows researchers to show how they are part of a larger context and to document the details of the lived experiences of individual people (Ellis & Bochner 2000 in Richards 2008: 1720). Emotions play a powerful role in the interaction between individuals, often transcending societal roles and structures. Further, it is essential to recognise that, emotions and emotional well-being can be and often are attenuated by dominant social role playing and imposed social hierarchies. Emotions are a social entity, both developed from and maintained by social construction. There are several universal emotions. For example: happiness, sadness, surprise, fear, disgust, and anger (Lutz & White 1986; Wierzbicka 1986). I would have thought that more socially constructed emotions would be included such as shame, guilt, love, jealousy and hate. Emotions can be used as power play and a communication tool in the negotiation between self and culture (Kelly & Kaminskiene 2016).

According to Liggins, Kearns & Adams (2013: 106, 108), autoethnography is a methodology that seeks to connect personal experience to cultural process and understanding. Perhaps, as Gadamer said, “it is not truth we are seeking, but understanding” (in Liggins, Kearns & Adams 2013: 108). It is important in this process to tease out the many hats we wear, to be overtly and reflectively aware that this autoethnography is shaped to a greater or lesser extent by the multiple positions we hold, so we develop over time to have a multilayered perspective (Liggins, Kearns & Adams 2013: 108).

According to Ellis (1999: 669), the autoethnographic author seeks to develop an ethnography that includes the researcher’s whole and vulnerable/able self. Stemming from this are evocative and thickly descriptive stories depicting reality, as they are socialised. Autoethnography looks
at how human experience features multiple voices. Not unlike my seven voices. As Heron (2001) says, “You are partially blown by the winds of reality and partly an artist creating a composite out of the inner and outer events”. The goal is to use your life experiences to generalise to a larger group or culture; the practices of social science with the living of life (Ellis 1999: 671). Construction and validation of reality involves an analysis of social action, how this is described in the social text and then how the text is cast. Social action is communicated through “ordered clusters of significant symbols” that individuals and groups of individuals use to employ and orient themselves in a world otherwise opaque (Geertz 1973: 363). The cultural anthropologist reads their structures of meanings out of the social text. Then the text is cast in terms of the anthropological universe of discourse. For my autoethnographical story, I am dependent on the communication tools of the anthropological universe of discourse for me to make sense of my world.

Often the aim of such writing is to win back some power to a certain group of people. Although, it is distracting attention from the bigger issues, and might result in self-subjection, voyeurism and pathologism. It might reduce the narrator to a generalisable patient example, instead of bringing about change. If it is too individualising it might create a dualism of individual/culture. This could lead to the individual being seen out of context and the dynamic of the individual and society being overlooked (Marks 1999 in Richards 2008: 1724).

Autoethnography and ethics
Autoethnography is a relatively new and burgeoning methodology. Of note, regarding ethics, is that an autoethnographer has ethical precedence over their own work. The autoethnographer authorises his/her own ethics, through its own authority, clarity and certainty from the voice of one. The eyes of one provide the insight of the many.

According to Bochner (2000), two of the significant ways of gathering autoethnographic data include memory work and storytelling. These methods, strengthened and entwined, depict the marvellousness and rawness of the past, and how that influences the present; displaying the purity and essentiality of the narrative; in the dynamics and relations between the self, and society and culture. Memories are personal, political and relational.

Ethical consideration of an autoethnography will always be incomplete. ‘Data’ (for want of a better term) gathered from retrospection and memory work and storytelling will always be piecemeal and wanting. It is difficult to show how these methods are ethical, especially when the foundations are so fragmented. The main ethical issue related to retrospective and memory data is that the reflective data may display a crisis of representation. There can never be a uniquely true, correct or completely, faithful autoethnography. According to Hacking (1999), we are simply stuck with the reality that there is no life apart from the stories told about it, and there are no stories apart from the ethical realm.

There are many reasons for undertaking an autoethnography. One of these is emancipation. That is the purpose of this work. An autoethnographer has a moral responsibility to be honest and transparent in their research, and to be true to themselves and the culture in the story they tell.
At times it would be unethical not to tell a story. There are consequences of not telling a story, and to not tell the story truthfully. Essentially, not telling an honest story would be avoiding the truth and would not be vigorous and reliable. Part of being transparent and honest in an autoethnography is about being true to your motive for undertaking such a study. This thesis is a part of an emancipatory practice, reflecting the truth of power dynamics and unpacking the complexities of power negotiations. My emancipation is realised, paving the way for more to be emancipated. My story illustrates, “I am the voice, the object, the focus” (Field notes December 10th, 2014). Other purposes of autoethnography include being therapeutic and ethical (Ellis 1999). It is about giving a voice to the silenced.

Using personal experience methods, such as autoethnography, there is little guidance in the literature about how to understand ethics. Autoethnographers justify themselves by observing that individuals do not exist apart from the social context, and for this reason, personal experience can be the foundation for further sociological understanding (Wall 2008: 49). Parker-Jenkins (2018) states that the autoethnographer is the appropriate authority, giving permission by the academy or otherwise to write their own story. Autoethnography as such is an avenue to explore self-understanding and social identity.

There are some basic guides/questions for autoethnographical ethical research that help to deconstruct what it means to experience the rawness of the basic grassroots of a culture, a rawness seen through autoethnographical consideration. Namely, the rawness is defined by the relationships experienced at the grassroots. Relationships are pivotal to all things socio-cultural. Here I will contemplate a few. Is there anyone who would be offended by my portrayal of them?

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Family, friends, partners, colleagues, medical staff, and of course myself. If they will potentially be offended, they will be excluded from the research, representation and experience. Regarding my medical professionals, they are deidentified in every way, given a pseudonym and changed location and other de-identifiable factors. And me? Am I okay with the portrayal of myself? I have been so extensively and falsely defined by everyone else that now, here I am, empowered to define myself. It is ethical for me to finally define myself.

There are ways to demonstrate and determine an ethical autoethnography. For example, the ownership of the story and the ownership of the knowledge generated from the story, and the power and empowerment that comes from representing this story. Indeed, representation of knowledge can be very political. The autoethnographer, that is me, is the authority, giving my own permission to write my own story. The autoethnographer has an ethical responsibility to represent their own story in the truest way possible, that is to be as transparent as possible. The transparency of autoethnography strengthens the rigour, validity and reliability of the study. Furthermore, Tolich questioned (2010: 1599), “Do I own a story just because I tell it?...Do I have the right to tell a story that is not mine?”

Autoethnography aims to be transparent and honest, and to unpack the most complicated as well as the most basic purpose of research. Autoethnography paints the rawest picture of the rawest subject. The individual: the culture, the politics, the perceived truth, the power displayed, the purity of autoethnography, in all its honesty, exhibits strong validity and reliability as it emphasises a method of true representation as seen through the lens of one – thus being
transparent and honest. In my case, “Telling an autoethnography, my story is my own” (Field notes February 27th, 2014).

The ethics of writing and representing through an autoethnography, gives me an opportunity to have a voice and to break through the barriers of research and research outcomes. The aim of an autoethnography is to critique and criticise the experience of one, and in doing so help to address issues of the many. As my story illustrates, “I am the voice, the object, the focus” (Field notes December 10th, 2014). My emancipation is realised, paving the way for more to be emancipated.

The researcher is empowered by an independent individual voice. The responsibilities of the researcher include avoiding a crisis of representation and a crisis of truth or facts, or socially determined facts, that are ‘factoids’ (Lea 2008). Essentially, the responsibilities of the researcher need to consider the utilitarian greater good. This includes being mindful of (post)colonialism which can completely derail and absolutely remove any autonomy or agency, precipitating another crisis of representation and precipitation of askew power negotiation. Autoethnography, a modern methodology of anthropology, aims to represent culture and self in its purest form.

An autoethnography is very sensitive to researching vulnerable people. Such a methodology benefits the vulnerable in the community. Through being careful of the rights of vulnerable peoples (Tolich 2010: 1601), an autoethnography underpins what we see, believe and hold important. I have sound experience in practising research with vulnerable peoples in the Northern Territory of Australia. The methodology and tools used were approved by the Menzies School of Health Research Ethics Committee (reference number 09/20). The research
participants ranged from youth gang members, to students and to palliative care patients all living in remote areas in the Northern Territory. As part of having an emancipatory purpose, this autoethnography exposes the crisis of representation under the realms of (post)colonialism.

There are several further issues relevant to autoethnography and academic ethics. These include the essential issues of autoethnography’s apparent lesser place in academia. There is also the issue of autoethnography not having the academic respect that is offered to more traditional methodologies in the social sciences (Allen-Collinson & Hockey 2008; Wall 2016). Those who can be called traditional ethnographers, do not believe in the more poststructuralist autoethnographer’s social creation of reality. Furthermore, there is the issue of autoethnography being too artistic, emotional, personal and essentially unscientific. These more so non-academic qualities add to the worth and richness of the study as situated and based in the culture. Some discord and disparity between autoethnographers and traditional ethnographers is still rife.

And so, my autoethnography, being an intensely personal research piece, and being told solely through my own eyes and perception, does not require formal ethics approval from my university. The authority of note for my research is myself. I represent myself. I am my own authority. I have produced my own knowledge – as much as my socialisation and culturalization will let me. The most unethical thing I can do in this case is not tell my story; to not be emancipatory for myself and other peoples living with a major psychotic illness. There is not an institution that has authority over my autoethnography. I do not seek ethics approval from such an institution. I am most mindful about the ethical and moral responsibilities that working with vulnerable peoples entails, of course, because I am one. I also hold a “working with vulnerable peoples’
card” from my state of residence, in my country of Australia, granting government approval for me to work with the vulnerable. I am ethically ethical.

Autoethnography methods

Ellis (1999) suggests the following pointers when writing an autoethnography. First, start structuring your story with chronological events, then fill it out with memories. If memories are lacking, rely on your feelings. Use emotional recall. Emotional recall is embedded in sociological introspection, a process accomplished in dialogue with the self and represented in the form of narratives (Ellis 1991). Reflecting between chronology and feelings, the thoughts will come. You may start the dissertation with a short story and then build to be a large chapter. An explanation of each step in the flow of the autoethnography must be acknowledged and structured to eliminate unexplained conceptual leaps in the thesis and to describe the logical, accountable and sound allegation. The creation of autoethnography become ideas, self-reflective in nature. This internal reflectivity is essential in any autoethnography.

Another perspective of understanding autoethnography comes from Pinchon (2003), who outlines an understanding of autoethnographical analysis. First, themes and interpretations in a text are not interpreted in isolation but with reference to Other in the text. Second, these methods typically explore themes omitted or repressed and hidden behind other themes. Third, these methods often analyse the social and political context of text. To deconstruct or decode is to uncover these hidden messages and themes behind the obvious themes or upfront messages.
The autoethnographic method, the gaze, is used in medicine. It is important to consider and define the subject under investigation as thoroughly as possible, to limit the gaze of the researcher and the gaze of the medical officer (Foucault 1965). Describing the autoethnographic method, the autoethnographers’ gaze goes back and forth, first through an ethnographic wide-angle lens, focusing outwards on social and cultural aspects of their personal experience; then, they look inward, exposing a vulnerable self that is moved by and moved through, refracted and somewhat resistant cultural interpretations. As the autoethnographic gaze zooms backward and forward, inward and outward, distinctions between the personal and cultural become blurred sometimes, beyond distinct recognition. “If thou gaze long into an abyss, the abyss will also gaze into thee” (Nietzsche 1886).

Importantly is the tool of memory recollection, where the autoethnographer is reliant on memory to add substance and depth and richness to the story telling. Obviously, an autoethnographer cannot rely solely on memory, but memory cannot be negated. Memory work adds to the complexity of the autoethnography. It is a part of the intense and dense form of data collection that is innately mine. As such, memory is an essential tool in an autoethnography. As well as relying on memory, I am aided by texts such as my medical records. The result is a sound autoethnography, a textual encounter of the experienced culture, and an analysis of self and other in text.

*Autoethnography and rigour*
There are many ways of ensuring rigour in qualitative research. Liamputtong and Ezzy (2005) describe a number of these. The first, as mentioned above, is theoretical and conceptual rigour. A study has theoretical and conceptual rigour if the theory and concepts are appropriately chosen so that the research strategy is consistent with the research goals. The second is methodological and/or procedural rigour. This involves maintaining and reporting an audit trail of methodological and analytical decisions which have allowed us to assess the significance of the research. Third is interpretive rigour and interrater reliability where an account accurately represents the understandings of events and actions within the framework and world view of the people engaged in them. While postmodernists have argued that there are no final grounds for accepting interpretations as ‘accurate’, this does not mean that such interpretations are more valid than others or will equally be acceptable to participants in the study. Fourth, is the method of triangulation. And fifth and pivotal in regard in autoethnography is reflectivity, as mentioned previously but worth repeating. Reflectivity is essential as it is the auto ethnographic main gauge of interpretation. This list is not exhaustive but cements the rigour and is most relevant to this thesis.

Autoethnography, being such a new methodology at times needs to prove itself as a method. An autoethnography, done well, is a robust and rigorous qualitative method that uses text as an avenue of formal expression. The text brings together various data collated in various ways. These methods, the ones I use include participant observation, unobtrusive methods, case studies, and narratives. Analytical tools used in autoethnography include memory work, gaze, discourse analysis, and thematic analysis and content analysis (Grbich 2007: 146).
This eclectic relationship between a textualized experience of culture and a personified text is well appreciated through Foucauldian method and analyses. An important methodology for Foucault is historical analysis and situatedness. No social phenomena can be understood without an understanding of its philosophical and historical journey. History is used by Foucault as a conceptual tool which defines the progression of all meaning and representation of knowledge. History is used as a pivotal tool looking at preconceptions of power as a base for interpretation. Historical analysis, explores meaning and representation through history, including politics, economics, environment, culture. One of the main purposes of using history as a methodology is to concentrate on power dynamics and tracing and mapping ideologies and their development over time (Grbich 2007: 146).

It is extremely important to note that when undertaking any Foucauldian analysis, the data is collected, the analysis is undertaken, and the text that is written are not the only truth but a reflection of the political reality of the social and the self. These have been situated and developed over time. There is no one narrative truth but a multitude of narratives and a multitude of institutions which house and nurture these narratives.

Regarding validity, language is not transparent, and there is no single standard truth. Our work is verisimilitude (Ellis 1999: 674). Regarding reliability - since we always create our personal narrative and situated location, we try to ascertain our present and imagined future; there’s no such thing as orthodox reliability in autoethnographic research. (Ellis 1999: 674). Regarding generalisability - we share culture and institutions (Ellis 1999: 674).
Part of the validity of an autoethnography is dependent on the researcher’s motivation behind the research. The researcher needs to be completely honest in their writing and analysis. This is at the epicentre of the autoethnographic methodology. The connections made within the writing and within the analysis needs to be transparent so that the reader may clearly see the logical connections made (Ellis 2004).

Reliability refers to “the consistency or dependability of the instrument or measurement strategy” (Liamputtong & Ezzy 2005: 33-34). Regarding autoethnography, reliability is ascertained by self-reflective practices and data saturation, that is ensuring there are no questions left to be asked or doubts or gaps in the data collated. Theoretical rigour, as with data saturation, then follows. The rigorous methodology of this autoethnography aids in the study being more transparent, honest, accountable, legitimate, and ensuring responsibility and respectful attention to those being observed (Liamputtong & Ezzy 2005: 33-34).

**Reality**

My goal in life is to prove to myself that I am smart, or at least not stupid. For much of my living memory I have been mentally ill, and have in turn had competing, confusing, baffling and bewildering ‘voices’ in my head. Again, I prefer to call them ‘noises’. I think that this term takes away the agency and power that the ‘voices’ try to claim. With these noises, I have limited capacity to decipher rival knowledge. I cannot trust the version of reality my mind gives me. Yet, I want to trust and feel that my thoughts and perceptions are valid and true. I want to be able to not always second guess myself. I don’t like feeling that I annoy people by my constant
need for reassurance and validation. With psychosis, I hear things that (I hope) are not true. I am constantly in a state of distrust and confusion about the version of truth in my head, my version of reality.

It seems ironic to try and describe the labelling of schizoaffective disorder when I hate to be labelled. I hate that my day-to-day experiences are scrutinised enough by the medical profession, so they know what perspectives of mine need to be mediated and medicated; to define what of my realities are objective realities.

A good autoethnography unpacks the observable fact and experience of the construction of reality. When examining questions about reality, I cannot escape nor negate the probability that I could just be making this argument up. After all, reality is relative (Hacking 1999).

When examining rigour and validity within autoethnography the questions can be asked: Does the instrument measure what the evaluator purports to measure? or Does the measurement strategy yield data that accurately represents reality? I have not come across any research which does not want to define its subject, even if it is to define what it is not. Some sort of comparison, or could it be called ‘measurement’ is involved, even in the most minute way. Similarly, even when arguing that one ‘reality’ doesn’t exist, it is still acknowledged as theoretically existing, even if only in a dichotomous relationship. I would probably add a slight twist to the analysis, by noting what hermeneutic realists argue, that there is a real world and our experiences of it are always and already interpreted (Ezzy 1998). An autoethnography fundamentally depicts the
world as it is experienced and interpreted through the observer’s senses. This is a real world and our experiences of it are always and already interpreted (Ezzy 1998).

There is no ‘standard’ methodological formula when conducting autoethnographic research (Moore 2012: 201). Through telling our stories, we make and remake ourselves. We validate our identities. We give meaning to our suffering. Our stories shape and structure our experience rather than simply presenting them to a reader. They tell others who we are, but they also tell us how they can and do make us who we are (Richards 2008: 1722). Sociological introspection through autoethnography allows me to study my lived experiences not just as an internal state but also as an affective process which I recognise internally and construct externally (Ellis 1999). By exploring social theory with the methodology of autoethnography, I will analyse my lived experience of being labelled as disabled with a major psychotic illness. This work may bring light to the complexities and dynamics of the lived experience of the sub-human.

According to poststructuralist and postmodernist understandings, one must either reject the idea of rigour or reconceptualise it involving the demonstration of the absence of a clear relationship between ‘reality’ and the study’s findings (Lather 1993 in Liamputting & Ezzy 2005: 36). Here there is the issue of a politically infused nature of all interpretation (Denzin 1997). To expand, rigour may also be reconceptualised as a moral and ethical task focused on emancipation and political action, particularly when postmodernism/poststructuralism are combined with critical theorists (Denzin & Giardina 2007; Le Roux 2017). Poststructuralist authors fundamentally challenge the epistemology, ontology and methods of traditional research. This is done in part via analysis of the power dynamics of historical situating (Steinberg 2011; Ellis 2004).
According to poststructuralist understandings there is no independent knowable phenomenal reality. All knowledge is based on *a priori* assumptions and interpretations that do not just confine what is seen but also define what is seen. Tyler (1986 in Lincoln & Ellis 2011: 36), for example, argues for an autoethnography to create its own objects in its unfolding, and the reader supplies the rest. Hammersley (1992 in Lincoln & Ellis 2011: 36) suggests, we form a relativism where all accounts are equal. Similar from poststructuralism, social power play is rife, which brings to light the nuances of the social in practice and the social in theory if there is an actual difference between the two.

Foucault was particularly interested in the socio-cultural dynamics of the underdog. These subcultures included prisoners, homosexuals and the mentally ill. Foucault was particularly interested in studying the ways in which power has been developed and exercised through the control of knowledge. In creating and maintaining discourses powerful interests obscured the voices, protests or challenges put up by others with an interest in a piece of knowledge. Foucault exposed the way the State had created the powerful discourses, for example of ‘madness’, and how through sovereignty and disciplinary power these ideas had filtered down to the (largely unresisting) population and had become the basis of their understandings and explanations (Grbich 2007: 147).

Amongst all of Foucault’s research is the common thread of an exploration and analysis of power. Power is the meaning of what we do, how we keep doing it, and why. In this case can power be a methodology and/or tool of analysis? And how is power enabled, valued and measured, if that
is at all possible? Power manifests itself in many and extreme ways in the social worlds. Foucault not only studied institutions like the prison, factory, hospital and school, but also strategies of power which embody themselves and adapt in relation to the institutions they are engulfed and acculturated by. This power is not exercised simply as an obligation or a prohibition on those who ‘do not have it’. It invests in them, is transmitted by them and through them. It places pressure upon them, and they resist the grip it has on them (Horrocks & Jevtic 2004: 112).

No power is exercised without extraction, appropriation, distribution or retention of knowledge (Foucault 1965 in Porter 1990; 1982).

“The genesis of the manufacturing of truth is also the genesis of the knowledge of truth”

Foucault (1973)
**Reality – medical realism**

Derrida (2001) argues that we must consider the meta-narrative. The meta-narrative in this case is medical science with its associated political and cultural foundations. The doctors and other health professionals are the powerful Us and the mentally ill are the Other. The two are hierarchised with the medical practitioners having power over the mentally ill deviant.

My own construction of reality, and my experience of it in my own social world, is a constant source of perplexity for me. How can I trust my senses? How can I trust the workings of my mind? Do I trust those around me? Can I trust my closest friends and family? Without any trust, how do I judge what is real and what is not? I do it many times every day. I ask my family and friends and my partner: Is that real? Did I understand correctly what that person just said to me? What about the construction of madness? And what about the construction of institutions of madness, including psychiatric wards? How does madness function as a socio-cultural phenomenon? How is madness a construct of reality and social phenomena? (Foucault 1961; Douglas 1992).

Reality can be defined in many ways. For example, there is reality as defined by our senses, and reality as defined by our thinking: empiricism versus rationalism (Markie 2017). Then again, how does a philosophical perception of reality differ from an individual perspective of reality (Mead 1927; Hurrelmann 1988)? As an anthropologist, I am consumed by the cultural and social construction of reality. Neither can I separate reality from other cultural/social phenomena like politics, economics and, spirituality. Then there is my perspective of reality in my crazy head.
How is reality constructed, albeit socially constructed, by someone with a psychotic illness that fundamentally skews all perceptions of reality? Is psychosis a social construction or a biological construction? Or perhaps psychosis is a social and biological construction? Is it a biological construction in the sense that the hallucinations and delusions experienced as part of psychosis are somewhat alleviated with medical therapy? Then again psychosis is also a social construction in the sense that its ramifications and true meaning are very much defined in social phenomena (Cooke 2017). If psychosis was not the stigma as it is, those suffering from this mental illness may not be so ostracised, demoralised and stereotyped as subhuman, sub-citizens and social denigrates.

**Social theories**

The social theories considered to be most relevant to this discussion are structural-functionalism, Marxism, postmodernism, poststructuralism and critical theory including feminism, queer theory and (post)colonialism. The most significant theories discussed here are critical theory and (post)colonialism. Foucault’s perspective is also very important. (For an expansion of Marxism and its relevance to this discussion please see glossary.)

These theories best define the role of the mentally ill and deconstruct their role and their position in the historical and social construction of reality. “Social rituals create a reality which would be nothing without them. It is not too much to say that ritual is more to society than words are to
thought” (Douglas 1966). These theories stand out because it has been my experience of having a mental illness, especially a major psychotic illness without concrete known and measurable boundaries.

The phenomena of mental illness and mental health service delivery seem to perform a certain function in the structured Australian society. Douglas (1966) argued that societal order encompasses and contains mental health wants to keep a close reign on something that is potentially harmful to its otherwise clean functioning. By ‘clean’ I mean that society generally wants the mentally ill to be invisible and silenced. I would also argue that the mentally ill and mental health service delivery play a role in the societal order and are expected to function in accordance. Parsons, a structural-functionalist, talks about the functional theory of stratification, and the idea that hierarchical class systems and orders are necessary for society to function. Inequality is expected to keep society progressing by motivating individuals to live a full life (Douglas 1992).

The structural-functionalist position argues somewhat that society is an organism where society is held together by its culture, that is commonly held belief and values (Durkheim in *The Sociology Book* 2015 p. 34-7). Culture, as a common group of individuals, maintains and supports the structure of a society (*Culture and Society* n.d.). According to Durkheim (in *The Sociology Book* 2015 p. 34-7), in simple terms, everyone has a role to play or a function to perform, and they perform it to support the structure of their society, hence the name ‘structural-functionalism’ (or perhaps an extrapolation to “structuralism”). Once a society adapts, has goals and gets its members to act within these, as per Weber’s idea of ‘goals’, (in *The Sociology Book*
Foucault has given great insight into the concept of stigma and power play (1965). Any undertaking of Foucauldian analysis, as with most poststructuralist theory, includes data collection, analysis, and the text that is written. This is not the only truth but a reflection of the political reality of the social and the self. These have been situated and developed over time. There is no one narrative truth but a multitude of narratives and a multitude of institutions which house and nurture these narratives. As Foucault has described, by studying a major psychotic disorder from an etic and emic perspective, the two views could possibly be incommensurable. Speaking from my own perspective, someone living with a major psychotic disorder, the realities between medical science and the person experiencing the disorder are often unmeasurable, undefinable and incommensurable.

The use of clinical language is one way that medical professionals alienate and ascertain power over the ill. Other disciplines dominate in their own way with language. Language is an avenue through which cultural difference and values are perpetuated. Language draws connections between the powerful and the powerless. Ultimately it is a form of communication, but it is also a template and mandate of who has power. The powerful, such as medical professionals, ultimately have control over the symbols of communication in biomedicine and the sense of power that comes with knowledge. As Foucault (1967) states, knowledge is power. For medical
professionals, their control of biomedical knowledge makes them supreme in the social hierarchy (Lindenbaum & Lock 1993).

As per critical theory, I abide by the belief that there is no single truth, no knowledge absolute or independent, and all knowledge is socially constructed. Everything underlying Foucauldian understanding and analysis is the subject and object of power: power in beliefs and values, power and social order, macro and micro social order, power in symbolism and language and power in economics and politics. How do we gauge this complex phenomenon of power? Foucault argued that the real political task in a society such as ours is to criticise the workings of institutions that appear to be both neutral and independent, to criticise and attack them in such a manner that the political violence that has always exercised itself obscurely through them will be unmasked, so that one can fight against them (Taylor 1984; Foucault 1982).

In Foucault’s book, *Madness and Civilisation* (1967), he discussed the way that our identities are historically produced. In the Middles Ages, the mentally ill were part of public life. In the eighteenth century, the mentally ill were classed as abnormal and removed from society. Then in the twentieth century, the mentally ill became medicalised, pathologised and subservient to medical science. The terms of what have defined mental illness and its association with deviancy could have changed, yet the prejudice and the stigma remain.

In modern times, according to Foucault, the mentally ill are subject to more measuring and surveillance and judgement as is relative to the recent legacy of medical science. Today’s mental health institutions and hospitals are all about measuring and judging and surveillance. The
mental health assessment tools and medical observations, cultural artefacts of modern psychiatry, are all about measuring and judging deviance. The mentally ill are not empowered by their institutionalisation into psychiatric wards, rather their function in society is to provide an Other to define in opposition to the Us. In the same way, the deviant and subhuman Other has a role in society as the underling. The Other is defined in opposition of the powerful Us (Said 1978).

Foucault spoke about the ’genealogy of subjectivity’ where we think we are free agents in our society but are defined by our historical development over time. This historical definition process is covert. It has meant that over time power negotiations between the Other and Us on all levels and facets, have become embedded in the social fabric and cultural values of the importance of science. Over the last few centuries, the pillar of science has been naturalised (Foucault 1963), that is science as supreme was considered an assumption before any other knowledge or perspective. Scientific fact is an a priori assumption. This version of reality is the version of reality. All analyses come after this fact.

Postmodernism is essentially a movement that is anti-modern. Modernism, born from the Enlightenment, bequeathed its supremacy to the new deities of science, technology, measurement, democracy, industrialism and capitalism. Religion and the autocratic State no longer ruled supreme. Postmodernism began the path of query and questioned the sanctity and presumptive reign of medical science of years earlier, and then introduced the notion of cultural relativism and subjectivity to psychiatry (Porter 2002).
Another analytical tool used in critical theory is the perspective of Marxism. Utilising Marxism, the role of the mentally ill is defined in the economic order, as one of a non-contributor. Foucault (1967) used the comparison of a mental health inpatient and a prisoner. The prisoner spends his/her days making number plates, whereas the mentally ill inpatient does not participate in any modes of production. If anything, the sick sapped resources from the economy.

Conclusion

In the last 50 years or so, there has been a paradoxical shift – a decentring involving the authority, autonomy, stability of institutions, subjectivities and texts. Out of this shift has emerged an emphasis on the personal narrative as fluid, emotionally and intellectually charged (Miller 1995: 49 in Denzin and Lincoln 2011: 773). The overarching construct of this shift, giving meaning and purpose, was the culture of society.

It is vitally important to consider the position of the individual in culture. Power dynamics function and outline the negotiation and method of interaction between citizens. And the function of the self is the mobile unit or pawn in the game. The self is a social construct - as are all phenomena in society.

The autoethnographical singular sample size enriches the study and analysis by depicting a different and alternative viewpoint – amplifying the whisper of the disabled. The individual subject is used to illustrate, emancipate and rebuild the broader meta-cultural phenomena.
In these autoethnographic texts, including discourse, dialogue, emotion, embodiment, spirituality and self-consciousness are all featured, appearing as rational and institutional stories impacted by science and social structure. Indeed, there is the social construction of phenomena like emotion. These are dialectically revealed through actions, feelings, thoughts and language (Ellis 1999: 673; Ellis & Bochner 2000; Kirmayer 1989). Jones (2005 in Richards 2008: 1725) notes the liminal nature of autoethnographic writing, describing it as being “between story and context, writer and reader, and prices and denouncement”. She also points to “the power of the in between”, of occupying the space between theory and practice, analysis and action.

The social world is structured, at times covertly, by our means of understanding and communicating in the world, which is through the prism of language. Narratives and discourses, directed by language, control us but we are not overtly aware as we are so engulfed in them - we are blinded by this power play. There exist differences between the Other and the Us, and these differences are reflected in the roles that the Other and Us have in the social order. The Other, in this case are the mentally ill, the lesser humans, the deviants, the misfits.

My experience of living with schizoaffective disorder has included repeated negotiating and struggling with multiple intersubjectivities of power play both within myself and outside in the broader societal contexts, determining multiple truths and multiple realities. As well, I am constantly in a state of cultural exasperation and epistemological and existential influx. My position is grounded in critical theories, specifically (post)colonialism. However, I am also
influenced by structural-functionalism, Marxism, postmodernism, and poststructuralism – in order of influence.

There are many blocks of time over the last twenty years that are a loss to me. I have some periods of my life, years and years, of being unwell where I remember only snippets. I have been lucky enough to have journals, letters, medical notes, personal accounts from friends and family, and my own emotions that have helped greatly with my recall. The whole process is rather humiliating, and damaging.

In this chapter, I have discussed methods and methodologies that I am using as part of writing this autoethnography. Through writing this autoethnography, I will explore and delve into the culture of my lived experience of what it is like to survive living with a major psychotic illness, as well as the experience of hospitalisation in three different psychiatric wards. For me, autoethnography allows for the most honest way of describing the most complex phenomena. Autoethnography produces not only academic texts, but in depth, rich and thick accounts (Geertz 1973), depicting many facets of the human experience, including emotional, intellectual, spiritual, psychological and existential. The depth of experience, through an absolute engagement and commitment with the culture of the mentally ill, adds to the unique position of a ‘real’ knowing of the social phenomena, best deciphered here via the individual perspective. The individual becomes the social and the social becomes the individual.
CHAPTER THREE

HISTORY OF MADNESS

“People tend to say, ‘I like independent thinkers, but they must think what I want them to think independently’”

Rassool Jibraeel Snyman (2017)

“Maybe the target nowadays is not to discover what we are but to refuse what we are.”

(Foucault 1982)

Throughout history, the mentally ill have been deemed as lacking. They are viewed as not fully human, not full citizens. They are most often deemed as social misfits. They are people who do not belong and are unwanted. This disdain is precipitated and justified by various policies of social control, policies developed by governments, in the name of managing ‘anti-social behaviour and those classed as ‘stigmatised’. Throughout history similar treatment has been assigned to women, homosexuals, indigenous peoples and marginalised historical and falsely accused groups such as witches. Not seen as fully human or full citizens, some were hunted, imprisoned and some were killed like annoyances. Others were rounded up and put in concentration camps, reserves or institutions like creatures to be broken and branded and put to work (Smith 1999: 28). The mentally ill are stigmatised as forms of outcasts. As well as the
goals of scientific measurement and healing, psychiatry plays a social role, again in classification, of a type of social class, a class that is defined as lacking.

It is imperative that I situate an analysis of subhumans/sub-citizens/social misfits, and the culture/s that perpetuate such labelling through my autoethnographic lens (Ellis 2004: 2014). The discourse below will explain the history of madness and why ‘social misfits’ are defined as such. To help in the understanding of madness and its social foundations, Foucault’s focus on history is paramount.

A critique of Western history argues that history is a modernist project which has developed alongside imperial beliefs about the Other (Said 1978; Smith 1999). The idea is that history is a self-actualising human subject. In this view, humans have the potential to reach a stage in their development where they can be in total control of their faculties. Have the mentally ill the potential to self-actualise considering their history and socialisation into the modern society, especially considering the self-actualisation achieved stemming from labelling theory (Smith 1999: 31-32)? How can those living with a major psychotic disorder be empowered when historically they have been starved of power?

History is fundamental to power. In fact, like culture, history is fundamentally about power. It is the story of the powerful and how they became powerful. And then, how they use their power to keep and entrench supremacy and continue to dominate. It is because of this relationship between history and power that the subhumans/sub-citizens/social misfits have been excluded, marginalised and Othered. In this sense history is not important for the mentally ill because a
thousand accounts of the truth will not alter the fact that the mentally ill are still marginalised and do not possess the power to transform history into justice (Smith 1999: 35). Power is not a thing but a relation. It is something enacted rather than possessed (McHoul, McHoul & Grace 2015).

A history of madness, or more precisely, a history of evidence of treating madness suggests treatment began around 5000 BC. Archaeologists have unearthed skulls which have been trephined or trepanned; small round holes have been bored in them with flint tools. The subject was probably thought to be possessed by devils which the holes would allow to escape (Joseph 2015).

Madness has been used as fate or punishment in early religious myths and heroic fables. There have also been many references to madness in the Old Testament of the Bible, such as stories of possession by devils, and how the Lord punished Nebuchadnezzar by reducing him to bestial madness (Szasz 1970). In Deuteronomy (6:5) it is written, “The Lord will smite thee with madness.”

Early civilisation, in Ancient Greece, saw madness as supernaturally inflicted. The philosophers who emerged in the Greek speaking city-states from the sixth century BC onward viewed the cosmos and the human condition naturalistically. Socrates (470-399 BC) notoriously slighted the gods and, with his pupil Plato (428-348 BC), analysed the psyche’s constituents: reason, spirit, the passions, and the soul. In due course Aristotle (384-322 BC), Plato’s pupil, defined man as a rational animal, within the system of nature (Szasz 1970).
“From a Christian point of view, human reason is madness compared to the reason of God, but divine reason appears as madness to human reason”

Foucault (1964)

Before Christ, the concept of madness focused on a back and forth, however bloody, between faith and religion. Then, after Christ, Christianity gained strength and credence as social currency and the vernacular when the Emperor Constantine recognised Christianity in the Roman Empire in 313 AD. Knowledge was decreed acceptable if the governing body declared it as such. Unlike Greek philosophy, Christianity denied that reason was the essence of man: what counted were sin, divine will, love and a believer’s faith (Massey & Denton 1985).

The rise of the institutions

By the 11th century, leprosy became epidemic in England. Those suffering from leprosy became the deviants of magic and witchery. Some people believed it was a punishment for sin, but others saw the suffering of lepers as like the suffering of Christ. As lepers were enduring purgatory on earth, they would go directly to heaven when they died, and were therefore closer to God than other people. Those who cared for them or made charitable donations believed that such good works would reduce their own time in purgatory and accelerate their journey to heaven (Brown et al 2008)
The outbreak of leprosy didn’t develop and heighten until the Middle Ages (500-1500). Yet, the official disease of leprosy was not scientifically identified until 1874 and the cause for the disease was not proven until the 1960s. It is difficult to diagnose even today, therefore there must have been much confusion surrounding the disease during the Middle Ages. Those diagnosed and labelled with leprosy did not necessarily exhibit any of the common symptoms. The classification ‘leper’ was given to many social deviants (Moore 1994). In the fourteenth century, after the last of the lepers exited the last of the institutions (Arnold 2008), political sway stepped in and the institutions became safe places where the mad could be hidden. The subhumans/sub-citizens/social misfits became an identity to themselves; they were labelled; this was the new stigma.

In London the religious house of St Mary of Bethlehem (founded in 1247 and lastingly known as ‘Bedlam’) was catering for lunatics from the late fourteenth century (Arnold 2008). Other cities in Europe soon followed suit and provided institutions for their mad. These were mostly charitable and religious based asylums. They were staffed by nuns and brothers. These institutions lodged the mad right up in to the twentieth century (de Young 2010). Since Bedlam was open to visitors, the sane and the mad were brought tantalisingly face-to-face: who could tell the difference? For its many critics, the fact that Bedlam allowed itself to be included among the ‘shows of London’, like the menagerie in the Tower, was central to its scandal. Having the Other on display in a human zoo or freak show courted shameless voyeurism (Lawrence 2018).
Foucault famously argued in the 1960s that the rise of Absolutism (1550-1800), typified by Louis XIV in France, inaugurated a Europe-wide ‘Great Confinement’ of the mad and poor, a movement of ‘blind repression’. Scandalous by law and order all those ne’er-do-wells tainted by ‘unreason’ became targets for appropriation in a vast street-sweeping operation. Paupers, petty criminals, layabouts, streetwalkers, vagabonds and beggars formed thebulk of this monstrous army of the unreasonable, but symbolically their leads were the insane and the idiotic (Foucault 1961). This demonising process may be regarded as psychologically and anthropologically driven and from the deep-seated and perhaps unconscious need to order the world. Demarcating the self from the Other (not the Us and the Other), we polarised distinctions. For example, black and white, sane and insane (Szasz 1970). The culture of madness ‘reality’ and ‘representations’ endlessly played off each other (Porter 2002: 64).

This ‘Great Confinement’, argued Foucault (1961), amounted to more than physical sequestration. It also represented the debasement of madness itself. Hitherto, the mad had
exercised a force and fascination, be it as a holy fool, witch, or a man possessed. Half-wits and zanies had enjoyed the licence of free speech and the privilege of mocking their betters. Institutionalisation however, maintained Foucault, robbed madness of all such empowering features and reduced it to mere negation, an absence of humanity. Small wonder, he concluded, that madhouse inmates were likened to and treated as wild beasts in a cage: denied reason, that quintessential human attribute. What were they but brutes? (Foucault 1961).

Foucault (1961) claimed that the Great Confinement essentially involved the requisitioning of the poor. There is little trace of organised labour in early asylums – indeed, critics accused them of being dens of idleness. Enterprising madhouse proprietors naturally sought rich and genteel patients, who would not be expected to work.

The time of the persecution of witches is a significant time for the history of madness. Madness noted within the Catholic Church was treated by institutionalism, spiritual means, or burnings at the stake for witches. Spiritual means included the performance of masses, exorcism, pilgrimages, and/or worshipping to a shrine. From the late 1400s, peaking around 1650, madness was associated with magic and witchery. The witch craze gathered momentum across Europe. It was believed that the witches were possessed and had compacted with the Devil. The craze of hunting for heretics, namely hunting for witches, led to the execution of 40,000 to 60,000 of the so-called heretics, which were mainly women (Szasz 1970).

The conflagration of heresy-accusations and burnings stoked by the Reformation (beginning with Luther in 1517) then Counter-Reformation (ending by the Thirty Years War 1618-1648), and the
Civil Wars in Britain (1642-1651) stirred strong reactions against religico-political extremism, condemned as ruinous to public order and personal safety alike. After 1650, elites washed their hands off witchcraft: now it was not a Satanic plot but individual sickness or collective hysteria. Eighteenth century magistrates similarly deemed converts who shrieked and swooned in a response to a belief in the supernatural. This was turned into a matter of psychopathology (Szasz 1970).

In due course this Lockean thinking, so highly esteemed in the Enlightenment, formed the basis of the new secular and psychological approaches to understanding insanity. Amongst seventeenth-century philosophers madness was increasingly identified not with demons, humours, or even passions, but with irrationality. Irrationality is associated with madness, whereas rationality is associated with sanity (Szasz 1970). Thus, did Rene Descartes’ (1594-1650) decree, “I think therefore I am”.

Following Locke and Descartes, madness was seen to be not only about irrationality. All societies judge some of their own as mad (any strict clinical justification aside). This is part of the business of marking out the different, deviant, and perhaps dangerous. Such ‘stigma’, according to the American sociologist Erving Goffman (1961), is the situation of the individual who is disqualified from the full social acceptance. Stigmatising – the creation of spoiled identity – involves projecting into an individual of group judgements as to what is inferior, repugnant or disgraceful.
Medicalisation

The sensibilities of the Enlightenment (1685-1815) brought about the medicalisation of insanity and the move to lock up mad people (Foucault 1961; Goffman 1961). To support this political and intellectual movement, John Locke wrote and insisted upon *The Reasonableness of Christianity* (1694 in Nuovo 2012). Even religion had to be rational. The new scapegoats included beggars, criminals and vagrants. This pathologisation of ‘religious madness’ led Enlightenment free-thinkers to pathologise religiosity at large. As it were, the subject of power was now in the realms of the universities not the churches. Religion had become rationalised and made part of medical science – pathologised.

Except in France, the seventeenth century did not bring with it any spectacular surge in institutionalisation – and it certainly did not become the automatic solution. Different nations and jurisdictions acted dissimilarly. Indeed, madness engulfed in its stigma had become a sort of entertainment. Jokes about the mad monarchs came home to roost remarkably rapidly: George III’s delirious descent in 1788 provided a golden opportunity for satirists and cartoonists. It was fashionable to be struck with melancholy or hysteria, mostly afflicted to women. (Tasca et al 2012; Malcalpine & Hunter 1968) There was now a glamorisation of the gloomy genius. The movement for female emancipation was gathering momentum from the mid nineteenth century. Women were moving against a domination of cultural stereotyping of mental disorder. For example, hysterics and young working-class women, far from being objective phenomena ripe for scientific investigation, were instead being viewed as cultural artefacts justifying for female subjugation (Lawrence 2018).
Absolutist France indeed centralised its responses to ‘unreason’ (Foucault 1961; Goffman 1961). In England around 1800, the confined mad were largely housed in private asylums, operating for profit within the market economy in what was frankly termed the ‘trade in lunacy’ (Szasz 1970). In England, not until 1808 was an Act of Parliament passed even permitting the use of public funds for asylums. Not until 1845, and against those who denounced it as a waste of money or an infringement of freedom, was the provision of such county asylums made mandatory (Porter 2002: 94). In urbanised Europe, and in Northern America, the rise of the asylum is better seen not as an act of State but as a side effect of commercial and professional society. Growing surplus wealth encouraged the affluent to buy services – cultural, educational, medical – which once had been provided at home.

The early history of such private asylums is obscure, for they prized secrecy: families would wish to avoid publicity, and only from 1774 were they required even to be legally licensed in England. Such receptacles go back, however, to the seventeenth century (Szasz 1970; Goffman 1961). Early asylums came in all shapes and sizes, some well run, and others atrociously run. In no country before 1800 was medical supervision a legal requirement, nor did medical overlordship automatically ensure good care (Goffman 1961).

*The science of asylum management*

Philippe Pinel (1745-1826) embraced the progressive thinking of the Enlightenment. He is credited as being the first in Europe to introduce more humane methods into the treatment of the
mentally ill. The term used to describe an ethical way to treat patients in mental institutions was coined ‘moral treatment’ or ‘moral therapy’. Pinel is credited with helping new ways of treatment including talking with each individual patient. Physical restraints were at best an irrelevance, at worst a lazy impediment and a lazy expedient and an irritant. For Pinel, treatment must penetrate to the psyche. Pinel instigated the argument that if insanity was a mental disorder, it had to be relieved through mental approaches (Bynum 2012).

William Tuke (1732-1822) was born into a leading Quaker family. Like Pinel, with a vision for the treatment and care of the mentally ill, ahead of his time, he had thoughts of moral treatment. Tuke established the Retreat in 1796 based on the concept of ‘moral therapy’, like Pinel. Tuke’s version was modelled on the ideal of the bourgeois family life, and restraint was minimised. Moral therapy, incorporated by Tuke, was a therapeutic and preventive philosophy for managing mental disorders. Treatment consisted of removing the afflicted from their homes and placing them in a surrogate ‘family’ of 250 members or less, often under the guidance of a physician. It emphasised religious morals, benevolence and clean living, in contrast to the somatic therapies of the day (such as bloodletting or purging) (Bynum 2012).

William Tuke modelled care with the idea that the mentally ill were equal human beings and they were to be treated with gentleness, humanity and respect. Physical restraints were removed from the patients, they were accorded humane and kindly care and were required to perform useful tasks in the hospital (Bowrey & Smark 2010). Patients and staff lived, worked and dined together in an environment where recovery was encouraged through praise and blame, rewards and punishment, the goal being the restoration of self-control (Porter 2002: 104). Ideas such as Tuke’s and Pinel’s were ground-breaking and the Retreat focused on healing of the mentally ill. Tuke’s ideas were like those of Pinel’s.
Everywhere, the care and the cure of the mad became the subjects of the new ‘science’ of asylum management. Alexandra Crichton (1798) argued that psychiatry should be based on the philosophy of the mind. The close of the eighteenth century brought a remarkable marriage across enlightened Europe between new psychological and reformist practice in what has been called ‘moral therapy’, as per Pinel and Tuke (Bynum 2012). In all the advanced nations, psychiatry gained a public face (if with little prestige and much distrust) after 1800 and psychiatrists found public employment in universities, especially in Germany, and in asylums. Psychiatry became a profession around the mid-century, when medical superintendents (‘alienists’) banded together to form specialised organisations (Harper 1997).

As mentioned by Foucault (1961; 1963), State organised receptacles for the insane hardly appeared at all before 1850, those who were confined were generally kept in monasteries, and across great swathes of Europe, few were psychologically institutionalised. Two lunatic asylums still sufficed for the whole of Portugal at the close of the nineteenth century, holding no more than about 600 inmates (Birmingham 2018).

The asylum solution should be viewed less in terms of central policy than as the site of a myriad of negotiations of wants, rights, and responsibilities. These considerations should be assessed between diverse parties in a mixed consumer economy with a burgeoning service sector (Porter 2002: 98). St Luke’s Asylum and owner of a private asylum, Battie, conceded in the 1750s that a fraction of the insane did indeed suffer from ‘original insanity’, which, like original sin, was
incurable. Yet far more common was ‘consequential insanity’ – that is insanity resulting from events – for which the prognosis was favourable (Szasz 1970).

The links between the Industrial Revolution (approximately 1760-1840), the Protestant Ethic (1905), Imperialism (1870-1914) and the ongoing history of science can be discussed in terms of time and the organisation of social life. Changes in the mode of production brought about by the Industrial Revolution meant there was an emerging middle class able to generate wealth and make distinctions in their lives. However, the subhuman/sub-citizen/social misfit class remained without a productive and positive role in the economy, that is, they did not own or control any of the modes of production that affect their lives. They will be forever in servitude to the middle class (Smith 1999: 56).

**Nineteenth century and the rise of the psychiatrist**

Throughout Europe, it was the nineteenth century which brought a skyrocketing in the number and scale of mental hospitals. In England, patient numbers climbed from 10,000 in 1800 to ten times that number in 1900. The jump in numbers was especially marked in new nation States. In Italy, no more than 8,000 had been confined as late as 1881; by 1907 that number had soared to 40,000 (Porter 1999).

Such increases are not hard to explain. Positivistic, bureaucratic, utilitarianism and professional mentalities vested great faith in institutional solutions in general – indeed quite literally in bricks
and mortar. Schools, workhouses, prisons, hospitals, and asylums – would these not contain and solve the social problems spawned by demographic change, urbanisation, and industrialisation? As well, perhaps the increase resulted from more people identifying as mentally ill (SANE Australia 2013)

In the late nineteenth century, many psychiatrists were now engaged in a career which was developing as a socially ‘well-to-do’ path, and as well, were now establishing their discipline as a truly scientific enterprise. Psychiatry could now take its rightful place in the pantheon of the ‘hard’ biomedical sciences, alongside neurology and pathology. As well as being utterly distinct from such ‘quackish’ and ‘fringy’ embarrassments as mesmerism and spiritualism (Nobel 1992). Providing psychiatry with a sound scientific basis was particularly important at that time, because of its strong positivistic and Darwinian leanings (Foucault 1961; 1973). The rigid segregation of the sane from the mad which the asylum had implemented no longer seemed to make epidemiological sense.

Following and developing from the nineteenth century, for some, the twentieth century brought Freud’s (1856-1939) revelation of the true dynamics of the psyche. For others, psychoanalysis proved a sterile interlude. Still, psychiatry had developed with a neurophysiological and neurochemical understanding - the brain was finally more understood and advanced and bore fruit from effective medications (Holt 1989). According to Szasz (1970), psycho-pharmaceutical developments certainly allowed psychiatry itself to function better, but pacifying patients with drugs hardly seemed the pinnacle of achievement and any claims as to the maturity of a science of mental disorders seemed premature and contestable. Meantime, mainstream academic and
hospital psychiatry remained committed to the program of describing and taxonomizing the mental health disorders stemming from Kraepelin (who is claimed to be the founder of modern scientific psychiatry).

“[Yet] the original or primary cause of madness is a mystery”

William Pargeter (1792)

**Madness in the twentieth century**

Moving to the twentieth century, a politics of psychiatry was emerging in which it could soon be decided that the very lives of the mentally ill were ‘not worth living’. In the 1930s Nazi led psychiatry deemed ‘schizophrenics’ as similar in class to Jews, ripe for elimination. Between January 1940 and September 1942, in what might be a trial run for the ‘final solution’, 70,723 mental patients were gassed (Strous 2007).

Modern psychiatry, from the mid twentieth century, emerged from the conclusion that the greatest proportion of mental disorders were to be found not in the asylum, but in the community at large (Goffman 1961). Thomas Szasz (1970) pioneered the ‘anti-psychiatry movement’, which won high acclaim in the 1960s and 1970s. Mental illness was not an objective, behavioural or biomedical reality or a negative label of a strategy coping in a mad world. Madness had a truth of its own. Mental health had a truth of its own. Mental health was now used in law courts.
In 1843, Daniel M’Naghten was found to be not guilty on the grounds of insanity after murdering the Prime Minister’s private secretary (Porter 2002: 154-5).

Psychosis could be a healing process and should not be pharmacologically suppressed. Mainly associated with left-wing politics, anti-psychiatry thus urged de-institutionalisation. At the same time, and from a wholly different angle, politicians of the radical right, included Ronald Reagan in the USA and Margaret Thatcher in the UK, lent their support to ‘community care’ (Szasz 1970).

Mental health had become labelled and socialised in the community, albeit negatively. It had become part of the language, the culture. It was more than a biomedical group of facts. The term ‘mental health’ had become part of the vernacular at about the same time the term ‘schizophrenia’ was introduced by Paul Eugen Bleuler in 1908 (Fusar-Poli & Politi 2008).

To paraphrase Porter (2002: 206), those whose lives were worth living lived long enough to benefit from the upsurge of new psychoactive drugs. The new drugs enjoyed phenomenal success. In the 1960s, the tranquiliser Valium (diazepam) became the world’s most widely used medication. In the 1970s, one American woman in five was using minor tranquillisers. By 1980, American physicians were writing ten million prescriptions a year for antidepressants alone. Introduced in 1987, Prozac, which raises serotonin levels and thus enhances a ‘feel good’ sense of security and assertiveness was being prescribed almost ad lib for depression. Within five years, eight million had taken this ‘designer’ antidepressant, said to make people feel ‘better than well’. “With the immense success of the anti-psychotic, anti-manic, and anti-depressant drugs
introduced in the last half of the twentieth century, organic psychiatry is arguably in danger of becoming drug driven. By permitting treatment of the mentally disturbed on an outpatient basis, psycho-active drugs have substantially reduced the numbers of those institutionalised” (Oxford University Press 2012).

“Maybe the target nowadays is not to discover what we are, but to refuse what we are.”

(Foucault 1982)

Australian experience of madness

As per The Black Dog Institute (c. 2018), an Australian advocacy organisation supporting mental health, mental illness is very common in Australia. One in five (20%) Australians aged
16-85 experience a mental illness in any year. The most common mental illnesses are depression, anxiety and substance use disorders. Schizoaffective disorder is rarer.

For some statistical background, in this instance, regarding suicide. The Australian Bureau of Statistics (2016) showed a total of 3,027 deaths by suicide (12.7 per 100,000), equating to an average of 8.3 deaths by suicide in Australia each day. Of this total, 2,292 were males (19.4 per 100,000) and 735 females (6.2 per 100,000).

Considering young people, all causes of death, suicide accounted for 28.6% of deaths among 15-19-year-old males, and 37.9% of deaths among 20-24-year-old males in 2015. For females, it was 33.9% and 31.4% for these age groups respectively. (Australian Bureau of Statistics. 2016).

Considering Aboriginal and/or Torres Strait Islander peoples, suicide rates are substantially higher in Aboriginal and/or Torres Strait Islander peoples, accounting for 5.2% of all Indigenous deaths, compared with non-Indigenous at 1.8%. The standardised death rate from suicide for Aboriginal and/or Torres Strait Islanders was more than double the rate for non-Indigenous people at 25.5 per 100,000 compared with 12.5 per 100,000 (Australian Bureau of Statistics. 2016). Additionally, reports released by the Australian Institute of Health and Welfare (AIHW) found that 1 in 3 Indigenous peoples experience high or very high levels of
psychological distress. It also reported that Indigenous individuals are managed by GPs at a rate of 1.3 times in comparison with other Australian individuals (AIHW 2019).

Australia is alike other developed countries with its institutionalisation of the mentally ill. Such institutionalisation has stemmed from the time of colonisation in 1788 (Dax 1989). One of the key moments in Australia’s history with mental health, was its deinstitutionalisation of the mentally ill in 1992 (Burdekin & Guilfoyle 1993). And the first mental health care plan, a primary health care intervention providing psychological treatment among other services, was also implemented nationwide in 1992. In Australia today, those living with a mental health disability are managed under the NDIS. It started July 1, 2013 (NDIS 2020a). The scheme aims to support the mentally ill with an ethos where the individual receiving support has choice and control over their care (discussed in chapter two).

Australia is ranked highly on the international stage on progressive mental health policy. In fact, Australia has contributed to and helped to form powerful and negotiative relationships in collaboration with other progressive and powerful countries to support lesser resourced countries. This group is called LAMIC and aims at reducing the burden of untreated mental disorders in low- and middle-income countries (Milton & Lewis 2017). “Of the 800 000 people who commit suicide each year, 75% are in low-income and middle-income countries” (Leeder 2015).

With other States, specifically powerful developed States that have a history of colonisation, the mentally ill in Australia have been subjugated as sub-citizens and subhumans and social misfits. The colonised are subject to a concept which has a history of disempowerment for the under resourced, that is the Silenced Manifesto. The mentally ill are hidden, their voice is stifled, and
their future is determined in this case by Australia, the State and culture which controls them. There are economic dynamics within Australia which can be associated with the more educated and better positioned class, that is the bourgeois. The bourgeois are better resourced to treat their mental illnesses. As well, the history of mental health in Australia been closely associated with psychiatry’s connection with medical science. This connection has disassociated with the development of the social sciences (Huxley & Evans 2009).

*The hidden mentally ill of developing countries*

The question remains whether labelling is precipitated by certain cultural dynamics. Nora Mweemba (in Chambers 2010), who works for the WHO in Zambia, explains that many people suffering from mental health problems don’t come forward for treatment because "communities still regard mental health as a misfortune in the family or some sort of punishment [from God]”. What treatment is delivered tends to rely on traditional healers who often interpret mental illness in terms of possession or curse.”

Nowhere is there more widespread a mental health stigma than in developing countries. There are more layers upon layers of disempowerments and discriminations and human rights violations than those existent in developed countries. The World Health Organisation states that we are “facing a global human rights emergency in mental health” Chambers (2010).

People living with mental illness in developing countries are further stigmatised and disempowered if there is a history of colonisation. Waves and strata and webs and connections of a history of colonisation/s develop into, again, layers of (post)colonisation, sustaining the
complexity of power subjugation of the developing country citizens. To emphasise, the mentally ill are not full citizens or fully human in society, further silencing them in the Silenced Manifesto.

Nowhere is the Silenced Manifesto more prevailing than in developing countries. “With so many health issues affecting developing countries, tackling mental health tends to be something of a luxury. Aid spending remains focused on the ‘big three’ communicable diseases of HIV/AIDS, malaria and tuberculosis, with many other health conditions receiving only a fraction of the attention and funding” (Chambers 2010). So, the silenced living with mental illness are further gagged and smothered by disempowerment and a massive lack of resources – “half of all countries in the world have no more than one psychiatrist per 100,000 people and a third of all countries have no mental health programmes at all” (Chambers 2010). And the stigmatised are hidden, hidden behind the more attractive and marketable health issues and illnesses. Nowhere are mental health issues more perpetuated and disabled and proliferated than by economic poverty. Further to Chamber’s narrative (2010), “Mental illness adversely affects people’s ability to work, creates a potential carer burden on their families and generally leads to greater poverty.”

**Wellness**

Today, mental health is encapsulated as embracing ‘wellness’. More so, mental health rejects the pathologisation of the ill, the old production of stigma, the abuse of misrepresentation and the colonialism of the mind. Wellness is a mix of influences for the human. Including the hard sciences (biomedicine), the social sciences (society, culture), and the humanities (politics, economics, religion, and sexuality).
“In the serene world of mental illness, modern man no longer communicates with the madman: on one hand, the man of reason delegates the physician to madness, thereby authorizing a relation only through the abstract universality of disease; on the other, the man of madness communicates with society only by the intermediary of an equally abstract reason which is order, physical and moral constraint, the anonymous pressure of the group, the requirements of conformity”

Foucault (1961)

Definitions of madness over time have been the result of a turbulent relationship between various views of religion and various views of science. Religion and science and all knowledge thereof in fact, have oft been at war with each other. The mad have been treated variously over time and generally have been labelled, never accepted as fully human or a full citizen. A holistic approach – is being attempted and ‘talked up’ across the present deconstruction of mental illness profession and sector (Berg & Sarvimäki 2003). However, labelling and categorisation prevails and remains central within this approach (Scheff 1974).
CHAPTER FOUR

7 LESIONS: 7 VOICES: 7 DRUGS: 7 STORIES: 7 CONCLUSIONS

7 DRUGS I TAKE BECAUSE OF CLOZAPINE: MY EXPERIENCE

LIVING WITH SCHIZOAFFECTIVE DISORDER

“The expressions of those moving about a picture gallery show ill-concealed
disappointment that they only find pictures there.”

Walter Benjamin (1928)

Living with schizoaffective disorder is inexplicable. It is dangerous and impenetrable and
enigmatic. It’s like negotiating the unfathomable – conversing in absolute incommensurable
languages. You never know what you are going to get.

I should be grateful. This is because I am what they call in mental health service provision
‘highly functional’ and ‘insightful’. This is a gift and seemingly not easy to find amongst the
mentally unwell. I am lucky to be equipped with the insight to be discerning, intuitive and
perceptive about my mental health. Being highly functional and insightful equips me for a state
of limbo, straddling across two life experiences - wellness versus ill health. I can almost
disassociate from being well and unwell through mindfulness. This way of thinking comes through heightened awareness and sound understanding of my health.

The highly functional are more likely to be able to appreciate, analyse and unload what it really means to have a health condition, in this case, a mental health condition. I am highly functional, but sometimes I wish I wasn’t. I consider myself in turmoil. When I am unwell, I hear the seven noises banging around in my head. They are an accusing, challenging and sometimes impugning noise.

When I am more well, this space is quieter and the noises fade, but they are always there to some degree. There is concern when the noises take a reality or personality of their own. I then need to negotiate between my reality, the reality developed from my psychosis, and medical science. Managing my mental health involves navigating an incommensurable space between the realities of myself, my illness, and my treatment.

Speaking from my perspective, that of someone living with psychosis, these various realities are often incommensurable. The languages spoken in and around this space are not always easily translatable. Medical science does not necessarily make room for the ontological and surreal experience of living with a major psychotic disorder. Although medical definitions can be inadequate, it is still important to consider and define the subject under investigation as thoroughly as possible, to limit the gaze of the researcher. What does this mean for me? A bunch of interference with my own thinking and natural sense of self. A bunch of doubt and diagnosis that are not always consistent or logical.
Often my appointments with the mental health professionals bring me into a state of anxiety. I try not to think about the issues that come up in my appointments, for example, ‘Have you had any thought of psychosis recently?’ What about, ‘Have you felt the need to kill yourself or others?’ I know these are staple questions that mental health professionals are required to ask, however, these appointments can be quite difficult to endure, and I often feel dissatisfied afterwards. I feel like I should be making the most out of these appointments. It is as if I have not squeezed the juice out of my psychiatrist for all the knowledge he has. Unless I am unwell, I won’t see my psychiatrist for two or three months.

I’m sure that my psychiatrist could easily write this thesis in a fraction of the time than it would take me. The difference would be that my perspective is personal, it is raw. With his biomedical training, as well as his left-wing bias, my psychiatrist could bring an outstanding insight into mental health. My version, however, is poignant. It is an insider’s view of a horrific all-encompassing experience that is schizoaffective disorder.

There is an autoethnographical gap in the literature about the lived experience of schizoaffective disorder. My autoethnography is crude, authentic, and intense. The inexact science of mental health is persistent. Are the viewpoints of mental health science commensurable with my own? Is there a comparison of the macro powerful history of biomedicine with a micro powerful self-reflection and transparency that can be analysed from a sample of one? (see chapter two).
Identity constructs

The construction of identity for the marginalised, the Othered, can be dependent and explained in more ways than just its dependence on government and institutions. The identity construction of the marginalised can be understood another way via the concept of the Silenced Manifesto. The agency of the marginalised Other, dependent on the State, and as per the Silenced Manifesto, is in turn dependent on the space of commensurability where the silenced is given a voice, armed with the language and discourse of freedom of their own. Freedom from false labelling, for example the disabling label of disability or difference, untranslatable narrative, discriminatory stigmatisation, and measurement that measures only that which can used as ammunition to the colonisers, the creators of difference. The marginalised, the different, the Other, are often stigmatised.

My own personal agency is again tied to others in governmentality and servitude to those with ownership of the modes of production, my employers (Marx in Rius 1994). This can be understood via the perspective of Marxism. Governance, politics and policy control the structure of identity for the marginalised, which in turn is cemented by the strong hold of bureaucracy and validated by measurement. The Silenced Manifesto represents a way to cut through the red tape, to de-colonise the colonised. The utility of identification with the Silenced Manifesto brings with it a resource that the marginalised can use to empower. The Silenced Manifesto creates a space where the Othered can be heard, seen and accommodated.

In defining a major psychotic disorder, or the identity of other marginalised groups, there is always an element of risk in confining something so ambiguous and hazy. Labelling someone
and defining them as having a disorder or Otherhood can pathologise and/or stigmatise them and limit them to a constrictive identity, or an identity impinged upon them rather than constructed themselves. The marginalised person can be defined as having less than human status, as a person who, according to the coloniser is unable to contribute equally to society and thus a social identity is constructed and forced upon them. Defining a major psychotic disorder goes hand in hand with precipitating and endorsing stigma (Goffman 1963).

As eluded to, marginalised groups can experience the same stigma as the mentally ill. They are suffocated and hidden – silenced - subhumans. The Silenced Manifesto explains how their stories and experience – their narrative - is shushed and not translatable to the dialect and narrative of the powerful. The powerful are typically the white, male, middle-class, able-bodied, non LGBTIQA+ of society who in many ways are the colonisers. The Other, for example women, non-white, low socio-economic grouping, disabled, and LGBTIQA+, are labelled by the powerful colonisers, labelled as lesser beings, where they live with a label of stigmatisation.

To try to explain a little how identity is examined, I use two closely related examples, communication and language. Communication and negotiation are significant ways that identities are developed. When I try to communicate, I feel that people look at me coldly and with judgment, as if I do not make any sense. I am paranoid that people think I am stupid, and I cannot communicate well. For example, I feel like my colleagues look at me with blank faces, stupor and annoyance. This could be my paranoia and oversensitivity, or it may be that my sense of self identity is deeply affected by stigmatisation. I feel disabled, powerless, unable to communicate. I would suggest that other marginalised groups would feel the same. Their negotiation of communication and the powerplay that endures leads to miscommunication and the ramification of discrimination.
To extrapolate, the uses of clinical language is one way that medical professionals alienate and ascertain authority over the ill, by precipitating and endorsing stigma. Language is an avenue through which cultural difference and values are perpetuated. Language draws connections between the powerful and the powerless. Ultimately it is a form of communication, but it is also a template and mandate of who has supremacy. Mental health professionals exert their command over the symbols of communication in medicine and from this they have privilege and influence that comes with that knowledge. As Foucault argues, knowledge is power. Creating an identity with schizoaffective disorder disempowers you as the language used between doctor and patient are governed ultimately by biomedicine. Reflecting on this, perhaps schizoaffective disorder endures in an incommensurable world where there is little understanding between knowledge and power. There are many ways that schizoaffective disorder comes to life.

So, a fruitful and empowered identity construction of the Other exists in the commensurable space between coloniser and colonised, that is the Us and the Other. This space exists despite governance and politics and policy, and the bureaucracy that holds it together and makes it tick. Identity construction for marginalised groups, or groups of difference and/or lesser power, relies on the negotiation and banter, be it possibly aggressive negotiation and banter. This intercession is transferred via the representation of the marginalised group, for example through communication and language, with consideration of not misrepresenting the Other and perpetuating those which are in more of a position of powerlessness.

Another example how the marginalised are identified is through measurement and labelling. The language, symbols, and knowledge production of the Us is validated by the acts of measurement. Those who have power over knowledge production through measurements become the monarch
of control of that socio-cultural entity. The marginalised measured become identified as cultural outcasts. The powerful rely on measurements to validate the power of the coloniser, the Us. Measurements inadvertently create a schism of (dis)empowerment and labelling between those who use the measurement tool and the Other (McMahon 2013).

The essence of labelling theory is that individuals are crafted by society and given identity by society. The Other learns to adopt, then actualise and accept, via self-fulfilling prophecy, the label of difference, disability and i from the participation of knowledge production. The labelled internalise the identity bestowed upon them, and this could lead to a crisis of representation and false categorisation. The identity construct that labelling creates is precipitated in the functioning of culture. How can I break through this divide of cultural misrepresentation? To break the development of the cultural divide from coming to life?

It should be emphasised that the marginalised do not always identify as marginalised. Some people who have a mental illness do not necessarily identify themselves as disabled. In fact, by suggesting that they are disabled or marginalised, I am labelling them. I am disempowering them by falsely identifying them as subhuman, sub-citizens, social misfits. I have welcomed a false representation and bought into the crisis of representation that I have fought against. Although not identifying as marginalised, some have adopted the identity in order to gain some government benefits. For example, I presented my self as disabled in order to receive the disability support pension, even though I hate to call myself disabled. In fact, I fought against identifying myself as such. I use the Silenced Manifesto to demonstrate that I have a voice of my own, despite government and institutional decree. I would hate to misrepresent those who do not represent themselves as Other. They will have their own representation and their own voice in the Silenced Manifesto. Everyone has a voice that isn’t always heard.
Some statistics about mental health in the Australia context

My life expectancy is less than someone else my age without living with schizoaffective disorder. Of interest, a study in the United Kingdom showed that life expectancy across all mental illnesses was well below the United Kingdom average of 77.4 years for men and 81.6 years for women. Specific to women with schizoaffective disorder, they have an average life expectancy reduced by 17.5 years, and men with schizophrenia whose lives were shortened by about 14.6 years. Of those most affected by mental illness were women living with schizoaffective disorder (Hughes 2011).

In Australia, those from a lower socioeconomic background are more likely to live with a mental illness. Approximately a quarter (26.4% or 2,277,210) of community mental health care contacts were for people living in areas classified as being in the lowest (most disadvantaged) socioeconomic status quintile. People living in areas classified as being the highest (least disadvantaged) socioeconomic quintile had the lowest number of community mental health care contacts (1,297,305) and rate (273.0 per 1,000 population) (AIHW 2020b). I may mention here that in Ward C (private), the private and most expensive ward that I have been admitted to, the severity of mental illness is tempered and minimised. Wealth foreshadows the ugliness of mental health.

Australia’s health system is complex — and so are its funding arrangements. It is funded by all levels of government (federal and states and territories); non-government organisations; private health
insurers; individuals when they pay out-of-pocket costs for products; and services that aren’t fully subsidised or reimbursed.

In 2016–17, Australia spent nearly $181 billion on health:

- 41% by the Australian Government
- 27% by state and territory governments
- 17% by individuals (for products and services that aren’t fully subsidised or reimbursed)
- 9% by private health insurers
- 6% by non-government organisations

Health spending was about 10% of gross domestic product. This means $1 in every $10 spent in Australia went to health.

(Department of Health 2019)

The foundation of the Australian health system is Medicare, established in 1984. Its three major parts are: medical services, public hospitals and medicines (Department of Health 2019). Mental health services that are subsidised through Medicare include: primary health care for instance GPs, psychiatrists, psychologists, occupational therapists and social workers (Parliament of Australia 2019). Medicare also supports public hospitals. State, territory and local government are responsible for managing and administering public hospitals (Department of Health 2019).
The Federal Government also shares responsibility with the states and territories for other activities under national agreements, such as the Council of Australian Governments (COAG). These other activities include funding public hospital services and the national mental health reform (Parliament of Australia 2019) as well, the NDIS. The NDIS is a ground-breaking, once-in-a-generation change to the way people with disability are supported in Australia. It is a social reform on the same scale as the introduction of Medicare or compulsory superannuation (Every Australian Counts 2018). In March 2013, the NDIS legislation was passed and the NDIS Act 2013 was created, along with the Scheme was the National Disability Insurance Agency (NDIA) (NDIS 2019).

According to Knaus (2018), about 81.4% of those who requested NDIS support for psychosocial disability (a disability particular to those with a mental illness) were accepted, compared with more than 97% for people with cerebral palsy, autism or intellectual disability. The scheme, at full rollout, is designed to cover about 64,000 people with psychosocial disability. That is well below the total number of people who require ongoing support for severe mental illness in Australia, which the government estimates at 230,000. The report casts doubt on the government’s figure, saying its basis is unclear, given there are an estimated 690,000 Australians with a severe mental illness (Knaus 2018).

Regarding government mental health expenditure in Australia, the AIHW states:

- **$9.9 billion**, or $400 per person, was spent on mental health-related services in Australia during 2017–18, a real increase from $382 per person in 2013–14.
• **1.1%** annual average increase in the real per capita spending on mental health-related services from 2013–14 to 2017–18.

• **7.6%** of government health expenditure was spent on mental health-related services in 2017–18.

• **$6.0 billion** was spent on state/territory mental health services in 2017–18; $2.6b on public hospital services; $2.3b on community services.

• **$1.3 billion**, or $51 per person, was spent by the Australian Government on benefits for Medicare-subsidised mental health-specific services in 2018–19.

• **$541 million**, or $21 per person, was spent by the Australian Government on subsidised mental health-related prescriptions under the Pharmaceutical Benefit Scheme and Repatriation Schedule of Pharmaceutical Benefits during 2018–19.

> (AIHW 2020a)

And so lies some knowledge of the governmental structural and costings of mental health in Australia. Though this presents with little knowledge to causes - the exact causes of schizoaffective disorder are not known. It is thought that the disorder is produced by a combination of genetic and environmental factors – nature and nurture. There is some evidence of a biomedical cause simply because medication can work. As well, the disorder tends to occur more in families where there is a history of schizoaffective disorder, schizophrenia or bipolar disorder (Kaplan 2003: 509; Daniel 2011: 20–22). Mental health issues run riot in my family. Most of my siblings are living with mental health issues. I have many cousins, aunts and uncles who also battle with mental health issues. Sadly, my cousin with schizophrenia committed suicide.
Seven drugs I take because: My experience living with schizoaffective disorder

I was diagnosed at first as having bipolar disorder for about four years, although I never fitted that label very well. I didn't have the definitive highs or lows that come with bipolar. Later, I was diagnosed as having schizoaffective disorder, after a psychiatrist changed his mind and disregarded the bipolar diagnosis. I never really agreed with this classification either, although I never really agree with being pigeonholed in any way. I can relate to some schizophrenia type symptoms: heightened senses, hearing noises (voices), hallucinations, paranoia, for example believing that people around me are able to read my soul by looking into my eyes or that I can sense what people are thinking about, experiencing strange sensations, and erratic thought patterns (demonstrated by inconsistent, illogical and changeable conversations)

Mental health issues do not discriminate against sex, race, culture and class. Their treatment, which involves taking medications and various therapies, are more complicated than what they may seem. For example, mindfulness practices I do include fortnightly counselling, where I talk my way out of poor health and am given tools to reduce and manage the debilitating effects of anxiety. I also practice meditation and yoga, eat well and exercise, all in my effort to manage anxiety. There may indeed be variations to treatment related to social and cultural indicators of the individual. My non-responsiveness to standard anti-psychotic medications has forced me to take a powerful anti-psychotic drug called Clozapine.

Taking Clozapine commits me to having a relationship of dependence on the State. It is an extremely highly regulated drug requiring regular tests: blood tests, blood sugars, blood pressure, temperature, weight, blood sugars, thyroid functioning, echocardiograms, psychological and
others, all monitored by a team of mental health professionals. I am constantly measured, prodded and assessed. Clozapine can potentially be a dangerous drug. It killed people in the early 1970s from a condition called agranulocytosis, a disorder involving a dangerous decrease in the number of white blood cells. By the early 1980s, was back on the market and was shown to be very effective in reducing suicide and reducing instances of psychotic episodes (Sinha 2020).

There is an irony about 7 drugs I take. I take three drugs a day which are not directly related to taking Clozapine, and seven drugs a day because of Clozapine and its side effects. Below is a list of my medications:

- Quilonum (lithium carbonate) – a mood stabiliser
- Thyroxine – a hormone I must take due to Quilonum affecting my thyroxine levels
- Lamotrigine – to treat clinical depression
- Oxybutynin hydrochloride – another anti-depressant that reduces bedwetting caused by Clozapine
- Amitriptyline hydrochloride – for bedwetting caused by Clozapine
- Betmiga – for bedwetting caused by Clozapine
- Abilify – another anti-psychotic to aid the efficacy of Clozapine
- Coloxyl with Senna – for constipation caused by Clozapine
- Atropt drops – to reduce drooling from the Clozapine
- Clozapine
A side-effect of Clozapine is that I drool at night. I wake up during the night over heated and saturated in my own saliva. When the drooling first happened, the Clozapine nurse, who had become a friend as such, in a dependent sort of way, suggested I use a terry towelling waterproof pillowcase. I remember feeling shocked at the suggestion of using such an item. It was a suggestion down the path of humiliation. Drooling – how undignified! I was used to having a dry mouth for many years, which has brought its own problems such as decayed teeth. Now, I produce too much saliva. The amount of saliva I drooled at night felt as if I had wet myself. However, bedwetting is a side-effect of its own.

After about eight months of taking Clozapine, I started wetting the bed at night. At first, it was only small amounts, of which I tried to ignore. Surely no one will notice, only small patches? Then it became more – more frequent and more of it. I cannot tell you the great shame I felt when this started happening to me. My boyfriend at the time didn’t take it very well. Who could blame him? He would wake up wet as well. The ignominy of it all was astronomical. Sometimes when my bed was wet and I was too oblivious to change the sheets in the middle of the night (having a very deep sleep was also a side effect of Clozapine), I would go and sleep on the couch. This didn’t solve the problem however, because I would wet the couch too. My strategy to my bedwetting was to avoid the subject. It was too obvious though once I started wetting the couch. My housemate brought the subject up with me. It could no longer be ignored. I remember negotiating with my housemate about what I should do. First, I had to book a GP appointment. Second, I had to scrub clean the couch. Third, I needed to start wearing adult nappies. Fourth, I needed to purchase a mattress protector. I felt absolutely gutted and mortified, like there was no way out of this putrid indignation and degradation. I felt so disgraced, so much that I lost all pride – I felt like I had lost my reputation and now sunk into a pit of sadness and dishonour. I
am mortified due to Clozapine, despite its success and its efficacy in treating psychosis. Medical science had ruined my strong sense of identity and self-worth in turn for which I had quieter noises in my head. Which is better to keep? My sanity or my dignity? It seems that I did not have the freedom to choose. Both are questionable spaces to be.

I saw two urologists about my bedwetting. The specialists admitted that usually their clientele is much older than me or had bladder cancer. I had to go through a series of humiliating tests. Yet again I am embarrassed by medical science. One of the urologists prescribed me some medication which worked (mostly). My bedwetting had decreased remarkably but I still had the odd night of shame. When I told the specialist that my bed wetting had reduced to seventy percent of the time, he was happy, as if it is still acceptable to be mildly incontinent. I don’t seem to be able to shake my association with bedwetting. I only recently took off my mattress protector because my boyfriend couldn’t deal with the crunching noise it made when you turn over in bed. One ironic benefit of bedwetting in the public mental health system is that you have case managers that can take advantage of the situation. It seems that I get about $500 every year to pay for the privilege of being incontinent.

There are other shameful side-effects that are absolutely dehumanising in themselves. There is the obvious side-effect of putting on a lot of weight. I have put on 23 kilos over the period since my first diagnosis. It is difficult for me to lose weight due to the medications. In addition, I am at risk of developing Type II Diabetes. I find this shameful. Then there are other physical side effects from taking so much medication, such as drowsiness, heavy sleeping (probable cause of bed wetting), slow responsiveness, slow cognitive functioning, poor concentration and memory,
increased effects of alcohol, constipation, nausea, dizziness and light-headedness. Other side effects include having an underactive thyroid, as a result of taking Quilonum for many years. I am now required to take thyroxine indefinitely. Alternate therapies are often necessary because medication cannot treat the social problems such as isolation, unemployment, lack of education, and poverty that accompany schizoaffective disorder. These therapies aim to address the multifaceted facets of social issues that affect someone with schizoaffective disorder. However, this is a huge topic warranting another thesis.

The noises (voices) are definitely quieter now I am on Clozapine. However, am I now free? This is a paradox for me, as a Clozapine patient. The noises are softer, but my identification as a crazy sub-human, sub-citizen and a social outcast is cemented by association with the treatment. I must give away my ultimate freedom, put my full trust in biomedicine. It is true that I need monitoring with the other drugs I am taking, but that is nothing compared to the regime of taking Clozapine.

I am forever labelled a Clozapine patient, not normal, not a fully contributing citizen, disabled and a cost to the State. I am stuck in a dynamic between health professionals and myself, where measurement and assessment are tools of engagement and care. I am in a measurement contract I am constantly being assessed and medicated accordingly. The misuse and exploitation of a measurement can in some ways be likened to the effects of colonialism, likened to mind abuse and rationality bombing. (Mistreatment and this association with colonialism is to be discussed further in chapter twelve.)
Clozapine belongs to a group of drugs called antipsychotics. These medicines work on the balance of chemical substances in the brain. Clozapine is only prescribed for people with resistance to other antipsychotics available. It is necessary to closely monitor someone taking Clozapine. The regulation when first given Clozapine involves staying at the mental health clinic for the first day, undergoing regular blood tests and being closely monitored. Then there are blood tests, a Clozapine nurse and a psychiatrist visit every week for 18 weeks. Now, the psychiatrist and Clozapine nurse visits are monthly. The psychiatrist appointments then fall back to every couple of months, or when needed.

*A basket case?*

I cringe when I think about creative therapies. All the psychiatric wards that I’ve been to have strongly advocated creative therapies. Personally, colouring in and threading beads just doesn’t cut it for me. There is the argument that craft puts you in the company of others, and I can understand doing craft in therapy is useful. Creativity is also helpful in calming the mind, very helpful. Creativity is therapeutic, and it should be nurtured. Another way of understanding creativity is that in its demonstration it reinforces a child-like relationship with those who care for me, specifically hospital staff.

Living with schizoaffective disorder requires constant awareness and mindfulness of the smallest signs and symptoms. I must be vigilant in my treatment and be compliant if I am to have any quality of life. For my friends and family, living with someone with schizoaffective disorder is more than challenging. However, I am living proof that you can be highly functioning and have schizoaffective disorder.
As far as I know, schizoaffective disorder is mine to keep. Not as a badge of honour, but a shackle that I constantly struggle with, a marriage made in purgatory - in a constant state of pain and dismay. I have heard stories about people with hallucinations becoming friends with their voices. Not me. It just goes to show how potentially powerful psychiatrists can be. People diagnosed with major psychotic disorders are in the lap of the psychiatry gods - diagnosis and treatment is predominantly controlled by these gods of (in)sanity. There isn’t a blood test or an MRI (magnetic resonance imaging) or an x-ray which will absolutely diagnose everything.

Assume that the mental health system is a clinical arm of the State. And the State’s bureaucracy creates cultural artefacts/biofacts from various (culture associated) measurements of the mentally ill. Bureaucracy has control over the knowledge generated, and the power it develops (Lea 2008). The mentally ill are dependent on the State and are as much a guinea pig for affordable health care and medicine. When you’re in the system, getting your medication from the government as I do because I take Clozapine, you are totally a ward of the State (Kleinman 1980; DiGiacomo 1987, 2013; Biehl 2005). That is, a dependent of the State.

I must admit that I cannot imagine life without schizoaffective disorder. Through schizoaffective disorder I have experienced the worst times of my life, yet it has also given me the most poignant insight and understanding to the meaning imaginable in my life.

To conclude, living with schizoaffective disorder, for me, is unreal: in the truest sense of the word. Basically, it is my experience to constantly be negotiating with myself whether something
is real or not. I am paranoid about losing my cognitive ability. I am also paranoid that I am stupid and will be locked in a cage of stupidity for the rest of my life.

I do feel the stigma from living with a major psychotic disorder. Loved ones have questioned my attention span and memory in simple tasks such as ordering a few drinks at a bar. This all makes me quite sad. I know all too well that there is an element of truth in the distrust of my loved ones. I loathe to admit it. I hate to think that I will always be like this.

Being highly functional, I have good insight into the paraphrenia that is schizoaffective disorder. This disorder, as with all medical conditions, has socio-cultural facets which need to be understood alongside biomedicine. The socio-cultural perspective of the disorder will always provide substantial depth and efficacy which needs to be a focus in the analysis of any mental health research.
CHAPTER FIVE

LIFE BEFORE INSANITY

“Social life is messy, uncertain, and emotional. If our desire is to research social life, then we must embrace a research method that, to the best of its/our ability, acknowledges and accommodates mess in chaos, uncertainty and emotion.”

(Adams, Jones & Ellis 2015)

I often try and remember what life was like before; before noises, paranoia, surrealism, anxiety and being fat; before being a subhuman, a less productive and valued member of society. Was I an active, productive member of society before I was diagnosed as crazy? What was I like before being diagnosed mentally ill? Was there a definitive difference in my life before and after diagnosis? The truth was that before being diagnosed with a mental illness, I had a full and wonderful life, heading towards a successful future. After being diagnosed as having a major psychotic illness, there was a switch that changed my life forever.
This chapter introduces the start of my mental health journey, in particular, experiences around early diagnosis and my first admissions into a mental health institution. I begin with some background to my early life prior to these. It also works as a foundation chapter to the proceeding three ethnographies of my mental health hospital experiences (chapters six to eight).

My narrative at times uses informal language – I employ the words that best communicate my feelings and my meaning, best portraying the history of me. Today, my mind and the way it functions, or dysfunctions, is an enigma to me. There is a weird effect on my line of thought which can confuse people as I jump back and forth in conversation, seeming like I have a short attention span. So, I ask you for your patience with my erratics. (See the introduction for an explanation of my fragmented thought processes and expression.) I find it difficult to remember linear events leading up to my diagnosis in the preceding years. My memory is sketchy and vague. It bounces tangentially back and forth, between and around various recollections. The result is a somewhat surreal, vague and dreamlike experience of what I think happened. I tried asking my Mum about what I was like when I first became ill. She said, “I can’t do it! I can’t go back to that time. You’ll have to ask your father about that.” My mother’s reaction really worried me. Surely those memories couldn’t be that horrible. I certainly have little to no memory of that time, but I thought that was just from the sedatives and antipsychotic medication they ploughed me with. The truth be told, I have few memories, even sketches of memories, of the times when I have been unwell, especially in the early years.

I was one of six kids. Such a large family was expected of devoted Catholics. I spent my primary school years being a sincere and dedicated Catholic. I was seven when I decided that I wanted
to try to be the first Saint Rachael. My godmother, Aunty Helen, was a Dominican nun. She encouraged me in my devotion to the Catholic Church. Aunty Helen supplied me with many books on saints and prayers. It was through reading these books that I noted that most of the ‘good’ saints started their devotion to the Church during childhood. What I classified as the ‘bad’ saints were mostly saints, canonised hundreds of years ago, with their Christian work centring on being part of royalty.

I had a little shrine at the head of my bed, decorated with a crucifix and a palm leaf attached to it out of respect for Palm Sunday (a significant day in the Catholic Church), a picture of the Pope at the time and the prayers and pictures of my favourite saints. I remember getting in big trouble from my Mum when I told my younger brother and sister the story of King Herod slaughtering babies. I went to confession a few times over that one. Mum and Dad encouraged my faith or, at least, tolerated it.

Years later I wondered if my obsession with the Catholic faith as a child, and my planning on becoming a nun could have possibly contributed to the development of my schizoaffective disorder? Was my faith within the realms of normalcy? Did my devotion embody some form of mania? Did I define myself as whole only though my commitment to Catholicism?

Ireland, a country with strong Catholic heritage, has an unusual and significant history, relationship and over-representation with mental health illnesses. A small town in the west of Ireland, on the Dingle Peninsula, has an especially unusual history, one where there are strong relationships and correlations between mental health, age, gender, and sexual history. The
recorded history of this small town shows that on a given census day in 1971, two out of every hundred men were in a mental institution. Nearly all those hospitalised men (89%) are lifelong celibates, most were between the ages of 35 and 50, and more than half were diagnosed as suffering from schizophrenia (Scheper-Hughes 2001).

Is there a correlation between schizophrenia, age, celibacy, and gender? Does spirituality have anything to do with it? Can I draw any correlation with my experience as a child and those Irish men living in a small Irish town? Can my history and belief in God, and a faith in the Catholic Church, be associated with the social and cultural indicators from the small Irish town? Either way, without my belief as I grew up, I felt incomplete.

This is uncanny, because the discussion in this thesis involves debate over the mentally ill being ‘sub-human’ and incomplete – as being set apart and detached from society. Could my faith as a child have disconnected me from the normal social experiences of growing up? I don’t know any other children who have committed themselves to religion in the same way. I hold true to the faith I developed as a child, to the bible message in Mathew 18:3, “Truly, I can say to you, unless you turn and become like children, you will never enter the kingdom of heaven.”

I remember wanting to belong, to someone or something, to feel loved and included. As a child, I wanted to belong to the Church. As I grew older, into my teens, I turned away from the Church and my faith as such. I felt less a need to commit on a personal level to my faith and more a need to grasp hold of social inclusion. My faith did not satisfy my developing need to be accepted and wanted socially. What was intimate and personal became a strong sense and desire to have
cultural connections. As a teenager I wanted to belong to as many groups as possible, to feel wanted.

My needs had changed. I needed cultural inclusion, a connection with the broader and more worldly sociocultural experience. Through this connection, I have been able to find meaning with my community. My social identity wins over my personal faith. My cultural identity wins over a relationship I have between myself and God. After many years, my relationship with God was overtaken in importance by my relationships within the society in which I lived.

My secondary schooling showed that I was a joiner, joining any club, charity or society, any event, happening or occasion. I was one of those annoying students promoting ‘school spirit’, receiving medals for it too, embarrassingly enough. There were many times in my teens when I was anxious and depressed, often ending in tears. I remember a strong sense of self-loathing. Still I was heavily committed to extra-curricular activities, feeling like I needed to belong somewhere. Through social inclusion, I strived to become human and complete, rather than sub-human and incomplete as I was too soon become. I remember feeling alienated, despite my heavy commitments to social activities. Similar to what Marx stated, “social potential has become the private power of the few...The less you are, the more you'll have. To have more, you must alienate yourself” (Marx in Rius 2012: 80-01). I was desperate to be wanted by others. I put this down to teenage angst.

The strong desire I had to belong and feel wanted carried through to the early years of adulthood. After some travelling, I settled into a Bachelor of Arts in Anthropology/Development Studies.
(third world development, as it was called at the time). I became unwell when I was halfway through my honours year in Development Studies. I was heavily involved with social justice organisations and other clubs, living with two of my best friends, and going out with a fantastic guy. I was one of those idealist types who believed one could make a career out of a degree majoring in Anthropology and Development Studies. I planned to save the world! I had my heart set on becoming an aid worker overseas, helping people with my (assumed) in depth knowledge of Foucault and Marx.

I did do some aid work, when I had just turned twenty-one. A friend and I decided we’d go to Calcutta and work hand in hand with Mother Teresa. This we did. Mother Theresa was to deliver to us, the group of admiring faithfuls attending early morning mass, a lesson of true charity. She told all the volunteers that it was wonderful that we could do this valuable work in Calcutta, but we should be made aware that there are people close to us, in our own communities, that need us just as much. It was time to wake up and take note. My personal needs were overtaken by the needs of those in my community. I realised that my cultural connections were the most important connections I had, and they also resonated with me personally. The personal had become the political. The personal had become the cultural.

So, I did it. I connected with my society and culture. There were people amongst my family and friends who needed support, so I set about to support them. However, this was not enough. I kept working as much as I could with social justice organisations, as well as my part time/full time job as an aged care worker. I also decided to join a public speaking group. My friends tell
me that at this time I was swaying towards mania, trying to organise myself and make the most of every minute, literally.

I remember feeling desperation to fit everything in, along with a great sense of self-loathing, and confusion. I remember trying to prepare for my honours thesis and panicking about it. I didn’t feel that I was smart enough to do it. I was left dumbfounded and bewildered. I have never felt good enough, never smart enough. I have tried over many years to compensate for these inadequacies. I would try to fit as much in the day as possible. I have never been good enough.

I remember just before I became acutely ill, that I was organising all my time, awake and sleep, in ten-minute intervals. I even allocated an exact time of just eighteen minutes to cook dinner for my housemates and allotted boyfriends. I wasn’t really sleeping. I felt desperate to make every minute of the day and night purposeful and fruitful. I couldn’t miss out on any opportunity that came to me. It all seemed quite okay and doable at the time. This proved to be one of the first definable signs of my psychosis.

I have been asked many, many times if I had any signs or symptoms of poor mental health before ‘the diagnosis’. With my shoddy memory, it is hard to say. I remember one time coming home with my boyfriend I started crying inconsolably and for no apparent reason. My arms also started to move spasmodically and involuntarily. The tears and the arm movements stopped after a couple of hours. A couple of months later, for no apparent reason, I started crying again, inconsolably. I also started cowering and hiding from people, not feeling safe to walk to the
shops, being afraid to talk to my friends and hiding behind furniture. These symptoms lasted a few days.

My friends and boyfriend were now very worried about me and my strange behaviours—mania and psychosis—although these terms were new to them. My boyfriend booked an appointment for me with a GP who was recommended to be sympathetic to people displaying such symptoms.

My boyfriend and I met the GP. When she saw me cowering behind a chair and showing signs of hallucinations and delusions, she said we had to go at once to the psychiatric ward.

I don’t know how this all happened. Was my hospitalisation related to my need to belong and feel wanted as in my younger years? Was I a social misfit, a sub-human, not belonging anywhere? I really have no idea! I have always claimed that the onset of my illness was out of the blue. There was no rhyme or reason. My mental health is mandated by my own biomedical composition. This would make sense looking at the massive over-representation of mental illness in my family. I cannot negate that the biomedical model is completely obsolete. Despite revision of psychiatric theory, it remains a strong force even after hundreds of years (Szasz 1970).

While I strongly believe that my schizoaffective disorder is intimately related and dependent on my biomedical make-up, I cannot negate the myriad of other factors that also take precedence in relation to my mental health. There is a strong argument that declares that mental illness is a socio-cultural phenomenon and, as an anthropologist, I feel that I must adhere to such a
declaration. To paraphrase Kleinman (1980: xiii), the socio-cultural medical phenomenon is being taught in universities. It is imperative to teach both undergraduate and postgraduate students in psychiatry social and cross-cultural psychiatrics, and as it is imperative to teach medical anthropology to anthropology undergraduates and graduate students.

Let us go back to my story. I will try to extrapolate the difference between the biomedical model and the socio-cultural model, recognising that they at times work together: a relationship that has been recognised sporadically over the centuries.

So it happened. I broke for the first time.

This was the beginning of my hell on earth. I was just 23 years of age. My sense of self was fucked permanently. I remember feeling that I had to find myself again, but I was lost as to how. Sadly, this has proved to be an ongoing and frustrating endeavour. My agency and self-determination were not my own. My identity and my future were in the hands of the mental health professionals, revered ‘demi-gods’ of Western medical science. These are the ones who utilised the tools of biomedicine to gain control: that is, achieving mental health as defined by the science of modern psychiatry.

My boyfriend was holding it together well. With instructions from the GP, he took me to the Emergency Department of the nominated hospital. The GP had already rung ahead to the hospital
so that they were ready for me. I didn’t have to wait. Thinking about it in retrospect, waiting in the Emergency Department would have been a new-found hell for me.

I was examined by who I think was a psychiatric registrar in the room allocated for mental health assessments. I remember the doctor asking me all sorts of probing questions:

“Do you know where you are?” – Yes, I’m at the hospital

“Are you hearing voices?” – There’s a lot of noise in my head

“What are the noises saying?” – Bad stuff. That I’m stupid and hopeless

“Do you see things that aren’t there?” – Not usually, but there are bugs all over the floor

“Have you ever thought of ending your life?” – Sometimes

“Do you want to end your life now?” – No. I couldn’t do that to my family and friends

“Who is the Prime Minister of Australia?” – What the! Really? Funnily enough I couldn’t answer.

Throughout all these questions, I was cowering behind a chair, tracing with my finger the lines of the tiles of the walls. I remember the tiles were white, but a bit grey with dirt and age. I think I was wearing a second hand top and skirt and old shoes - typical student uniform. My clothes wouldn’t have been black. I always thought that black was a depressing colour and I didn’t want to be perceived as depressed, ironically. I had lost a bit of weight in the last couple of months, probably due to my manic activities. My senses were terribly heightened. I remember the smell in that room. It was that typical disinfectant and bleach smell that one associates with hospitals.
The smell makes you realise that this is a cold clinical setting – it is the kind of smell that reminds you of getting vaccinated as a kid, and the related fear. The hospital was not a place of nurturing or love. It was a place that worshipped the science of medicine, of sterility and hygiene, of dead germs. Mental health does not fit into such a germ focussed/disease focussed medical science paradigm. Mental health, in today’s world, requires therapy centred on feelings and perceptions. Treatment involves talking therapies and medication and various other psychological tools.

In the mental health examination room, I felt overwhelmed and suffocated, frightened. I could not shut them up: the noises. Terrified, I cowered further behind the standard and ‘safe’ hospital chair provided in the psychiatric assessment room. By safe, I mean that there were no sharp corners on the chair that could be used for self-harm. My boyfriend was trying to help me answer the questions. By doing this I think he was trying to hasten the treatment process, telling the doctor the answers that he perceived were needed. He wanted me to be well now.

I read in my medical notes that my boyfriend declared that I had a history of nine months of paranoia. That I was edgy, agitated, unable to focus or concentrate – and not getting any study done. He stated that I had panicky episodes, poor sleep and poor appetite and that three weeks prior I had become more edgy, stifling easily, hiding behind lounges and doors and was “afraid to be here”. The mental state examination on admission recorded that I was an acutely agitated, disturbed young woman; that I had severe psychomotor agitation; that I was tearful with dramatic gestures, that I was initially unable to speak much, but later able to give some history. It was recorded that my mood was depressed, despairing and anxious, that my thoughts were paranoid.
ideas. I had no suicidal plans although I talked about it and thought about it. I thoroughly blamed myself.

And so, after what felt like a gruelling examination, I was admitted to a psychiatric ward, Ward A (public), for the first time. I could hardly believe it! This was the beginning of a lifelong relationship - no, a war - with my insanity. From then on, each day has been a battle. My first admission was voluntary. There is a thin line between being a voluntary and an involuntary patient. Basically, if you are at risk to yourself or others, and non-compliant, you will be sectioned or given an involuntary treatment order under the Mental Health Act (for example, the Mental Health Act 2015; Mental Health (Treatment and Care) Amendment Act 2014; Mental Health Act 2015 (ACT); Northern Territory of Australia Mental Health and Related Services Act (2018). Each Australian state and territory have their own version.) Most of the times that I have been considered insane, I have been in enough control of my faculties to be admitted as a voluntary patient. That first admission, despite being psychotic, I was deemed sensible enough to be a voluntary patient.

I don’t remember how I got from the Emergency Department to the psychiatric ward. I do remember that when I first arrived in the ward, I was given a dose of Neulactil – an old school anti-psychotic medicine and my first ever psychometric drug. The first of what seems like thousands now. After taking the drug, I remember saying, “Okay. That’s all good now. I’ll just catch a cab home.” I was very serious, but the doctor and my boyfriend thought I was hilarious!
In my first admission, I remember feeling overwhelmed and inundated. It dawned on me that life would never be the same for me again. My dreamed of future was ruined. At this stage, I didn’t have the cognitive capacity to complete my honours thesis.

Of course, mental health professionals are interested in any mental health history in your family. And, as it would transpire, many of my siblings, cousins, aunts and uncles are afflicted with mental health disorders. We cannot seem to escape it. Is this a biomedical problem or a cultural problem? Mental health disorders are still seen as biomedical in the first instance. The doctors give you a physical examination, mainly so that they can rule out any biological causes. For instance, my hypothyroidism came about from side-effects from one of my medications. Hypothyroidism can cause depression. Hyperthyroidism can cause psychosis. Quilonum makes your hands shaky, it makes your writing difficult to read. So, we have to be mindful of that.

In the early days I hid behind furniture. I was full of self-deprecation and shame. I also kept saying variations of the following:

“Other people need the bed”

“I’ll make the bed dirty”

“I don’t want anyone to know”

“I’m probably just putting this on to get out of doing my [honours] thesis.”

“I’m not really sick.”
In the early days in the ward the doctors struggled to find the correct medication. I was very withdrawn, very suspicious and ultimately paranoid. On the first day I was given the drugs Largactil and Valium after the Neulactil. According to my medical notes, I settled after taking medication. There was an incident on the first night of my admission when I fainted. It so happened that I had not eaten for over 36 hours. The nurses quickly laid me down, took my blood sugar level and gave me some juice. And then I was able to eat dinner.

I remember, on my first day in hospital, being extremely anxious about receiving a diagnosis. I was desperate to understand what was happening to me. The health professionals seemed hesitant to give a certain and confident diagnosis. A fixed diagnosis would pin them down and commit them to a definition which they were essentially unsure of themselves. As has been emphasised so far in this thesis – psychiatry is an inexact science.

After five days of being in this initial psychiatric ward I was given a more thorough interview with the psychiatrist. Reading through the notes of my first hospital admission, the term ‘acutely agitated and disturbed’ was repeated over and over again. I also experienced severe psychomotor agitation, this involved involuntary arm and leg movements. There was reference to my behaviour potentially stemming from psychosis or depression, beginning at the age of 15. It was at this age, on reflection, that I noticed occasional but pronounced emotional lability: I would withdraw for days at a time, became agitated, and experienced feeling lost, confused and disorientated. As well, there was the possibility that my symptoms were brought on as part of post-traumatic stress disorder caused by a rape at the age of 19. I really didn’t want to bring that up again.
Some visual hallucinations I had during this time in hospital included hundreds of bugs crawling all over the floor, as well as animated faces in my blanket. I was also paranoid, endlessly. I felt that the nurses talked to me (when they didn’t) and that they could read my mind. This is a common symptom when I am unwell, I am afraid of looking in people’s eyes because they will be able to read my thoughts and feel what is in my soul.

I experienced pretty much all the time a thing called thought blocking. This is manifested by me losing comprehension and track of my thoughts midsentence. My memory loss also started. I was devastated to lose some cognitive functioning. I was mortified to start my life as a sub-human. It seems that the symptoms that I’ve had over the last twenty years will continue. The major symptom is my mind going blank without warning, me losing track of the conversation I was just having. My mind is just vacuous, nothing more.

I remember something that was very upsetting to me during that first hospital admission. I was afraid of quitting my honours year. I felt a great sense of obligation and commitment to finishing my honours. I felt shattered and broken about failing that year. The fear has carried on until now, when I am writing a PhD, afraid that I will be a failure again.

It is interesting to note what is considered therapeutic on the ward. Groups and group activities are a priority (Frame 1984). Group activities consist of several things such as reading the newspaper, cooking, a great deal of craft, and for those considered more advanced there is the
option of group discussions on anxiety and depression. In this first admission, and consequent admissions over the next couple of years, I was deemed only suitable for doing craft. I remember thinking it is quite a joke that making beaded necklaces, painting and sticking things together were considered the most therapeutic actions for me to be involved in. I remember feeling quite insulted that sticking things together, in no particular way or inclination, was considered the upper limit of my capabilities. I asked the nurse if I could go to the anxiety and depression groups, but she thought this was testing my capabilities.

It is interesting to look at structure and compliance on the ward. I was only starting to be labelled as improving when I started to comply with the ward structure. For instance, my medical notes were more positive in their description of me and my symptoms after I had participated in some craft activities. Needless to say, craft did not make me feel better. I was permitted towards the end of my stay to attend the assertiveness group. The best thing that the nurses could write about me attending these activities, was that I stayed the duration of the whole group.

Perhaps the visits from my family, my boyfriend and my friends made me feel better because there is a cultural/relational facet entwined in positive mental health. Nurturing and developing my relationships made me feel better. The right drugs, at the right dose, at the right time also made me feel better. A mixed approach between biomedicine and social connectedness is the most therapeutic treatment for me. The powerful nexus between social connectedness, specifically relationships, and power is a strong Foucauldian concept (O’Farrell 2005).
Another measure of assessing wellness is by examining a balance between feelings and thoughts, and how these are negotiated and managed off the ward. By feelings and thoughts, I mean non-psychotic feelings and thoughts - manageable anxiety and manageable paranoia for example. I was deemed as dischargeable once my mood and my reasoning was considered more real and rational, as defined by the mental health professionals.

A major factor in being well again is the ability to manage within society off the ward. What does that mean? To be competent in society? I don’t think even the sane know. We do seem to know what is not acceptable: a mentally ill social misfit. It wasn’t until I had had a successful run of outings from the ward, showing that I displayed appropriate behaviour, that I was deemed well enough to be discharged. In preparing for my discharge I was expected to manage my own drugs and talking therapies, while managing my socio-cultural needs, for example nurturing and relying on relationships. (Kleinman 1980)

The medical staff were focused on the way I felt and the way I thought. The notes say things like “thinking more clearly” and “feels less confused, lost, dislocated”. It seems that throughout my stay I required constant reassurance from the staff, saying that “I’m not supposed to be here”. In these early days of my illness I lacked insight. It wasn’t until I had my first hospital admission that I first started to gain insight. I started saying to the nurses and doctors, “I’ve just realised something. Maybe I’m sick”. My admission at this time lasted a total of 39 days. I was discharged May 27, 1997.
Later, being somewhat of a mystery for my psychiatrist, I was diagnosed as somewhere between bipolar disorder and schizoaffective disorder and schizophrenia. I am currently thought to have schizoaffective disorder (for now). I was also thought to have the symptoms of post-traumatic stress disorder, anxiety and depression. Diagnostic labels are very haphazard. There seems to be a myriad of tests, scientific and not so scientific, that assist in the labelling process. Some mental health professionals are lost without their tests, while others are comfortable with things being vaguer. I will discuss later the use of the term ‘scientific’ married with ‘mental health’.

My second admission was 20 days long in 1998. My third admission was 17 days long in 1999.

Below are listed some of the tests that I was subjected to during each admission:

- Advanced Clinical Solutions
- Basic 23
- Wechsler Adult Intelligence Scale, 4th edition
- Mini Mental Examination
- Wechsler Memory Scale, 4th edition
- Test of Everyday Attention Version A
- The Speed and Capacity of Language Processing Test Version A
- Delis-Kaplan Executive Function System
- Depression Anxiety and Stress Scale
Numerous blood tests measuring levels of medication, such as Quilonum, must be given within the therapeutic range so as not show any great effect on the grander biology of the body. As I have mentioned my long term taking of Quilonum has caused my thyroid to be under active

Brain MRI - testing for physical causes of my mental health disorder

During my third admission (11 May – 28 May 1999) I was given a nursing care plan. The care plan went into detail about what I was supposed to be achieving by what date. The plan, simply put, outlined my milestones to get well. The initial plan, day one, was to have all pathology and planned physical tests. Days one to three required assessing my individual needs. Days three to seven involved learning to make decisions that increase a sense of control over the situation. Days seven to fourteen were about nurturing relationships and reconnecting with society. The nursing care plan was not completed. It missed out the allied health interventions, and feedback on my progression each week. The nursing care plan was not completed due to lack of staff. The plan was not high up on the staff’s priorities, although it was valued and considered an important part of quality assurance and evaluation.

The therapeutic group program involved:

• 0600 - get up and shower and dress

• 0730 - walk

• 0800 - breakfast
• 0900 - relaxation

• 1000 - group work covering
  o self esteem
  o managing depression
  o anxiety management
  o assertion
  o quiz groups
  o education groups

• living skills including
  o craft
  o self-development
  o healthy lifestyle
  o creative expression
  o current events
  o options

• 1200 - lunch

• 1330 - more activities as mentioned above

• 1600 - free time - visitors allowed
- 1800 - dinner
- 2100 - visitors leave
- 2130 - bed

As I have said, I believe that my memory was shaky for those first four to five years or so of my illness. I think that is my mind's way of protecting itself. Psychosis is a terrifying experience. When I try to think about psychosis and what it felt like, I can only grasp at thin wisps of fleeting nothingness. The thing that I remember the most clearly is the noises in my head. Mental health professionals like to label them ‘voices’. To hear ‘voices’ is an extremely tell-tale sign of schizophrenia and schizo related disorders. I have called my voices ‘noises’ in my effort of depersonalising them; to make them unreal and take some of the power away from them. My ‘noises’, are lessened these days due to Clozapine – a very effective anti-psychotic drug. I do still, however, get snippets of the noises, just to remind me, it seems, that I am still nuts. The noises frighten me. They engulf my mind. I cannot keep them away. They entrap me. Their whispers infiltrate my consciousness, and possess me with their messages:

“You are profanely absolutely bloody stupid...You are completely loathed... unwanted by everyone and everything.... never to amount to anything... ugly... disgusting...pitiful. No one cares about you in the slightest, even your family who are supposed to have unconditional love for you... You are not even deserving of that! Dying would even be above you...you are not even worthy of the expense of a funeral, though no one would come to the funeral anyway... I hate you, I utterly hate you, I loathe you! Just die. Just melt away into nothingness where you belong...”
All of these are spoken in different voices. About seven voices. They are shouting and hissing at me in total disgust.

During a psychotic episode, while the noises are saying such things and they are getting louder and louder, my senses are extremely heightened. I can feel the world caving in on me, crashing around me, I am asphyxiated and crippled. I can hear people talking to me, such as doctors, nurses and loved ones, but what they are saying is muffled into silence so that the noises dominate my sense of the real. The world has morphed into chaos. All I can do is hide. I hide behind chairs, tables, behind a cocoon I make with my arms. I try to detach from the world, ironically, while it crushes me down.

Just to make things perfect, I also live with extreme anxiety and depression. My anxiety is related to my psychosis. It is a battle to keep calm when your sense of reality threatens and demeans you.

I had three hospital admissions in the same hospital in the first three years. In those early years, my boyfriend who originally supported me broke up with me, I moved back home to live with my parents, I put on 23 kilograms, and I was put on the disability support pension. I was then labelled by the government as ‘disabled’, a lesser citizen who is dependent on and in servitude to the State. I tried to fight this derogative and patronising label, although in order to continue receiving the disability support pension, I had to keep convincing the State that I was sub-human and in need of their governance. That is, in order to receive the funds, I needed to define and precipitate myself as ‘lacking’, a sub-citizen and in need of dependence. I always fought the
category of being an insipid ward of the State (See Smith 1999; Lupton 2013). Fortunately, I always made sure that I was doing a course or volunteering so that my resume had no gaps in it. Apparently, employers are suspicious of gaps in resumes.

I spent those early years, those times I remember, in varying states of anxiety, paranoia and depression. I would try and exercise every day, when I wasn’t too crippled with anxiety or depression. Frustratingly I was unable to read at times. My cognitive functioning was adversely affected. I usually had about three mental health professional appointments each week. I have a healthy mistrust of mental health professionals. I remember one psychiatrist telling me not to trust any man who had a beard. My Dad has a beard.

I’m now relying on information given to me by loved ones to explain those times to me. The loved ones then are still my loved ones today, minus the boyfriend, who ultimately couldn’t cope with my illness anymore.

I learnt quickly that mental health was stigmatised. I decided not to disclose my illness to many, due to the shame associated with it. I was made to feel incompetent, incapable and unreliable. It was at the very beginning of my illness that stigma raised its ugly head. My illness was a secret kept hidden from friends and relatives. It was a private thing and we couldn’t talk about it publicly. Stigma is so entrenched it was and is hard to dissociate from it.
In 2000, I had not long before failed at working as a travel agent. That job proved to be far too stressful. I was in a constant state of panic. I wasn’t coping. I was mortified, humiliated and defeated again. It was when I started volunteering in aged care that things started to look better. I was about 26, three years after my first admission. Aged care was familiar to me as I had worked in the field during my undergraduate degree. I was soon asked to attend an interview for a paid job as a personal care assistant in the dementia unit. It felt good to be employed at last, in a job that I could potentially do.

With my new employment things were looking up, although I still suffered extreme anxiety. Soon after commencing my new employment I suffered another relapse. I was 27 years of age. I had collapsed several times, semi-conscious, and was taken to hospital via ambulance on each occasion. Once I was at the GP’s surgery when it happened. She was very concerned about possible neurological causes. The ambulance came that time too. The collapsing experience was quite unique. I would lose bodily control and just slouch in a chair, as if I was fainting. I felt extremely weak and powerless. Conversely, I remember feeling gratified that I didn’t have to worry about things, and I could just close my eyes and forget about everything. I felt safe. My anxiety levels decreased. I was going to the hospital. I felt validated; my symptoms must be real if I went to hospital by ambulance. These were physical symptoms. I was convinced that I was physically unwell. They would look after me there. By the time I reached the hospital, I was able to speak. Each time, the Emergency staff couldn’t find anything wrong with me. After my last collapsing episode, I think at number four, a doctor suggested that my condition seemed to be psychosomatic. This was the worst news! I was gutted! I felt disempowered because what I thought was a validated health problem turned out to be fake and made up in my head. I had lost
yet another battle! I felt like I needed to start all over again. I was absolutely determined to beat this!

I took some time off work. My medications were adjusted, and I received counselling. After this relapse (they never diagnosed my collapsing episodes as having a cause other than high levels of anxiety) and with some adjustments to my medication, I came back to work a new woman! My anxiety had decreased, and my confidence and cognitive functioning had increased. I had lost weight. Life was looking great!

I was able to move onwards and upwards, more so than I had in years. I decided to make the most of my strengths. It was then that I started to study to be an enrolled nurse. It took me two years to do the nursing course. I studied part time whilst working at the dementia unit. Once qualified, I began working at a residential mental health rehabilitation centre. I loved working there and felt empathetic to the clients from my own experiences. I felt comfortable working in this centre.

By the time was twenty-nine, I was in a relatively good place. I was working in an area I was good at. I had moved out of home. I started dating again. My friendships were supportive. I was having fun. I then met George. We fell in love and decided to move interstate. It was a happy time.
After moving interstate, I worked in the public hospital. I spent some time working in the Ward B (public)—the psychiatric ward, mainly caring for one patient at a time when they were a suicide risk. One patient that I took care of had to have her bra confiscated as she tried to hang herself with it. I was a newly trained nurse in mental health, yet I could tell the difference between a well-run ward and one that was not. As a nurse working on Ward B (public) I remembered the experience as unstructured and disordered. The ward was so hectic that I wasn’t given an orientation of the emergency procedures. The nurses seemed stressed and frenzied, working reactively—putting out spot fires as they arose. It was obvious that they were under resourced to manage the high number of patients with mental health issues. The entire ward was chaotic.

I soon left nursing. I was tired of dealing with the minutia. I felt powerless. What could I do? I started working in a mental health non-government organisation. I was a support worker in a program that aimed to prevent hospital admissions to Ward B (public), or to reduce stays at the Ward B (public). It was surreal being on another side—being the mental health worker.

My own mental health needed maintaining and nurturing, requiring me to have some sick days. I had to tell my boss about my mental health status. I didn’t want to disclose but was pressured to do so. I have been pressured to disclose to all my employers over the years. I don’t know which has the most precedence, the employer’s insistence and supposed ‘right’ to know, or my right to privacy and self-determination and the right to define my own self-identity. My own personal agency is again tied to others in governmentality and servitude to those with ownership of the modes of production, my employers (Marx in Rius 1994).
I tried to remove myself from anything related to mental health. I was sick of being tied so thoroughly to the category of disabled. I wanted to be free, in control of my own identity and governance. I wanted to be a full citizen, in control of my own resources of production and my own voice. I started to work in project management, then research. My psychiatrist at the time was not happy with me working full time and studying part time (I had just commenced a Masters in Public Health). She believed I only had the capacity and the ability to work part time. I felt disempowered by her views but was determined to move forward!

My relationship with George at this stage had ended, but I took it better than expected. I began my doctorate. For about eighteen months, I was stable and productive. I was 36 years old and happy. I was working hard, studying hard and enjoying myself.

The next memory I have after this time of productivity is a vague one of my lying on my couch, hiding. I had become delusional and paranoid again. I remember my boss at the door, knocking and calling out to me to see if I was alright. My employer got in touch with my psychiatrist who stated that I needed to be looked after or I would be admitted to Ward B (public). It seemed that there were no services to support me in the community.

After talking with my GP, my employer kindly took me in to stay with her and her family. I remember being embarrassed to learn that I was to stay with my employer, but we had also become friends by this stage. They had two small children and I was afraid I would scare them with my strange involuntary arms movements and foot tapping (these symptoms are typical of me when I am experiencing psychosis). I told the children I was playing the drums. I stayed
with my boss and her family for about a week. I spent my time scrubbing and cleaning, tidying and arranging things neatly and obsessively. When I wasn’t obsessively cleaning, I was smoking. In a period of about three months, I spent close to a thousand dollars on cigarettes. From what I can gather, I manically spent another few thousand on stuff that took my fancy – art, travel, pretty dresses, shoes, skin care products and whatever else I was attracted to. I didn’t have this money. I put everything on credit, maxing out every credit card that I could put my hands on.

I felt terrible that I was encroaching on my boss and possibly affecting her children with my crazy behaviour, although, my boss and her husband assured me otherwise. I opted to leave their home and stay with another close friend. I stayed with her for about a week, after which I stabilised a little. I did a lot of obsessive cleaning and ordering wherever I went. One time when my boss took me to see my GP, I proceeded to organise all the brochures in the waiting area. Firstly, in order of topic, then, in alphabetical order. I threw myself into my work, quite manically. My boss pulled me aside at work to tell me to calm down. I was being manic - overwhelming myself by overworking.

I was starting to show signs of psychosis. My employer contacted my father, who then travelled interstate then came to see me.

I have a memory of my Dad and I seeing my GP. They discussed my needing some time in hospital. It was agreed that Ward B (public) was the last option. They decided on me going back home to go the public ward there. I had been to this ward during the first years of my illness.
My life will never be the same.

I will be forever broken.

And so, I begin the narrative of the three wards.
I often wonder what it would be like to think like a normal person, to feel like a normal person, to experience life and to love as a normal person. As someone living with schizoaffective disorder, I wonder if my experience of life is that different from the so-called ‘normal’ people. I will forever be ‘Othered’, subhuman, dependent on the State, and somewhat a deviant. As Said argued in ‘Orientalism’ (1978), describing (post)colonialism, there is a divide between ‘West’ and ‘East’. West are the colonisers, having power over the East the colonised. Those with major psychotic illnesses are the colonised (East) who are controlled by the colonisers (West). People from the East are here called the Others. The East have been Othered. The West has exiled us from normalcy.
This is my life living with schizoaffective disorder. I will try and describe to you in this chapter what living with schizoaffective disorder is like. This chapter describes some of the cultural phenomena I must deal with day in day out.

Every day I have to manage my illness. Some days are harder than others, some minutes are harder than others. Over the years I have developed exceptional insight, according to many mental health professionals, a far cry from the confused individual I was when I first became ill. Even though I have this supposed great insight I still find it difficult to make judgements about what is real and what is not. The most reliable yardstick for reality that I have is asking people that I trust around me, “Is that real?” , “Did s/he say that?” These people include doctors, nurses and psychologists, and more commonly and importantly my family and my dearest friends.
This ever-present confusion about reality adds up to me having poor self-esteem. I doubt everything I hear and see and smell. I constantly hear the cruel noises shouting at me, telling me how stupid and hopeless and worthless I am. It is tremendously difficult navigating between these noises and the stimuli I manage externally in the supposed ‘real’ world. What do I believe to be real? What do I believe? Without knowing what is real, and when I cannot ask another, I am forced to make leaps of faith in judgement. Negotiating a thought or a sense becomes an exercise in second guessing what is right and what is wrong. I will always live with this uncertainty. (I have noted, however, that since commencing Clozapine, the unwelcome noises are a lot quieter.)

The sense of touch grounds me. When I am unwell, or beginning to get unwell, I am often seen tapping: tapping the chair I’m sitting in, the table I’m sitting at or tapping my head. The sense of touch centres me. The surface stays the same. I cannot distort it. The senses of hearing and sight are subjective for me. Whereas touch is stable. As I go about my everyday routine, I constantly ground myself through touch. I touch the wall I walk past in the corridor, the floor at my feet, the computer keyboard I type on, the pages of the book I am reading, the hair on my head as I brush it for the day. With touch, I don’t need to ask others, “Do you feel that?” I trust in my own sense of touch.

It is difficult to use my tried and true method of touch whilst navigating my own self-identity. Without this stabilising method of assessing truth and with all of the second-guessing and confusion about reality, I am left with having the construction of a negative self-identity. My identity construction is not my own. It is determined by the values and beliefs purported by
society and the power influences that sway the culture, politics and economics of society. My sense of self identity is already consumed by the social forces in the processes and production of socialisation. My identity is not my own. It is given to me. I do not have the power to say who I am, where I belong and what I value. I often lack the strength and power to create my own identity, as I am unable to take control over the resources that affect my life, or the outcomes of relationships I have formed. That power is taken from me.

For the 20 plus years I have lived with schizoaffective disorder, I have battled with my perception of reality. It is difficult to decipher what is real when the noises are loud in my head.

Are they real? This is a reoccurring question. How does one assess what is real and what is not? There is reality judged by the senses. There is also the reality judged by our thinking. Then
again, how does the philosophical perception of reality differ from an individual perspective of reality? Can they and should they be separated? In my readings of philosophy, constructions of what it means to be real are cerebral. As an anthropologist, I am concerned with the social construction of reality. I cannot separate the cerebral with the social and cultural. Neither can I separate reality from other social and cultural phenomena like culture, politics, spirituality and economics.

An important premise of my thesis is my belief that medical science disempowers the mental health patient. Regardless of how institutionalised – as an inpatient or outpatient – they are disempowered through misrepresentation and the tunnel-vision of medical science. It is through this misrepresentation that the mentally ill become sub-citizens and social misfits (Szasz 1970): they are often perceived as engaging in anti-social behaviour, so they must be removed from public sight. There are some correlations between public policy dealing with the psychotic and the Indigenous. My identity as a subhuman is crafted for me by medical science, carefully measuring me and labelling me. I am misrepresented by the dominant and powerful mental health professionals as a mental health patient, not a full and equal human being. This part of identity construction is authorised by the scientific paradigm. I am, in effect, socialised through modernist medical science and the cultural phenomena and socio-historical context of which medical science purports to (DiGiacomo 1987). My identity is overwhelmed and overtaken by just one fraction of who I am - a biomedical facet - which can be treated by medication which, simply put, balances the biochemical phenomena in my brain. (Goffman 1963; Kleiman 1988) Can I be wholly identified by brain chemistry?
The label bestowed upon me has left me powerless (Becker 1963; Scheff 1974). Powerlessness is demonstrated in many realms. I am powerless to construct my own self-identity, be it an identity as defined by mental health, or not defined by mental health. I am an object of medical positivism, to be measured and weighed. I am forever battling the right to identify myself holistically. I am frustrated because I am so much more than my illness. I am more than a client with schizoaffective disorder, identified by psycho-metric testing and blood tests - biomedical indicators. I am Rachael Jane McMahon. Socially, I am a daughter, a wife, a sister, an aunt, a friend, an employee, a student, and a girlfriend, plus more. Spiritually, I have the heritage of being Catholic; currently I practice mindfulness. Culturally, I adhere to the values and ethos of my community. Economically and somewhat politically, I endeavour to have control over the resources affecting my life. I am all of these things and more.

I can negotiate these facets as best as I can, in the non-medical world, with the limited agency I have. However, as someone living with schizoaffective disorder, who is dependent on medication, medical science and the State to remain as well as can be, I cannot escape being pathologised and having my identity crafted by medicine. I cannot escape science, as the treatment for me is mostly and historically pharmaceutical. Psychiatry is now exploring and learning about its social situatedness in the social sciences. It is hard to describe which treatment is more effective – medical or social. I’ve come to believe in a combination of both. The emphasis on either remains the preference of the individual. As an anthropologist, I would love to argue that society and culture are the main foundations to sound mental health, but I can’t. Even from my example, I need the support of my family and friends, being grounded in my values and beliefs, as well as the psycho-metric drugs that have been prescribed for me. Wellness
is a balance between the healing properties of socialisation and culture and those of medicalisation.

My identity is also defined by social stigma. There is a public perception of major psychotic illness which confines its sufferers as deviants. As alluded to earlier, there is a hierarchy of mental health conditions. Depression and anxiety are the best ones to have. It is not unusual for famous people to be suffering depression and/or anxiety. Indeed, it is very common to have such a diagnosis of depression or anxiety. There is merit in that, seemingly a badge of honour, especially for the creatively minded or those who call themselves ‘artists’. Eating disorders also seem to be a phenomenon of the modern age where the concept of the self is pivotal. Schizophrenia and its friend schizoaffective disorder are not esteemed illnesses. There is great shame in any illness with the prefix ‘schizo’. When one hears on the news about a person who is wielding a knife down a street, they are often identified with the prefix ‘schizo’. Those of us living with schizoaffective disorder look to the likes of John Nash to save our reputations.

Public portrayal of madness in contemporary Australia does not empower the mad. The television series, Changing Minds (Australian Broadcasting Corporation 2014) depicts a psychiatric ward in the present day. Changing Minds gave the viewer some insight of being mentally ill and being treated in a psychiatric ward. The Liverpool Hospital, where the series was filmed, houses one of the busiest psychiatric wards in Australia, where 1200 mental health patients are treated each year. In Australia, for males aged 15 to 24 years, suicide is the major cause of death. Twenty people attempt suicide each day. For those living with schizophrenia, a third become well and don’t relapse, a third remain well on medication, and a third worsen. Some
people living with mental illness will never recover completely, some of their cognitive functioning will be lost with each episode of being unwell. This is the case with me.

Each time I have a psychotic episode, my cognitive capacity diminishes. I really notice when this happens. I could read a page of a book, the same page, for two hours and not have a clue about what is said. My memory is terrible, and retaining knowledge is hard. I must take extra time, using varied methods, so that I can begin to be in a still place to study. With a calm mind and repeated ways of reading and processing information, I can just get by. A long-standing and ongoing effort for me is to control and manage my anxiety levels, to limit further psychotic episodes. It is a mammoth effort for me to put all my mental resources into controlling my anxiety levels. Limiting anxiety means limiting psychotic episodes which means maintaining cognitive functioning.

_Changing Minds_ also illustrated the intense powerlessness and lack of autonomy of the mentally ill. One patient became aggressive with a nurse when, after waiting for hours to see his assigned clinician, he was told that the clinician couldn’t meet him yet because the clinician was heading off for his break. The patient arced up yelling, “I want a break too! Where’s my thirty minutes off the ward?” The nurse tried to reassure the patient saying that they understood, but the patient retaliated by yelling, “‘I understand’ doesn’t cut it for me!”

The television series depicted the warped sense of reality displayed by the patients. The job of the mental health professionals in the hospital was to support the individual patients to get well, that is to minimise depressive, anxious and psychotic symptoms. The mental health professionals
take the lead in reducing symptoms so that patients can have clarity about reality. The main tool employed to assist patients to have a clearer mind are psycho-tropic medications. A structure is provided by medication in conjunction with cognitive and emotional supports provided by psychological therapies. Patient and staff can together unpack the psychotic episodes and try to make sure they never or rarely happen again.

I have adopted an anthropological study of mental health. Specifically, an autoethnography of schizoaffective disorder, looking at the ways I have been labelled as a lesser human, and understanding that labelling is part of the culture which encompasses it. The job of an autoethnographer, such as me, is to unpack the cultural phenomena of psychosis, to better understand the values and purpose of living with a major psychotic illness. There is more to psychiatry than medical science. Cultural analysis commands depth of understanding, bringing symbols such as medicalised ‘shrouded’ language into clearer meaning. There are limitations to medical science in its approach to effect recovery. Medicine arrests symptoms but is not a tool for recovery for the patient as an individual or a social/cultural actor. Treatment of the mad under psychiatric medicine can be correlated with the treatment of the Indigenous people under colonial, metanarrative hegemonies, as per Derrida (1978). This in turn supports the grand narrative of medical science. The mental health professionals are agents of this grand narrative. Similar plights have been identified by feminists, race theorists and queer theorists (Campbell 2000).

Apparently, the mental health ‘misfits’ of society need parameters, governance, control and ruling. To live like this, to feel imprisoned by my own mental health, I am left without cause or attribution. I am judged by my capabilities or assumed lack thereof. I am judged to be lacking
as subhuman and basically stupid. Yet again, I am not considered to be fully human and lack the competency to live a full life. I am labelled.

I have not the social strength to resist such labelling. Indeed, according to labelling theory a label of ‘psychotic’ can become a self-fulfilling prophecy. I become what I think and feel, guided and stemming from the decree of powerful others (Becker 1963). The psychiatric profession labels me in such a way, and the community follows suit, especially if the subhuman is displaying anti-social behaviour. Such behaviour is undesirable.

A prominent way people with mental illness are dehumanised, by professionals and non-professionals alike, is the telling of a narrative in which they are unfit to be parents. It has been suggested to me by those in my social networks that as someone with my condition, I lacked the skills to be able to be pregnant, survive the psychological stress of the birth, and give the newborn enough love so that I could form an attachment to my baby. Basically, it was assumed that I lack the ability to raise a child because I have schizoaffective disorder. I don’t remember there being such a side effect on the back of any of my medication boxes.

This is a very confusing state of affairs. Can I or can I not have children? Should I or should I not have children?

Many doctors and nurses over the twenty plus years of my illness have suggested that I couldn’t and shouldn’t have children. Other reasons given to suggest that I cannot have children are: that
I could relapse and never be as well again; and/or the compounded stress of being pregnant and having a baby could precipitate into a larger psychotic episode worse than I have ever experienced before. I have heard people say, when talking to women with a major psychotic illness, that they should consider the option of having their fallopian tubes tied. Similar suggestions have been made about people living with Down Syndrome (ABC 2016). For many, many years I was told both by family and professionals, that I could not and should not have children. I was told that I am almost guaranteed to get post-natal depression. Also, apparently, I won’t be able to breast feed.

Anyway, pregnancy and being a mother will be difficult. At the very least, I will need to take extended time out with a lot of support, which will undoubtingly bleed me dry financially. What to do? Should I bow to the accepted cultural norm of being a mother? Although, more and more women are choosing not to be mothers; to have an identity separate from their reproductive capabilities.

I went to see a psychiatrist earlier this year who specialises in pre, peri and postnatal care for those mothers requiring psychiatric treatment. He stated that I was in fact able to have children. I could stay on all of my medications. The only medication I would have to come off would be Quilonum and that would only be during breastfeeding. The doctor said that I would just need extra support during pregnancy and afterwards, just like – I imagine - a normal mother would. Again, he emphasised that I was perfectly able to have a child.
This was overwhelming news! For twenty years I have been told that I lack what is needed to be a mother. Also, that due to having a severe mental illness, I should not have a right to have children because I am incapable of loving a child. It is uncanny to label someone with schizoaffective disorder as someone who is not capable of love. Other symptoms, yes. Lacking the emotion of love, no. The emotion of love is omnipresent across all cultures, all faiths and all values (Kleinman 1988). And – all illnesses and disabilities. The sad thing now, knowing that I could have had children, is that I am reaching my biological limits on having children due to my age. For many, many years I wanted children. For many, many years I was told I could not have children.

It is often emotionally painful to hang out with my friends who have children. Some years ago, I went for a trip to the coast with some very close friends, their husbands and children. In the three days that we were away together I had one two-minute conversation that did not involve pregnancy, stretch marks, birth, breast feeding and toddlers. After three days I broke down in tears, I told one of my best friends that I didn’t think I had anything in common with my oldest friends any more now that they were married with children. She rightfully replied that she is a skilled engineer capable of running a sewage plant but did not know how to deal with her two-year-old child. She needed to talk about her new experiences with her child so that she could feel supported and gain valuable knowledge that talking with other mums could give. I thought this was a good call. We have been much more understanding of each other since.

For many years those closest to me have attempted to console me because they thought I couldn’t or shouldn’t have children. After talking with others about the ‘trials and tribulations’ of having
a family, how fulfilled their lives are now and how life was meaningless before the euphoric
experience and feeling of motherhood, I would get a nod of condolence. “Don’t worry Rachael”,
others would say, “You can fulfil your mothering wants/needs elsewhere”.

So, I find myself reflecting, why is it alright for my friends to have children and not me? Why
have I found it so hard to find a life partner when so many of my friends have loving long term
relationships? Culturally, where do these questions lie? What values and beliefs are instilled in
my culture that dictates the definition of a fruitful life? And, more importantly, what values and
beliefs installed in my culture state that I lack the ability or capacity to live a normal, albeit
fruitful life? Obviously, I need help, medical help to change the way I am; a biological mishap.
Though, as an anthropologist, I am interested in the cultural perspective of being mad, and how
that affects my capacity, or results in incapacity. Why am I discriminated against? (Smith 2004;
Mordock & Hall 2002; Gladstone, Boydell & McKeever 2006)

I’ve had those closest to me question my capacity and ability to complete this thesis. They have
questioned why I am so determined to finish it and why I put so much pressure on myself. Their
concern comes from a good place. Yet, I feel defeated. My loved ones think that I must, of
course, be struggling. The very strong message I hear is that I am not able to live a full life. I
lack the capacity, capability, competence, internal resources and aptitude.

As well, I am disabled, handicapped and labelled by the State, via the power of medical science,
as requiring constant monitoring and measurement. I am required to maintain close contact with
my team of health professionals. If I do not comply, this entices the health professionals to
become suspicious and wary, assessing the risk of another psychotic episode and the possible necessity of interventions and involuntary treatment?

I am in servitude. I am a subject of prejudice and judgement. I am in servitude and will be for as long as I am sick, which will most likely be until I die. There is no end to my dependence on the State. I am forever trapped into a reliance on the public health system where I need the State for my highly regulated treatment.

I don’t think I’ll ever be free. I have certain freedom in my everyday life, freedom in so much as my everyday experience of living with a major psychotic illness will allow. However, my everyday experience includes quieting the noises in my head, and managing high levels of anxiety about many things, such as, going to work, socialising, negotiating relationships, and other things like heights, stairs and driving. For example, I cannot drive above seventy-five kilometres, over bridges, long distances, or in merging traffic.

I still must see a mental health professional at least once a week. This commitment takes up five hours. Each week I see one or more of the following: a psychiatrist, psychologist, neuropsychologist, Clozapine nurse, pathology nurse, dietician and/or the GP. At least a third of the five hours spent with the health system is waiting. The people waiting with me are generally unkempt, unhygienic social outcasts who do not respond to or engage with social niceties; they seem really disabled from their illness. In my medical notes I am often described as “well kempt”. I always feel misplaced as I sit and wait. I feel like I don’t belong. I feel isolated, in a separate existence to the misfits. I know that the Clozapine nurse will bump me up to the top of
the queue, as I usually must come to the clinic in my lunch hour. It shouldn’t be the case that sometimes I go to the top of the queue. It’s not fair.

I feel terrible making judgements about my fellow Clozapine users. I do not know the various facets of their lives, and what has happened to them to bring them to this point in time. I ask myself, “Am I stigmatising the other patients? Am I categorising? Am I a misfit?” I think I am a misfit too, not fitting into my chosen world of academia. I can very well be an academic misfit, not meeting the standards with my limited and stunted cognitive functioning. Perhaps I am in academic purgatory, wanting to come to intellectual heaven but am lacking the fundamental tools, like a functional brain, so I slide back down to a life with limited opportunities. Living with the label of “disability” makes sure that I have limited opportunities.

Mine is a disabled existence, possibilities are limited. I don’t want to say that a disabled person cannot have a full and fruitful life, yet at the same time I want to acknowledge that having a disability does place a confinement on what you are able to do. For example, with the use of a wheelchair or hearing aid, things can be done, but they must be done differently. I will find it difficult to complete a PhD. No mental health professional has said that I cannot complete a PhD. Rather, they have said it will be harder and may take me longer than the typical PhD student. I just must try different tactics, take extra time and go to hospital every now and again to get a mental health service, tweaking the medication and my functionality. I just must keep on fighting, trying to figure out the most likely reality as I go along.
The possibility of a future hospital admission is always lurking in the back of my mind. Now that I can go to Ward C (private) for respite if needed, without fear of poor treatment, with the comfort of knowing the staff will treat me well, I feel some solace. (A description of Ward C (private) is given in chapter nine.) The choices that money buys for you! Money eradicates many ramifications of psychosis it seems. I don’t want to be that engaged with the mental health system. As little engagement as possible is my desire. I have seen too many people with mental illnesses come in and out of the wards, like a revolving door, with recidivism a way of life. I feel dishonoured as it is by the structure of my treatment. I want to run away from being involved in any sort of institutionalisation that facilitates recidivism – for me it is dehumanising, pathologising, disempowering and shaming the self. Being a part of institutionalisation, that is being an inpatient semi-regularly or being engaged as an outpatient regularly, cements your dependence on the State.

Be real. Does money really buy you better medical treatment? Are there better drugs, better doctors and nurses and allied health professionals in the more expensive wards? Is the treatment more holistic or does biomedicine reign where there is cash? There is less pressure to attend group activities, and more opportunity to spend time on your own in your private rooms with television and an ensuite. How is the culture of medicine, psychiatric medicine, different in private psychiatric wards than say, for instance, in the Ward B (public)? (A description of Ward B (public) is given in chapter eight.) Is being institutionalised by private medicine the same as being institutionalised by public medicine?
It is fruitful here to employ a Marxist model of mental health service. I posit that the rich have control over the resources that control their lives and the poor are subject to the owners (Bracken & Thomas 2005; Grob 1990; Brown 1984.

July 2016

The strangest thing happened to me. I took note because it only happens once every two years or so. I felt calm, at peace, content. The sensation just sort of came upon me. Not a wave, but a centring. It was incredible. I felt still in my mind. I had what one might describe as clarity. There was no noise in my head whatsoever. I remember thinking tonight that it is incredible how much I take for granted. I have grown used to the noises over the years. I never really realise how noisy it is in my head, until they are gone. I must say that the stillness is awesome! My thoughts are quiet and still. My thought processes are lineal rather than chaotic. God it’s good to think rationally and systematically instead of randomly and haphazardly! To think in order rather than disorder.

I felt happy.

What a release!!
I really have no idea why this came upon me tonight. I was out watching the grand final of the local roller derby competition with some friends. Then it came upon me that my mind was still. It lasted for about two minutes. Two minutes of clarity and bliss. Then it started to get noisy again, in my head. Again, I felt overwhelmed by aural stimuli. After only two minutes of stillness was I reminded of the hell that I put up with day in day out. The centeredness and sweet feeling of peace gave me a taste of how I imagine the broader population thinks. Is it true that most people live without noise in their head? It must be liberating having such a clear, lineal mind and calm thought processes. I’ve never been so envious in my life, now that I have an inkling of an idea of what life could be like. Oh, sweet normalcy! Oh my God what a phenomenal feeling! And why on earth would it happen to me while watching roller derby with friends?

Now of course, as I am writing, my gratifying oasis has passed.

Damn that noise!

Even though I have two-minute hiatus every two years, I will always be broken. My life to various degrees, will always involve noises, paranoia, surrealism, anxiety, being fat, being a subhuman, and being undervalued. I am an active, productive member of society. I work and study, and have goals and aspirations and enjoy fruitful, beautiful relationships. Living with schizoaffective disorder, I will always be shackled and under the scope of medical measurement and observation, even when it seems that the mental health professionals are just going through
the motions, finding their way in the dark. Has there been a definitive difference in my life after diagnosis? With diagnosis, am I in servitude forever? I believe so.
There is a fundamental problem I have in life – trying to gauge what is real and what is not real. And from that, who or what has power over me and my thoughts? A huge issue for someone wanting a career in academia. Being an anthropologist who is in love with all things Foucauldian, I can happily describe my knowledge as being socially constructed (Hacking 1999; Haslanger 2012). In fact, I would argue that all knowledge is socially constructed and acculturated. All knowledge has an historical birth time and place, development and maturation. Whether the knowledge is right or wrong, true or false, valid or invalid, is relative. Reality for a person with schizophrenic tendencies is a subjective and turbulent phenomenon. (Foucault 1967; Szasz 1970)

My common symptoms are not being able to trust my thoughts, not knowing what is real and what is not real, extreme anxiety and paranoia, poor memory, poor cognition and poor concentration. Then there are physical side-effects: weight gain, dry mouth and decaying teeth (Note: these are side-effects I experienced before I had started taking Clozapine).
A nurse in Ward A (public) wrote in my notes, “[Rachael’s] anxiety is due to the constant chatter of voices in her head which at times can become quite overwhelming and distressing.” Sometimes I think people see me as vague as I stop talking mid-sentence, but it is because of all the chatter in my head. Honestly, I don’t know which version of reality to believe.

This and the following two chapters comprise three narratives on a rough timeline from 2012 to 2014. These fit into an overall chronology of my illness, which is as follows:

**Town A**

1997 – First hospital admission – initial psychosis

1998 – Second hospital admission – more issues with psychosis


2000 – Presented to Mental Health services with thoughts of self-harm

2002 – Sudden episodes of collapsing. Episodes turned out to be psychosomatic. Recovered well.

**Town B**

2011 (October) – Acute manic/hypo manic episodes.
Town A

2012 (October) – Paranoia and anxiety and depression.

Admitted to Ward A (public)

During Ward A (public) stay - PAI (personality assessment inventory) assessment done

Town B

2014 (February)

Admitted to Ward B (public)

Town A

2015 (June)

Admitted to Ward C (private)

2015 (October) – Neuro-Psychological Assessment done.

In the years prior to this narrative, I lived in Town B and had been monitored by my psychiatrist and GP for close to seven years. By then, my diagnosis was committed to that of schizoaffective disorder. I had not been in hospital for 15 years. I had been mostly well in recent years. I had a relapse of my symptoms in October 2011 when I became hypomanic/manic. I am oblivious as to the cause. I always seem to be. During this time, I hardly slept, I worked ridiculous hours, and I spent thousands on whimsical things, including commissioning a painting of myself entitled
‘St Rachael of the Plentiful Milk’, because I drank a lot of milk at the time. I felt like I was running a million miles an hour. I had never been so productive.

Mania isn’t sustainable. I managed until October 2012. By this time, I had exhausted my friends and family. I remained dysfunctional in everyday matters. I was working two days a week due to the restrictions of my PhD scholarship. I was so unwell. I took five months off work and study. My supervisor and a close friend took time off work to look after me. Other good friends in Town B also took care of me so I didn’t have to go to the Town B hospital.

I lived in constant anxiety and paranoia that I might offend someone or let someone down. I wanted to get back to work and do a good job. I never wanted to offend anyone. I had been told that I over apologise. It’s just that I didn’t know what was real and what wasn’t. So, I over compensated, and this led me to detach from reality, becoming dissociated. At the time of this admission I was working as a researcher and studying for a PhD and believed that my medications were making my mind unclear, and that my concentration and memory were poor.

My manic symptoms had changed to anxiety and paranoia. My anxiety and paranoia were out of control. My psychiatrist prescribed me Valium for such occasions. Up until now I only used Valium about four times a year. I started using Valium when needed around the time of my relapse, and soon enough I became tolerant and dependent. My psychiatrist had been decreasing my doses slowly. I felt that my mood had become low. I had been depressed over the last few months.
I had been seeing my GP in Town B. She noticed deterioration in my mental state and recommended admission to a psychiatric ward. I reported briefly working in the psychiatric unit in Town B and felt that this was a frightfully awful place to be. I therefore decided to come down to Town A and to stay with my parents, until a vacancy arose at Ward A (public), where I had been before. I was assessed in Town A and had been waiting for a bed on Ward A (public). Here I felt safe.

My GP wrote a letter to the medical staff at Ward A (public). My GP stated that I had deteriorated at the end of 2011 due to decreases in medication: I was managed as an outpatient by mental health services and supported by my friends in Town B. This episode was different from my previous deteriorations and had features of mania with little sleep, impulsive spending and agitation. Valium, or its generic name diazepam, was introduced as part of the management strategy. I stabilised over the last months and the psychiatrist saw me and discussed a weaning regime off the diazepam from a starting position of 15 mg. This was commenced but it transpired that I had been taking more than I thought, more like 30 mg a day, so again I deteriorated quite acutely. I experienced intense anxiety and difficulty with thoughts – pervasive and negative thoughts - as well as issues with cognition, with a possible suggestion of diazepam withdrawal underlying the condition. My GP had taken the diazepam dose back to 20 mg a day with an idea of stabilising me and then weaning me off diazepam again. My GP stated that my mental state remained very fragile and that my medication needed to be reviewed and stabilised.

And so, I was accepted for admission to Ward A (public).
And so it begins, again

Not long after admission, a nurse helped me identify some aims for my time in hospital. My aims for this admission were to review my medication so that the symptoms, especially auditory hallucinations, improve and so that side-effects are minimised (in particular, weight loss is attained, and I am able to think more clearly when studying and working). My Town B GP and psychiatrist believed this episode was due to a reduction of medication – olanzapine and diazepam.

The Ward A (public) medical notes go on to say that I have been experiencing auditory hallucinations for years, and I state that these have never really gone away. They take the form of female or male voices that I do not recognise, who address me directly saying derogative comments. At that moment these were soft voices, like whispers. I stated that I was pretty good at ignoring these and not thinking about them.

One of the initial inpatient notes made in my 2012 Ward A (public) file was:

“Presented to [Ward A (public)] having returned to [Town A] five days ago - staying with parents - has a list of diversionary techniques to ignore her thoughts. Experiencing auditory hallucinations for years – ‘has never gone away’. Was 23, 24 and 25 years when she was in Ward A (public). She has very little memory of the events. For 12 years Rachael was moderately fine and functional. Then in October 2011 suddenly became unwell and had five months off
work and study. Rachael presented as hypomanic/manic. Has poor concentration and memory. Works as a researcher and is currently doing a Ph.D. Is concerned about weight gain, as well. Wants to be able to think more clearly so she can study. Has worked briefly on the mental health Ward [in Town B] – finding it both frightening and awful. [Thus, the travel interstate to a less daunting and more therapeutic ward.] Rachael also worked in a mental health rehabilitation service and a dementia unit [in Town A], before moving [to Town B].”

I felt paranoid and anxious all the time. I had very good friends. I had to check with them constantly - “Did that just happen, or did I imagine it?” I have had this constantly since the onset of my illness, over twenty years ago, so I am pretty much used to it. I don’t know any other way to think. I tried to work on myself to improve myself.

A nurse in Ward A (public) wrote these notes, “Rachael told me that she was the fourth child of six children and the oldest girl. She told me her parents were in their 70s and found it difficult to manage her.” Rachael said, ‘I feel terrible that they have to support me. My parents are both sick with lung problems. They are very devoted parents; their lives are centred on supporting us, that is, their children. I don’t like being sick and depending on them. I feel guilty.’”

Out of respect for my parents, I was committed to getting well in hospital. An important part of the healing process on the ward was to commit to the ward program; to the ‘therapeutic’ and ‘rehabilitative’ ward activities. However, I disengaged with the ward program. I rejected the notion that the ward program was good for all. I rejected that notion that biomedicine was good for all. (A discussion of ward programs follows later in this chapter.)
Importantly, it was at this stage in my healing, healing that is current up until now, that I turned my gaze as an amateur anthropologist to the culture of biomedicine. Biomedicine was and is an overwhelming paradigm in the science of medicine, a paradigm that epitomises the hard sciences and dissuades the social sciences. Ward A (public), where I had my first mental health service experiences, was the place where I began to conceptualise the methodology of autoethnography, although I didn’t know what it was called at the time. It was at these early stages of my illness, that I first gained some insight to what I was to call the Silenced Manifesto - the suffocating silence of the shackles of the marginalised and the discourse that embeds it. I first began to understand how the Silenced Manifesto engulfs the institutions of mental health.

_Day one - I am broken_

Christ not again! Who’s saying that to me? I haven’t heard you being so loud in ages. Why are you all being so cruel? Am I really so despicable, incompetent, stupid and hopeless? So, is it a fact then? I am fundamentally a screw-up who is stupid and has no place trying to work in academia. It’s a wonder I still have a job! What was I thinking?! So, it is actually true then? Needless to say, my productivity was practically zilch as I was trying to quieten the noises in my head. And then there are all the other feelings. The walls falling in on me, the people reading my thoughts and seeing my soul when they looked in my eyes, the paranoia and escalating anxiety, well, I had to try to ignore that because people would think I’m bonkers. Sadly, this is the truth, and I couldn’t hide it like I have learnt to over the past 20 years of my illness. I have
schizoaffective disorder. Basically, that means that I am broken, and often so. I also have bouts of depression, which are more acute and less frequent.

I was disappointed to have to leave Town B. Though, Ward A (public) is a better and more progressive loony bin than the one up north. Besides, I have a lot of support from family and friends in Town A. Over the years I have learnt to hide my illness, to silence it as it is not socially acceptable to be talking about noises in your head, or to repeatedly ask people what is real or not real. Angrily I had to accept that I needed professional help.

I stayed with my parents and waited for five days to get a bed at Ward A (public). Meantime, the community mental health team kept an eye on me. I felt a failure during this time. I had lost the battle that I have been fighting since the last hospitalisation 15 years before. My sense of self had diminished. I now had to put my faith in the mental health professionals that I had also been fighting, or more likely negotiating with, ever since I was first assessed and diagnosed. My psychiatrist in Town B fought with me for years to get me to modify my lifestyle, or slow it down so to speak, so that I could avoid becoming unwell. She was concerned that my illness would affect my reputation in Town B, specifically in my work culture. On returning to Town B, that psychiatrist stated that none of her clients go to psychiatric wards and eluded that I find another psychiatrist. I did do this, after I started taking Clozapine.

So, as I have said, I have lost the battle that I most hate to lose. Succumbing to mental health treatment is like surrendering yourself to biomedicine. Almost like offering yourself up for medical experiment. Mental health treatment relies very much on trial and error. The patient
has very little agency. You surrender your freedom. You have few rights. If you show signs of too much defiance and little signs of compliance, there is a strong chance that you may be sectioned or given an involuntary treatment order.

Yet I was desperate to be admitted to the Ward A (public). I remembered the times I have been admitted to Ward A (public) for treatment. I certainly didn’t feel safe by possibly being admitted to Ward B (public). Ward A (public) seemed to the best option available.

During these times of illness, I admitted defeat. I submitted myself to the science and the politics of medicine. I relinquished myself to biomedical treatment. I conceded to the orders of the mental health profession. I forfeited my personal freedom to the current mental health discourse. I handed over my basic human rights and became dependent on the State for treatment. I had become a sub-citizen with little agency and what little agency I did have was dependent on opinions in the mental health system. The socialisation of the mentally ill into the broader social strata is heavily influenced by the psychiatric ‘expert’ opinion. This socialisation process involves creating social stigmatisation of the mentally ill (Foucault 1967; 1973; Kleinman 1980). And yet, I ached to be admitted, to feel safe – feelings that trumped any rights or personal freedoms that I have in the ward. I was desperate to be admitted to Ward A (public). So here I was, being admitted, once again, into Ward A (public).

Day two - yes, I am broken. Can being a psychiatric inpatient glue me back together?
Well I am now officially in the loony bin in Town A because, yet again, I am having issues with anxiety and reality. The situation had grown beyond my usual coping technique of asking close friends and family, “Is that real?” or “Did I hear that right?” This is the fourth time I have been in this loony bin. I am admitted to the same ward at the same hospital, but they have had a refurbishment since I was here near 20 years ago.

After my admission yesterday, I awake after my first night in the ward. I observe my surroundings. The walls are lemon with feature walls of mustard. All the rooms are spread out down a corridor with lemon walls also. The doors and the wall railings are finished with a wood veneer. The nurses’ station is at the end of the corridor of rooms. The ‘sacred’ medication room is a locked room by the nurses’ station. It is preferred that patients don’t hover around the medication room as access to the site might be compromised. Who knows what mayhem would arise if the patients compromised the sacredness and secrecy of the medication room? Each time, the nurses must go through a rite of passage to qualify to give out some of the ‘dangerous’ drugs, including diazepam, which I have become addicted to – thus my access to diazepam, what they call a S4 drug, needs special vigilance. The rest of the ward offices make a rabbit warren where the allied health professionals hang out. Further down the warrens are the particularly sacred offices of the psychiatrists.

Each patient has a single bed, with a corner style unit desk and chair, a cupboard and drawers at the end. Of course, there are no coat hangers in the cupboard. We may top ourselves after all. There is, however, a full-length mirror in the door - a necessity for all girls. We may be loonies, but we are still ladies! I was supposed to hand in all sharps and devices with cords, for example,
nail clippers, tweezers, and hair straightener, but I have hidden them. I am also supposed to hand
in my crochet when not in use, but I have not done that, and no one has noticed. I attempt to
personalise my new space as much as possible. On my desk are some bush flowers I have picked
on my walks around the hospital bush grounds. I also have a large arrangement of dried flowers
from my sister’s friend’s wedding. I have a pile of necklaces, brooches and earrings. I have a
few weird toys that I am quite fond of due to their utter strangeness. The floors are carpeted in
blue. I have a quilt of mum’s and a teddy and pillow from my sister’s home that I sleep with
when I stay with her. I have two drawings from my god daughter on the wall, and a few
gorgeously cute drawings from other friend’s children, plus a drawing of a funny looking bearded
guy drawing to cover up a hole in the wall. All in all, my little alcove feels quite friendly.

Off the corridor where all the crazies sleep is a couple of lounge rooms with a TV, DVD player,
piano, games and old magazines and newspapers. You’re not exactly kept up to date in here.
The nurses’ station is the hub of the ward. Anything worth happening happens at the nurses’
station. It is power central. All major nursing decisions are made at the hub.

Outside is a beautifully landscaped garden with chairs warming in the sun. There is a smokers’
area under cover of the eaves, just in case in rains. Wet cigarettes are not very popular. This
was in the time before smoking was completely banned from health facilities.

Will this space glue me back together? The following days will tell…
**Day three – my need to have control**

I crave to feel safe. I crave to be in control. Having my schedule means that I am productive. I can’t have control over my thoughts and feelings, but I have my schedule! Note nurses’ entries below:

Nurse one:

“Settled, warm and reactive early in the shift. At approximately 11am Rachael reported feeling agitated and anxious. Nil trigger identified. Regular 11am diazepam given. Seen shortly after - reported that she felt ‘I had lost half an hour’. Concerned about this as it put her schedule off. Minimal settling effect from diazepam. Reported visual hallucinations to medical student (walls moving, changing colours). After lunch observed a lot of crying and agitation, paranoid about people walking past her door, not sure what their motivations were. Upset about her ‘failure’, felt that her schedule had not been able to stop her becoming unwell.”

Nurse two:

“Rachael has generally been settled this morning, using distraction techniques to manage anxiety and minimise ruminations. Good eye contact, circumstantial at times although, has improved from last week. She reports some feelings of things not being real. Rachael states that others read her mind at times - and they talk to her when doing so. She wondered whether she was ‘just making things up [symptoms] to get attention’. These thoughts were challenged, and the theory was discounted.”
Day four - will vanilla scent mend me?

The psychiatrist’s office has a lovely vanilla scent that I always comment on, probably ad nauseam. I am always scared of seeing her. She is the ultimate sacred deity of my care. When I first met with her, and the next few times, I tried to explain to her that I was paranoid, but she didn’t believe me, thinking I was confusing it with anxiety - semantics. When the sacred deity didn’t believe me, I felt disempowered and more broken because I was made to feel like I was making up my symptoms. Paradoxically, and to make things worse, I get paranoid about reality and whether I make stuff up or not. So, I am a disempowered stupid patient who doesn’t know how I feel or view reality, unless my version of reality is supported by observant medical staff.

In fact, it wasn’t until a medical student observed firsthand one of my paranoid episodes, which I told my psychiatrist about, that my psychiatrist believed that perhaps my constant anxiety was due to my constant paranoia. She then instigated the process of changing my medications. Finally! It seems like sacred deities only believe other deities. The nursing staff and allied health professionals are further down in the mental health pecking order. The patients are the menagerie. I am fascinated by the power dynamics played by the health professionals – doctors versus specialist nurses versus allied health versus students. The power dynamics are silently respected and not obviously at least, contested.

Day five – is it real?

Nurses’ notes describe my incompetent view of reality in varying ways. For example, “Rachael stated a number of times, ‘My brain is not working as it should’. I also challenged Rachael’s use
of the words ‘have to’ and ‘should’ statements. Rachael then became quite confused and thought she was making up her symptoms. I was able to identify a number of indicators that she is not making up herself and after about 10 minutes of reassurance she accepted that I do not believe she is making up her illness. The medical student later reported that Rachael believes I think she is making it up”.

Day six – the schism of brokenness and belonging

I got up at 5.30am this morning, due to the luxury of setting my alarm I was the only one in the room. The rooms are shared by two people. I keep my distance from the other ‘inmates’. I don’t want to get caught up in the confusing and sick views of others’ realities. I struggle enough with my own.
The weekdays are filled with a rehabilitation program which I refuse to participate in because it is frustratingly unchallenging, doesn’t develop any new insights for me and is rather simplistic. I have tried to attend the activities and have grown so anxious by their simplicity that I now don’t attend. The ward’s group activity program is an insult to anyone above the mental age of twelve. It is based over a five-day period and consists of a community meeting every morning where patients are granted the freedom to have their say in the running of the ward – in reality a very little and tokenistic agency. Discussions are had, for example, about whether there is enough salt in the kitchen. Then there is the group walk where about six patients go for a short ramble though the bushland behind the hospital. No one really talks to each other, for various reasons. I tried the group walk which I found terrifying as people were getting inside my head and seeing my soul. Then just before lunch are the pinnacle activities of planning for discharge, life skills of gardening, mood management and cooking. To complete the week, there is a psychology-based activity for Friday.

Let me describe the basics of mood management (two hours of my life that I’ll never get back)

Q: “What’s a good emotion?”  A: “Happiness”

Q: “What’s another good emotion?”  A: “Excitement.”

Q: “What’s a bad emotion?”  A: ”Sadness.”


Sadly, that was about as challenging and exciting as the group got. After lunch is craft, an outing, baking (again), and visits from the mental health foundation (a community based mental health agency).
In comparison, my self-designed rehabilitation program trains me in the skills and provides me with the resources that I will need to return to work and study when I get well. I feel that my self-designed rehabilitation program prepares me to be a full member of society. Writing practice and reading is more useful for reintegration than the simplicity of classing emotions. The hospital program ostracises the mentally ill deemed as lacking, lacking the skills and intelligence to fit in to the rest of society, precipitating their identity as social misfits and sub-citizens.

My self-designed rehabilitation program involves a 5.30am start with meditation and mindfulness, catching up with news from the outside world, showering and dressing, breakfast, a half hour walk, more meditation, creativity (usually crochet – a bit more complicated, and I find it more relaxing than other craft, and it helps with cerebral functioning (Brain made simple 2019)), reading, lunch, two hours of writing, another walk, then free time for visitors and catching up with any activity I was unproductive with, for example reading. I then do another meditation after dinner and have an early night.

My program is an effort. I have been putting off writing due to high levels of anxiety. I painstakingly made myself write yesterday. Today was helped by a very fruitful meditation session. I am listening to Triple J radio station in the background. Quite incredible because it means that I am concentrating on two things at once – listening and writing – a miracle!
I slept in this morning until 6 am. The joy of staying in a communal ward is that you have personal encounters with inappropriate people. First is the young woman that doesn’t seem to understand that the shower cubicles have doors and not everyone needs or indeed wants to see you naked. Another woman, who I just refer to as the crazy obsessive woman, has obsessive cleanliness rituals that cannot be disturbed, in all places such as the bathroom and the dining room. No one dares to interrupt her routine for fear they will be yelled at.

I have had a shower (didn’t beat crazy obsessive lady), washed my fringe so it is all over the place, and haven’t put my make-up on. I haven’t had my thyroxine and I was told I wouldn’t get it until 8am, so I can’t have my muesli until 8.30am, by which time will be famished! Oh, and I haven’t done my meditation yet! What’s this topsy-turvyness coming to my world?

Later, a nurse took me for a walk off the ward. As members of the public walked past, I would look away and then after they had gone, ask if they saw me. When asked why I didn’t want people to see me I replied, “If they get in my head they will see what I am thinking and they would not like it. They won’t like me, and they will see how jumbled my thinking is.” I then apologised to the nurse for not looking at her or making eye contact, “I am sorry I can’t look at you! I don’t want you to steal my soul”.  

Day seven – everyday lunacy
I then went on to say that I didn’t understand why I had gotten worse since admission and not better. We discussed the possibility of not having to keep up a front anymore, that Ward A (public) was a safe place, and to work on getting better and not to be afraid to ask for help when I’m becoming overwhelmed.

**Day eight – an anthropology of loneliness: the emotional frontier**

I do not get many visits apart from daily visits from my mum and dad; mum when she is well enough. Jude (my ex-fiancé) comes in every second day. My sister has been in a few times and one of my brothers visited once. There is a family birthday tomorrow when I will see the whole family. That will be nice. Hopefully I won’t be too paranoid.

I am ashamed to tell my friends I am unwell in hospital and have them feel obliged to visit me. Not only do I feel like a sub-citizen, but a sub-friend who my friends charitably include in their social planning.

I felt so guilty yesterday, as people were being nice to me and I didn’t deserve it. I did three meditations before taking 50mg of Seroquel prn (when needed). I can’t get the emotions of guilt, shame, hate, disappointment, anxiety, fear... out of my head. I also feel like I’m a fraud, a failure, a mean and selfish bitch, two faced and bloody ugly.
I would like to argue that our emotions are a fundamental part in people making decisions of all different types. We reason, but when it comes to the crunch, any decision made cannot be separated from emotion; a gut based reaction. Emotions are decision makers. As are our senses. As are our rationalisations – maybe all three separately, or together. Are individual, personal feelings a social fact or phenomena? What are the discourses behind feelings and thoughts? Behind anyone’s personal discourses of their feelings and thoughts?

Day 9 – fashionista

Another interesting theme I discovered in my medical records, was that I was commonly described as “well kempt”, “well-groomed” and “well presented”. I thought it humorous how the nurses noted on a few occasions the colours of my clothes. For example, my physical state was described as “brightly dressed in green socks and a red top”. Another nurse ended her medical notes entry by stating, “Well kempt. Dressed appropriately”. There seems to be a focus on my appearance in many entries, especially my being “well-kempt”. What does being ‘well kempt’ mean? And how is it related to mental health? Goffman (1963) stated that visual presentation is related to mental health capacity. To be ‘unkempt’ is to welcome visual stigma. To be ‘well-kempt’ represents potential capacity and healthiness. Is there actually a correlation between being well-kempt and being mentally well?

Other comments in my medical notes include that I am “polite on engagement”, however at times I will become “distracted and appear to respond to stimuli…pausing mid-sentence and looking at a spot on the wall.” Numerous times I was also described as “warm” and “reactive”.

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Day ten – hell on earth

During my stay in Ward A (public), I began a withdrawal plan to get me off diazepam. I was very keen to move back to Town B and resume my life again; though the mental health professionals in Town A strongly suggested that I stay as an outpatient so that I could have support in my diazepam withdrawal. I disagreed with the mental health professionals until my first two weeks of the withdrawal. It was hell. I honestly could not have imagined how terrible it was. So, I quickly changed my mind and decided to stay the extra two months. I remember the pain, repeated, day in day out. My diazepam reduction plan, as it was called, outlines very slow and gradual withdrawal over four months. By the time I was admitted to Ward B (public) I was still on small doses of diazepam. I remember the pain and I promised myself I would never ever get addicted to drugs again knowingly or unknowingly, if at all possible. Frustratingly diazepam

Day eleven – being in the world

I will now tell you about my discovery of a marvellous super glue. It is based on the theory of phenomenology and mindfulness, as described by Didonna 2009, that I first heard about on my admission to the ward. Apparently I am not the first to make this discovery. In fact, mindfulness and phenomenology are well grounded, researched and established concepts in psychology, as well as philosophy and religion, and other disciplines. Many psychological therapies are based on mindfulness and phenomenology. For example, acceptance and commitment therapy,
cognitive behavioural therapies and mindfulness-based cognitive therapy (Didonna 2009), and in my case the use of meditation.

Lundh (2020) states that phenomenology can be defined as the scientific analysis of our subjective experience of ‘being in the world’. Lundh (2020) describes how Husserl used a phenomenological method to turn attention to conscious experience as such. As he formulates it, this represents a shift in perspective from our usual natural attitude with its focus on the world (and our practical engagement with things in the world) to a phenomenological attitude characterized by a focus on our experiences of being in the world. Instead of focusing on the objective world as it appears from our subjective perspective (i.e., our natural attitude), attention is turned to the subjective perspective as such (a phenomenological attitude).

Meditation is an esteemed tool for mindfulness and phenomenology. It helps me to centre on the present, accepting it for what it is. Mindfulness is about the present, not regretting the past or projecting into the future, thus lessening anxiety. Mindfulness isn’t about punishment but about a gentle and loving approach. Meditiveness mindfulness, for me, is like super glue for my broken mind. Meditative mindfulness has had a brilliant therapeutic effect on me. Funnily enough, due to my illness, I read a big book on it but due to being so unwell I can’t remember anything that was written! However, I seemed to have picked up on the gist of it. It’s about being present in the moment, consuming my mind and all emotional attention. It’s also about an ethos of gentleness, connectedness and forgiveness of the self and everything affecting the tranquillity of the self. It is associated with a commitment to regular, at least daily, meditation.
It is about meditation on the now and the experience of the now. Reality now. Feelings now. The purpose and meaning of life now.

This view of reality marries transcendentalism with the physical, psychological, emotional and the experiences of the senses now. We cannot change the past. We don’t know what the future brings. We do know what is now. Any therapy that does not address any elements of mindfulness is deemed to be inadequate (Kabat-Zinn 2006).

**Day twelve – thoughts to trust**

My main goal for the first four weeks was to trust my thoughts. This is an ongoing issue for me as I battle to find reality. Below is an outline of the plan.

<table>
<thead>
<tr>
<th>Goals/issues</th>
<th>Strengths and supports</th>
<th>Action plan</th>
<th>Who is involved</th>
<th>Follow up date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medication review</td>
<td>Dr</td>
<td>Trial and error</td>
<td>Team</td>
<td>(None made)</td>
</tr>
<tr>
<td>Come off Valium</td>
<td>Nurse</td>
<td>Wean off Valium</td>
<td>Team</td>
<td>(None made)</td>
</tr>
</tbody>
</table>
This plan was made eleven days after being admitted. I am curious as to why such a plan takes so long to develop. One possible suggestion is that the staff may have been waiting until I was better, with more clarity of thought and thus more capacity to think in such terms. Their perspective of my self-efficacy was influenced by what they knew of my symptoms; and particularly about the insistent and persistent thoughts that were a major part of my presentation when I was admitted.

Day thirteen – clarity of insanity

A report from a psychologist I was seeing on Ward A (public) stated that I had been practising mindfulness and using distraction techniques when distressed and was finding this helpful. I stated that I remained fixated on the belief that I had to be productive all the time, especially at
work. I said several times, “I need to write well, I need to be productive”, putting emphasis on the word ‘need’. The psychologist encouraged me to take rest and have some fun in my life as this will help me to be more productive. I reported feeling stressed at the thought of doing something fun and was very focused on returning to work, I noted that part of the reason I am consumed by work is because it offers distraction from the fact that I am single and it helps me to challenge my beliefs that I am not very bright and that I was and am weak. The psychologist suggested that I believe I became unwell because I am weak.

It is very important to me to have firm structures and a detailed plan for productive work. This is possibly because my world is so unclear. I continue to question whether things are real or not. I need to control what enters my cognition. Knowledge is power and the more knowledge I have secures my sense of reality and provides me with the foundation to live a fruitful life. My self-image may be largely influenced by a belief that I am handicapped by my mental illness.

*Day fourteen – AWOL*

I was very apologetic about getting lost on my walk - walking for one hour instead of 20 minutes - and it went as far as to say that I thought I may be punished for not returning on time. I required reassurance and support. I was able to distract with meditation and a visit from my father. Staff note, “When anxious, Rachael appears to be in an associative state, downcast eye contact with anxious affect, and stooped posture, although able to be distracted with verbal prompts, nil reported psychotic symptoms this shift, however reported psychotic symptoms noted in Drug and Alcohol Clinical Nurses Consultant documentation dated today.”
Day fifteen – productivity

I need to write well. I need to be productive.

Day sixteen - assessments

One of the assessments the staff at Ward A (public) administered to me to measure lack of confidence in social interactions was called ‘The Holistic Assessment - Tidal Model’. This assessment included some of the reasons that lead me to be admitted to Ward A (public). I had poor clarity of thought, poor memory, and diazepam tolerance. I would describe my pre-admission state as feeling crap and increasingly paranoid, which led me to use more and more diazepam, and become less and less able to work and study. I resented having to come to hospital again, but I recognised that I needed to be able to work again as well. I identified the needs of my mission as having my medication reviewed and acquiring more management tools to cope with my mental health. Most importantly I wanted to be able to trust my thoughts again.

My pre-admission mental state examination (MSE) showed that I was pleasant, at times anxious, that I lost concentration at times, and had a dry mouth. I had no abnormality of speech and no formal thought disorder. My affect showed some reactivity and anxiety.
My admitting MSE noted that I looked my stated age. Again, it was noted that I dressed very brightly with red top and green socks. I was cooperative with good eye contact. My speech was normal considering weight volume. My mood was subjectively and objectively euthymic, my affect reactive. There was evidence of auditory hallucinations, but no evidence of delusions today. “Rachael appears to have good insight”.

It was interesting to note that a risk issue included ‘risk to reputation’ specifically via ‘diazepam withdrawals’. This insight depicts the intense socialisation of psychiatric care.

*Day seventeen – Personality Assessment Inventory*

Below is some context of my Personality Assessment Inventory (PAI) used in my stay of Ward A (public). (I repeat myself here and in chapter ten and in more detail due to the significance of the material.)

“With respect to negative impression management, there are indications suggesting that the client intended to portray herself in an especially negative or pathological manner. Some deliberate distortion of the clinical picture may be present; evaluation of the critical items indicates she is not malingering. Also, such results often indicate a ‘cry of help’, or an extreme or exaggerated negative evaluation of oneself and one’s life. This exaggerated negative evaluation is consistent with how the respondent describes herself in interview. Regardless of the cause, THE TEST RESULTS POTENTIALLY INVOLVE
CONSIDERABLE DISTORTION AND ARE UNLIKELY TO BE AN ACCURATE REFLECTION OF THE RESPONDENT'S OBJECTIVE STATUS – THE FOLLOWING INTERPRETATION IS PROVIDED ONLY AS AN INDICATION OF THE RESPONDENT’S SELF DESCRIPTIONS (Assessor’s bold and capitalised effects.)

“Despite the general level of negative distortion noted above, there are some areas where the client described problems of great intensity... These areas could indicate core problems that stand out from the general level of distress and dysfunction reported by the client, such problems merit particular focus in further inquiry. These areas include disruptions in thought process; unusual ideas or believes; feelings of helplessness; tension and apprehension; heightened activity level; irrational fears; and compulsiveness or rigidity.” (See chapter ten for more discussion)

Some clinical notes from the PAI:

Self-concept

“The self-concept of the client appears to involve a generally harsh, negative self-evaluation. She is prone to be self-critical and pessimistic, dwelling on past values and lost opportunities with considerable uncertainty and indecision about her plans and goals for the future.”

Interpersonal and social environment
“The respondent’s interpersonal style seems best characterised as a self-effacing and lacking confidence in social interactions. She is likely to have difficulty in having her needs met in personal relationships, and instead will subordinate her own interests to those of others in a manner that may seem self-punitive. Her failure to assert herself may result in missed treatment or exploitation by others, although, at this point, it appears that the strategy has been effective in maintaining her important relationships.”

“In considering the social environment of the client with respect to perceived stressors and the availability of social supports with which to deal with the stressors, her responses indicate that both her recent level of stress and her perceived level of social support are about average in comparison to normal adults. The reasonably low stress environment and the impact of social support system are both favourable prognostic signs of future adjustment.”

Day eighteen – still broken

I’m having a bad day where I am disillusioned by the possibility of my recovery. I am puzzled by the values and techniques of the staff and the biomedical model they seem to esteem. I haven’t seen a lot of holistic therapeutic techniques. The group program is the closest attempt to a holistic model, but it is ineffectual. Craft, a seemingly panacea for mental health rehabilitation, does have its therapeutic properties, despite my qualms and scepticisms.
Final day – has the glue worked?

My inability to concentrate on anything for long may fundamentally ruin the validity of this thesis unless one holds on to the postmodern/poststructuralist value of multiple and relative truths. The discourse of the therapeutic processes of an inpatient in a psychiatric ward depends on the biomedical model where doctors are sacred deities, nurses and allied health are their followers, and the patients are inadvertently disempowered as they are not able to be taught all the holistic skills necessary to live a productive life outside of the ward. They may not be able to be taught all the holistic skills necessary for them to survive life outside the ward. This is due to the possible deterioration of the cognitive functioning which that can happen to people with major psychotic disorders. The token holistic allied health professionals do their best with the limited resources available to them. The reality is that psychiatric wards have revolving doors for chronic sufferers, of whom there are many. So, the cultural discourse of the psychiatric medical system produces band aids for what they can patch up with medications, knowing full well that the treatment is inadequate. The follow up treatment in a perfect world is taken over by the community mental health team but much of their attention is based on crisis management not chronic management. So, this had better be good glue to keep me together for a good while longer. I hate being broken, a lot.

Below is a brief description of my 2012 discharge summary from Ward A (public):

“Rachael settled well on the ward. Champix [a medication to help stop smoking] was decreased then stopped since this may exacerbate psychosis. She was started with a nicotine patch. Her medication was changed. She was seen by the Drug and Alcohol officer, who advised to reduce
one of her daily diazepam doses by 2.5mg every other week. She was encouraged to structure her day and take regular exercise. She was seen by the ward psychologist. She made good progress and leave went well. She has decided to ask her employer whether she may be able to work from home until the end of the year. Upon discharge Rachael had no paranoia ideation. Rachael is currently considering whether she would like to spend further time with her parents [in Town A] or go back to Town B.”

There was also a description of current, revised medications on discharge, a brief description of my social situation which included living arrangements, nurturing relationships with friends and family, and employment, and a list of the mental health professionals I had to see.

Risks to reputation and of misadventure have been noted several times as possibilities in my notes. This illustrates the hazards of stigmatisation of the mentally ill (Goffman 1963). These points were made aside notes of my mental state. These included descriptions such as: “disorganised, latency of speech, tangentiality and loosening of association, disoriented, cognitive deficits apparent, circumstantial in speech, and reports poor memory”. The notes acknowledged that I experience auditory hallucinations but stated I had strategies in place to manage them.

My medical notes go onto say, “Rachael reports feeling paranoid at times, feeling as if people are out to get her. She hears voices of different people, of both genders, but thinks that the voices come from inside her head. She feels at times that everything is surreal, that sometimes the world and things in it are holograms. She tends to incorporate higher philosophical knowledge into her
thinking and complicates her thoughts in this way. She has been encouraged to simplify her thoughts and is finding that she can best ground herself using her sense of touch.”

*Reflections*

There are about seven voices, of different sexes and ages, living in, but not attached to me. I don’t like to call them ‘voices’, this feels too much like schizophrenia cliché for my liking. Instead, as previously mentioned, I prefer to call them ‘noises’. I haven’t named them individually, on purpose. I don’t want to empower them with an acknowledged identity. Usually they all remain a whisper, and it is easier to control them. I’ve spent twenty years training myself to disassociate from them; to negate a reality.

From my understanding of Hegel in his *Phenomenology of Mind*, consciousness (what I like to extrapolate as ‘reality’) is what your senses (smell, taste, sight, hearing and touch) tell you. Aristotle (in Evans 2001: 42) states that you can’t experience your senses separate from some kind of reason or rationality of them. Senses are the data and enable reason to de-code and transcribe. My senses were not sensing what they are meant to, according to mental health professionals, and my reasoning was completely paranoid. I didn’t trust my sight, smell, hearing, taste, as these senses are arguably more subjective. I did trust the sense of touch because touch was the only sense that grounded me to reality. Even sick people have their version of the postmodern relative truth, but their truth is often ignored. What sane person would have faith in the insane?
It is assumed by my mental health professionals, *a priori*, that my knowledge and constructions of reality are unfounded and obsolete. The mentally ill cannot be trusted; their opinions are invalid. What makes the production of knowledge so consequential is the power play that it is founded on. As I have already been categorised as subhuman, my knowledge is inconsequential. Knowing that I am subhuman everything that comes into my ‘disabled’ mind is largely ignored by health professionals. I suffocate in the desperation to be heard. I would like my voice heard, not judged by the approximately seven noises that I hear or belittled by the mental health professionals that essentially have my life in their hands. I would hope that I have some intelligence or some credence of knowledge that I have been socialised into. How has having a mental illness, a schizo illness at that, enculturated, categorised, made (dis)ease and de-humanised me?

The mentally ill are disempowered, similarly to groups in the present and the past, like women, Indigenous peoples, homosexuals, and slaves. Said (1978) spoke about the concept of the ‘Other’ in describing how the West view themselves as having power over the East. For example, this idea relates to how after the World Wars I and II the West effectively drew on maps where they thought countries should be, defining and delineating colonies according to their Western mandate.

The Other includes the disabled, like the mentally ill. While the mentally ill are classified as Others, the mental health professionals including policy developers, are the Us. The mental
health professionals have power over the mentally ill. Us are perceived as having knowledge and power over the Other (also a concept developed by Foucault).

There is an air of patronage, superiority and supremacy in the way the mental health staff relate to you. At times they are dismissive and vague, like they are not really listening to you. At other times they are paternalistic, as if they are hearing only what they expect to hear. The health professionals disengage from the plight, the reality of the patient, by not really listening. They only hear what they have to hear to be able to classify the mental illness that the ‘disabled’ person is defined as having.

Fortunately, there are some mental health professionals who are committed to improving the quality of life of those living with a mentally illness in ways that do show a true desire to listen and to hear the mentally ill as people not just patients. There have been countless times over the years of my illness when I feel like I am choked, paralysed and muted, unable to communicate to doctors, psychologists and nurses how I am feeling and what I am thinking. What is at most an issue is the added marginalisation and subjugation that mental health patients receive when they are an already marginalised and subjugated group.
Above is a drawing of Ward A (public). It is based on Bentham’s model of a prison, where the inmates could be monitored efficiently and effectively from within a hub. All the wards in this thesis are based on a similar model.
CHAPTER EIGHT

WARD TWO – WARD B (PUBLIC)

FEBRUARY 2014

Day one – a very bad day; a very long day

Five months on...the worst thing ever...the glue has disintegrated....and I’m back to Town B.

This has really come out of nowhere. I cannot think of any real cause. I seemed to have snapped.

This is bad. This is really really bad. Fuck!

I’ve lost again. Damn it!

The world is caving in. I cannot breathe. Noises are so darn loud. I cannot escape them. Stop it!!! Get out of my head!!!

Damage control needs to step in to now.
One thing at a time Rachael. Breathe. One thing at a time.

I need to see Dr P, my GP. She will help me, look after me. Past seeing her, I don’t know what will happen. Focus on Dr P. One thing at a time. One thing….

I have managed to drive to the GP. My GP is four hundred metres down the road, yet it is too terrifying to walk the distance in the open spaces – too much stimulation in the wide spaces for me to handle. The world whizzing and spiralling out of control around me.

Breathe.

Breathe.

Walk through the door.

You can do it.

Breathe.

I’ve somehow made it to the GP’s surgery. My body has taken over. I am shaking; trembling. I go to a corner of the waiting room and hide there. The noises are too much! I am flinching away from the noises. It is so noisy I cannot cope. Aarrggh!!
I didn’t think about checking in at reception. The staff know me and would have taken note. I have been seeing Dr P weekly for a couple of years to manage my mental health.

The noises make up some of the racket. I am dodging the noises. They are terrifying me. Stop saying those things! I am disorientated amidst the noise of deprecating yelling – the noises – and the everyday noises of the GP clinic. I don’t know what to listen to! What is real? I dissociate, a technique I use to protect myself from these very situations.

I cannot engage with my mind. I feel so detached from the here and now. It is like I am drowning in air, with the world sweeping, spiralling and crashing in on me, from all and no directions at the same time, smothering me, choking me, and overwhelming me from any possible escape, completely disorienting me, taking away any sense or comprehension of reality.

Dr P comes out to see me. I flinch away at the noise that her saying my name makes. Dr P’s voice cuts and pierces through the intensity and screams of the noises. The impossible task now is to make it to her room. I hold on to the wall as I slowly make my way. God it’s petrifying! So many threats and dangers. The noises are everywhere. I am engulfed; captured!

When I finally make it to Dr P’s room, I cower in the corner, I start rocking back and forth and chanting something in time (not sure what) to the rocking, hoping to make the noises go away, and the room stop collapsing in on me. I remember feeling desperate. I didn’t know what to do.
I was lost, but I do remember that seeing Dr P was my best bet at getting rid of this panic, anguish and extreme anxiety.

I think Dr P was a little desperate herself. The way I was acting was definitely in the ‘too hard’ basket. With reflection, I know that she cared about me and was doing everything she could to help me. Dr P rang up the mental health team straight away. I heard her make this call and panicked. She was negotiating what she should do. I heard her talk about sectioning me under the Mental Health Act (as per the state). As discussed before, that is when a patient is put under care of the State and forced into treatment. I used to be a nurse working with the mentally ill, so I am aware of the system. My nursing experience both equipped and disarmed me from dealing with my mental illness. Seeing my distress, Dr P assured me that the main reason she was going to section me was so that there would be someone looking after me all the time. She rang the ambulance, and after what seemed like a decade, but was really minutes, the ambulance came and collected me. It was terrifying walking with the ambulance officers to the ambulance and then strapping myself in, under close guidance from the ambulance officers. I likened it to walking the infamous Green Mile, walking closer to my imminent death.

I was to be transported to the Town B Hospital. It seemed to me to take hours, when it was really a ten-minute trip. Detachment from time seemed to be symptomatic. There is no other alternative for individuals suffering psychosis in the Town B region. I had to suck it up, despite my pure fear and despair about having to have any association with the Ward B (public). I was in a state of hopelessness and absolute devastation. Being connected and linked with the Ward B (public) was my worst fear come true.
When we got to the Emergency Department, I was escorted by the ambulance officers and two nurses to a private room. It was like I was in a medical factory. There was machinery and apparatus everywhere, making beeping and meeping noises that overwhelmed my heightened senses. I paced up and down the room as fast as I could. This was my attempt to manage the stimulation, with exercise and the production of adrenalin. I was also evaluating the room and its threats. I remember trying to assess the obvious threats to my safety or supposed threat/s at least. I remember feeling very suspicious and guarded about my surrounds. This was a new experience for me, being ill in Town B was very different to the system they have in Town A. At this time, I had never been sectioned before, so I was extremely distrustful and dubious. I felt that my life was threatened by the strangers made to look after me.

I was convinced that the people assigned to look after me were looking into my soul, reading my mind by looking into my eyes. As such, I didn’t engage in eye contact. There were two nurses who stayed with me. There was also a security guard. The guard petrified me; I felt extremely paranoid that he was a threat to my safety, and he was ganging up on me with the noises. I could sense his thoughts and his desire to catch me off guard. I kept hiding from him, behind the machinery. I was panicking. Seeing how distressed I was with the security guard; the nurses asked the security guard to watch me without me seeing him. I heard all of this and was trying to negotiate the obvious conspiracy that was looming. I remember preparing myself for an attack. I doubted the motives of the nurses, and I especially doubted the motives of the security guard. How could I be safe when there are all these people creeping up on me to capture me, take control of me and imprison me, to drown me in this new world of powerlessness?
The nurses gave me some medication that dissolved on my tongue. Within ten minutes I began to calm down. The medication was five milligrams of olanzapine – an anti-psychotic. I was given a number of these wafers in this first night, as well as diazepam, to help calm me.

I now had some of my old reliable insight back. It was always there, somewhere, trying to make sense of the foreign world around me.

I was able to sit on the bed in the medical factory room and stay there for a few minutes at a time. Yet I was still twitching at the quietest noise. I did feel less threatened yet remained very suspicious and paranoid. The edge was just taken off.

The mental health clinical nurse consultant came around and examined me for potential risk: to self and/or others. After seeing none, only a horrified shell of a woman, she lifted the section. With that, the security guard went away, as did the nurses. The magical powers of Mental Health Clinical Nurse Consultants! I wonder who grants them this awesome power? The State. For what reasons?

It seems as if the mental health system is a clinical arm of the State and the State’s bureaucracy, creating cultural artefacts/biofacts from various (culture associated) measurements of the mentally ill. This is so that bureaucracy has control over the knowledge generated, and the power it develops (Lea 2008). The mentally ill are dependent on the State for affordable health care.
and medicine. When you’re in the system - having to get your medication from the Government, such as I do because I take Clozapine - you are totally a ward of the State (Biehl 2005; Kleinman 1980; DiGiacomo 1987; 2010).

I was then escorted to what was obviously a room reserved for the insane. It was coloured beige and had smooth, corner-less couches – the purpose of which is to safe-guard against injury or self-harm. It is interesting that the mentally ill require a room created under such a different paradigm of medicine. The ‘medical factory’ hell I was in at the beginning of my encounter with Town B hospital, with its noisy medical technology to measure and cure people, can be compared to the beige medical wasteland of mental health. Here there is no objective technology for measurement or cure, and no other intervention or noises discussing my position and plight, other than the chaos of what is in my head.

Ironically, it was in this room that I regained some composure. I decided to contact a couple of friends. My friend A dropped everything and came straight away. My hopeless boyfriend just wanted to be kept informed. This was mostly due to his sense of shame in having a loopy girlfriend who was admitted to Ward B (public). Ward B (public) is heavily stigmatised in Town B.

After what felt like days, the psychiatric registrar came to assess me. He wanted me to go to the dreaded and horrible Ward B (public) I had hoped so much to avoid. It was known around Town as ‘the arse end of the world, where the arse holes congregate’. The local stigma of mental health was amplified by horrific urban legends. Ward B (public) was basically the last resort for
society’s greatest misfits and deviants. If there are sub-citizens or subhumans partaking in anti-social behaviour, they were taken to the Ward B (public). Anyone who gave the community a bad look was expelled via police to Ward B (public).

I did not want to go! I was adamant! The registrar was adamant too. At this point, with the release of the section on me, I still felt I had a degree of agency about my own health. The registrar ‘reasoned’ with me. He negotiated with me, or at least that was what I thought we were doing at this stage. He stated that I needed admission to the Ward B (public) so that I would never have to go through this again. I also needed my medications reviewed. He said we could work together to get me well and keep me well. Part of the selling point the registrar made was that I could smoke there. I trusted the registrar. We had reasoned well with each other. Still thinking that it was my choice, I agreed to stay in the Ward B (public) for at least one night, for now. The registrar left, content that I was going to Ward B (public).

Hours passed. According to my medical notes it had been about eight hours of waiting. Every so often a nurse would pop their head in the door, sometimes accidentally. Thank God I had friend A with me. I was in desperate need of a friend, someone on my side. I was suspicious of the medical staff. Paranoia is a huge part of my mental illness repertoire.

The noises had quietened but were still a threat to my sanity.
Midnight came. I was escorted to Ward B (public) by two huge security guards, a nurse and a psychiatrist. Four strong and well-equipped adults ready to use their self-defence skills on me in case of any threats to safety. Apparently, I was deemed a threat to someone or something such that I require such an escort. One of the security guards knew me. He was a boyfriend of a friend. He tried to spark up conversation, somewhat unsuccessfully. I was focused on entering the locked Ward B (public). I remember trying to be congenial, for the sake of my reputation. Damn! There is no anonymity in this town! I cannot hide my failed mental health. I was paranoid that my insanity could affect my trusted friendships. Mental health is such a stigma, placing me in the subhuman category. I just didn’t want to become an obligation to my friends – subhuman becoming subfriend.

I made it to the ward. There were four locked doors we needed to negotiate.

I wanted to run away at every turn of lock.

Four. Oh God!

Three. Shit!

Two. Close my eyes.

One. Close my heart and hope for recovery and freedom.

Lock negotiation complete. Now let me out of here!
The nurse on duty was tired, cold, stern and non-obliging. It was 12:30am and the ward was quiet, except for me. Apparently, I was shouting. The nurse took my basic observations – blood pressure, temperature, pulse, respirations, and weight. The registrar had ordered me my usual medication (as noted by my GP), as well as some extra medication when needed, ‘prns’ as they call them, to calm me down. I took the medication. I knew the ramifications and risks of not taking the drugs of course - I used to be a mental health nurse. After I took my medication, the night nurse ordered me to go to bed.

My friend A had not yet come with my bed clothes and toiletries. I wanted to wait till they arrived. The nurse coldly and firmly ordered me to bed again, as if I was in a prison rather than a safe environment. She should know that safety and security are foundations of care, especially needed for the psychotic. As I was to discover later, she had a default punitive manner with patients.

I said that I wanted a cigarette. I knew that it was hospital policy not to smoke on hospital grounds. However, I had a caveat - I repeated what the registrar had said – that this was allowed for me. The registrar then lied – to my face - and stated that he never said that was an option. I couldn’t believe it! This lie concreted my psychosis for the nurse – I was obviously completely loopy, making up conversations. My reaction definitely warranted her (questionably effective) punitive approach. This angered me. I said in a loud stern voice that I wanted to leave. The registrar said that if I left, I would be sectioned, or else I could go to the high security forensics ward where insane criminals are ‘managed’.
So, if I stayed, I was accepting the label of uncontrollable lunatic, hearing untruths from doctors. Or else if I tried to leave, I would be sectioned. Either way I was imprisoned at Ward B (public), completely disempowered and demoralised. There was nothing therapeutic about the nurse’s dealings with me, or in the pretence that the registrar entrapped me. To appease me, the nurse offered me a (plastic) cup of warm milk. I was more humiliated and concretely labelled a sub-citizen/subhuman/social misfit without self-determination or free choice. Psychiatry is unlike other forms of medicine. As Szasz states (1970: xxiii), “In the changing attitudes towards witchcraft, modern psychiatry was born as a medical discipline”. Psychiatric patients are assumed a priori as lacking and unable to rationalise or negotiate their own treatment. Psychiatry deals with the whole of the patient and not just the biomedical facets. For example, psychiatry claims to concern itself with the risk of loss of reputation – the whole of the person.

My friend A, the darling that she is, finally made it to the ward with my stuff. It was about 2am by this time. She couldn’t enter the ward due to high security. I wasn’t allowed to see her. I had to wait till visiting hours. That was the ironic nail in what felt like a coffin, fastening me to this seemingly punitive treatment at Ward B (public). Friendship with darling A was more therapeutic to me than a plastic cup of milk – yet this was being controlled and limited. She told me later that she had walked to where I had left my car at the GPs and driven it home.
The nurse admitting me took all my belongings from me. Below is a list of my confiscated belongings:

- Handbag containing:
  - Wallet containing various cards, including Visa, student card, health care membership card, bank key card, Medicare card, driver’s licence
  - Coin purses
  - Memory stick
  - Half a packet of cigarettes
  - Three lighters
  - Tissues
From reading my medical notes from that first night, I found out that the nurse admitting me thought that I was not capable of comprehending at least a third of the admitting paperwork. I was apparently too confused and verging on aggression and could not be reasoned with. This was her reality, mine was that I was defeated by a lying registrar and devastated that I had lost another battle with insanity.

My friend bought me three chocolate bars when she dropped my things off at Ward B (public). The admitting nurse did not allow me to have these chocolate bars. The next day, a more agreeable nurse graciously allowed me one chocolate bar.
It is hard for me to believe that I was incapable of going through the processes of being admitted. What I did find to be the case was that I was patronised by a registrar lying to get me to come to Ward B (public) and a nurse who is focussed on managing behaviour not treating psychosis. I was very, very unwell, but I am really, really not completely stupid (or I would hope to believe). I have insight to my illness, unusual insight. I was 23 when I was first diagnosed, I’ve lived with my illness for long enough to know when I am being patronised.

*Day two – a rude awakening*

Upon waking the next morning, I realised that my worst nightmare had come true. I really was an inpatient in Ward B (public). I was now committed to be in a ward that I had run away from five months earlier. How the hell did this happen? I thought I was smart enough to negotiate the mental health system and find it therapeutic. I thought I had some power, some rights to self-determination. It seems that I have been treated as I would have been centuries ago. Punished for being a heretic; punished for being mentally ill. My voice had been muffled and silenced. My freedom shackled. (Somewhat congruent with the Silenced Manifesto.)

I don’t think I have ever felt more alone, helpless, powerless and ostracised before in my life. I was terrified, imprisoned by my psychosis and imprisoned by my horror that I was actually an inpatient of Ward B (public). My psychosis amplified my terror. The walls were caving in on me. I looked around my room for the first time. All the furniture was bolted down to the floor
– a single bed and a bed side table. There was also a small built-in robe. The furniture edges were rounded and padded to eliminate the temptation of self-harm. The colours in the room, beneath the stains and dirt, were beige and pale green. The walls were covered in graffiti. The bolted shut tinted windows had satanic messages scratched into them. One that was repeated a few times, for purposes of clarity perhaps, said ‘Die you fuck!’ In the ensuite was grime that seemed to have festered there for years. The water in the shower was tepid only, again for the purpose of minimising self-harm. With all these precautionary ‘decorating’ features, it was hard to imagine how one could be healed and grow in such an environment. I remember comparing the conditions to inmates in prison (through a work project), wondering if prison was more supportive of the socially unwell than the mentally unwell in Ward B (public), both populations defined as misfits.

I was panicking, petrified! How do I get out of here? It all seemed like a whirlwind of horror, my sense of reality and grounding spinning out of rational control. I was trying to deal with psychosis and negotiate the health professionals at the same time. It was too much for me. I recall the events of the night before, my first minutes of being in this ward. I couldn’t believe it! Dr: “You will be a voluntary inpatient.” Me: “Good. I’ll leave then!” Dr: “If you leave, I will section you.” Me: “So I have no choice! I am stuck here!” I panicked! I recall the nurse’s paternalistic and derogative tone, the registrar plainly lying to me, making me seem crazier, making stuff up. Dr: “You are a voluntary patient.” Either way I was to be admitted.

That first morning I hid in my room, behind the bed. There was a knock on the door. It alarmed me, making me jump, adding another source of confusing stimulations to my hallucinatory world,
sort of like being slapped on the face. The person behind the door knock was a nurse telling me that breakfast was ready. I would have to come out of my room into what was called the dining room.

The Ward B (public) looked different in day light. I walked out of my room with the nurse, my door was to be locked for the day, so the nurse told me. I walked with my head down, scared stiff of the sight of my new surroundings. I still to this day walk and sit with my head down, my body slouched. Hiding? The world was spinning. I felt like I was going to implode with fear. I tried to take in all in. My noises were loud. I was finding it extremely difficult to process what was happening. It seemed like a horrible, surreal nightmare! Panicking again, I was finding it hard to breath. I was stifled with the plethora of stimulation to process.

I laid low that first day on the ward, doing my best not to communicate with anyone. It was best that I do that, minimise any potential damage, or other interactions with cranky nurses or lying registrars.

**Day three – they’re watching me**

Third day and, despite still being suspicious, I was well enough to take in the layout of the ward, even though it was explained to me yesterday. It was based on like a hub and spoke model, where all corridors spread out in arms from the nurses’ hub in the middle. The ward consisted of a central glass hub bowl, the staff centre, where staff could monitor patients safely. The hub
was locked and secure. It reminded me of architecture described by Foucault - Bentham’s Panopticon. The Panopticon was designed by Jeremy Bentham (1748-1832). It is a tower from which wards men, doctor, teacher, or foreman can spy on and penetrate behaviour. The subjects under surveillance never know quite when they are being watched, and so effectively police themselves (Horrocks and Jevtic 2004: 118).

Patients in Ward B (public) could speak to staff through a small slit in the glass of the hub and voice their concerns. With the staff hub at the centre, with views across the ward of the lounge room and dining room were like spokes. Off the dining room was the courtyard. Morning meetings were held in the lounge room. There was a TV in the lounge room, which was monitored and not left on during the day when patients were to be attending activities. The activities room was through one of the locked doors, opened for patients at set times during the day. Patients were encouraged to participate. The activities room was the litmus test for good mental health and looming discharge. If you were seen to go and participate, and remain congenial, then you were successful in playing the power game with the staff. It seems odd to me that one’s wellness depends on your ability to make a bead necklace or to ride on an exercise bike. Wellness is dependent on health cultural artefacts – technologies/apparatus, and they may be gendered. These skills, to me at least, do not equip the mentally ill with tools to attain and maintain rehabilitation and be an active, fruitful member the community. Skills and tools are needed to manage good health. The non-biomedical tools I use to manage my own good health are dissociation, mindfulness meditation, yoga, good diet and exercise, talking therapies, and supportive relationships. These were part of my self-designed rehabilitation program.
There were twenty rooms and about twenty-five patients. The other patients in the ward were so publicly unwell that the ward seemed like a showing at Bedlam, a little bit like a madhouse of old. And here I was, one of these madmen! The stigma of Ward B (public) was genuine and true. To add to my paranoia, I noticed that there were security cameras covering the whole ward. Whether it was a hospital policy to have cameras throughout all the wards, I did not know. I was too paranoid to comprehend.

I was trying to focus on what the nurse was saying, despite the noises and sensations engulfing me in a crushing world. I recalled that the ward was not that unfamiliar to me. Years before I worked casual shifts for a nursing agency. I worked some shifts in this ward. I remember how chaotic and disorderly the ward was. I remember the nurses’ frustration with the patients. Some nurses even seemed to resent an unwell patient for making their shift that much more difficult, as if monitoring someone for suicide risk was a hassle. The ward seemed to me to be a turbulent and tumultuous social creature, whereby the hierarchy of medical staff breathed the breath of punitive treatment and behaviour management into the patients.

As I have mentioned, I worked for a mental health non-government organisation. One of my clients in that organisation was now in Ward B (public). She was oblivious to me being there, sleeping most of the time on the ward couches. She is the definition of recidivism; someone who rarely, if ever, recovers. Other patients, apart from the ones yelling, pretty much kept to themselves, although it was clearly visible that these people were unwell. For example, those patients with psychosis looked as if they were responding to noises or voices external to themselves.
Day four – learning to play

Ironically, the medical hierarchy who assume such power and authority as to imprison someone against their will, themselves have little to rely on and validate their roles and work on the questionable medical ‘facts’ of modern psychiatry. These facts validate the mental health professionals’ hierarchy. Facts and knowledge go hand in hand with power.

The Ward B (public) staff can be defined as demi-gods, they are so outstanding and powerful in this context that they are close to the divine. The hierarchy of power in the ward goes as follows: the highest demi-god is the psychiatrist, then the psychiatric registrar, medical intern, clinical nurse consultant, senior nurses, junior nurses and enrolled nurses. Then what Foucault (1967) calls the underdogs - subhumans, the patients – the plebs. The medical staff decree that the patients deserve little to no power. The only way the patients can gain power is to obey the staff and their own visions around what constitutes therapy, like their vision about the power of craft.

Otherwise, and not uncommonly, the patients are deemed as misfits, unfit for society. Perhaps these misfits are unable to look after themselves. They go against the norm; so much so that they are deemed incompetent and incapable to manage their mental health.

According to SANE Australia (2017), a national mental health charity, there are circumstances where you can be legally hospitalised for a mental illness without your consent. You can also
be legally compelled to receive treatment — medication and/or therapy — without your consent. This isn’t rare: in 2014–15, just under a third of all mental health-related stays in Australian hospitals with specialised psychiatric care were involuntary. The laws covering involuntary hospitalisation vary from state to state, but generally, you can only be hospitalised involuntarily if you’re judged to meet all of the following criteria: you have a mental illness; you need treatment; and you can’t make a decision about your own care. Plus one or both of these criteria: you are considered to be a danger to your own safety; you are considered to be a danger to someone else’s safety (SANE Australia 2017).

Interestingly enough, and an example of marginalisation in one territory, the Northern Territory, 52% of admissions to mental health inpatient facilities are Indigenous (Department of Health 2014) and only 18% of all inmates are voluntary. The estimated number of involuntary admissions has been increasing steadily (Anti-Discrimination Commission n.d.).

I had yet to learn the power play apparent in the ward, such that I could claw my way back to freedom. The ward was completely un-therapeutic. I was to find that Ward B (public) was a parent State. I had to obey the staff and heed to their power structure, otherwise I would become a ‘ward of [this] State’. I had to play the game.

Ward B (public) aims to manage and assimilate their social misfits and deviants so that they may be situated and developed to be a part of the community. The only methods deemed efficacious for managing the deviant is by prescribing and administering medication, as well as the threat of
the forensic ward and loss of all freedom – this ward is already a locked ward, but the forensic ward has even stricter security.

Day five - smoke and power

Values of self-determination, empowerment and agency - all essential for therapeutic healing from mental illness – were dead here. I was choking, gagging. My spirit was rotting. I was dying.

Punitive action often trumped therapeutic action. I remember watching an encounter between a nurse and an Aboriginal patient, not an unusual encounter. The patient wanted a cigarette and was getting extremely anxious because he was told he could not have one. The nurse suggested he use a nicotine substitute. The patient was getting more and more agitated. The nurse was getting more and more angry. The nurse was getting more and more patronising too, speaking in slower simpler language, despite the patient speaking perfect English. It seemed that when it came down to it, ‘therapeutic support’ on the ward was actually simply behaviour management. Behaviour management, in a child-like State, was simply about belittling the ones that need support the most; about disempowering the already disempowered; about disarming the ones that most need the resources to keep them well, taking away any form of self-determination possible. The staff on Ward B (public), seemed to be concerned more with behaviour management then with therapeutic treatment (DiGiacomo 1987; 2010).
Day six – a day in the margins

Having been a nurse working in mental health, I was probably better equipped than other patients about the inside knowledge of psychiatry, and about what is considered therapeutic care, albeit appropriate care at a minimum standard.

That is what makes the tragedy greater. If you are an Aboriginal person, you are already marginalised in society. Just as it is not uncommon to be marginalised by the dominant population, it is not uncommon for Aboriginal inpatients at Ward B (public) to be further marginalised. For example, Ward B (public)’s inpatients can also be socialised within a certain ethnicity, disability, race, sexual orientation or some other category of sub-citizen. I remember watching the other patients, most of them were Aboriginal. Many of the patients from remote communities had an escort with them, usually a relative. They were often cowering in the lounge area, playing music (if permitted) or hiding from themselves and others throughout the ward. Those who were well on the route of recovery were engaging with the craft program and the exercise program. Recovery meant the same for everyone, that is, making beaded necklaces and completing three minutes on the exercise bike. I managed to make my niece a necklace but failed at the exercise rehabilitation method.

Below is a typical day for me in the Ward:
<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>0530hrs</td>
<td>Wake and read novel</td>
</tr>
<tr>
<td>0700hrs</td>
<td>Breakfast</td>
</tr>
<tr>
<td>0845hrs</td>
<td>Ward meeting</td>
</tr>
<tr>
<td>0900hrs</td>
<td>Group activities in gym. See health professionals as required</td>
</tr>
<tr>
<td>1200hrs</td>
<td>Lunch. Bedroom unlocked till lunch is over</td>
</tr>
<tr>
<td>1300hrs</td>
<td>Group activities in gym</td>
</tr>
<tr>
<td>1500–2000hrs</td>
<td>Visitors allowed</td>
</tr>
<tr>
<td>1730hrs</td>
<td>Dinner</td>
</tr>
<tr>
<td>1830hrs</td>
<td>Free time</td>
</tr>
<tr>
<td>2130hrs</td>
<td>Bed</td>
</tr>
</tbody>
</table>

There is some flexibility in the schedule. I spent a lot of time relaxing and contemplating in the courtyard. I also spent a lot of time reading and writing. If I had my wits about me earlier, I would have realised that the quickest way out of the ward was to do what the nurses wanted you to do, which is to participate in group work.

I have never found any extensive peer reviewed evidence supporting group work as being so important, nor how group work is supposed to fit in so well with the culture of the inpatient unit. Therapeutic care, as decreed by ward staff, epitomised the perceived value of group
work. It seems that group work relates to the symbols and semantics of an apparent or assumed culture of healing, and there is a power associated with that. The staff stand behind these symbols and use them to protect themselves. I wondered if I was being marginalised because I did not participate in group work enough.

*Day seven – out of mind, out of sight*

I felt alienated and alone, like I was wrongly imprisoned. I was not like the other patients. I was functioning within the economy. I had a job, family, boyfriend, friends, a place of study, a secure home. Amongst other patients, many lacked basic hygiene, unable to wash their hair let alone comb it. They wore the same clothes day in and day out. I don’t know why this is. Perhaps it was because they didn’t have any other clothes, or couldn’t afford them, or perhaps because they had no family or friends that could bring them some clothes. Or perhaps wearing clean clothes was not a priority for them. I guess that personal grooming and presentation becomes less of a priority once you are categorised as sub-citizen and a social misfit. I think most likely that they were defined as social misfits, not belonging anywhere, categorised as sub-citizens, not being in the right place and not accepted within the wider community.

Being a social misfit, deviant and sub-citizen is part and parcel of the socio-cultural identity of being an inpatient of this ward. We are shamefully hidden from the community, ignored by the public, ignored by those that love you the most. My boyfriend could only manage a quick visit once, because of the huge stigma associated with the place. Ward B (public) was part of local cultural image management, hiding the misfits and deviants from sight and keeping the
community image serene. It was general consensus in Town B, as an example, that ‘anti-social behaviour’, is behaviour deemed as inappropriate and unacceptable by the broader community, was caused and instigated at least in part by the mentally ill (Department of Health 2014).

There is a desire to hide the mentally ill, they are not pretty, they are not pleasant to listen to. The mentally ill should be put somewhere out of sight. There are not many options for hiding mentally ill sub-citizens. A public ward is the only option in many cases. The ward also, temporarily, assists with the problem of homelessness of these misfits. They are tied to many social and social welfare issues, signifying and highlighting the failure of society. They do not belong anywhere (for example, so is the case of the Northern Territory Government Department of Health, Northern Territory Mental Health Service Strategic Plan 2015 – 2021). This kind of provision of shelter for misfits is not a long-term solution. In this system, misfits have no place, not even in the outskirts of society.

From a Marxist perspective, the severely mentally ill are considered to be non-contributing members of the community. Although there are now organisations that support the mentally ill in finding and keeping employment, there are those considered grossly disabled by their mental illness and unable to work. There is seemingly not a place for the mentally ill in the workings of our economy. Their economic role is passive and dependent of the social welfare of the State for survival. For several years after I was first diagnosed, I was seen as unfit to get a job and keep a job. During these years, I did not contribute to the functioning of the economy. I did not own or have control over any resources affecting my life. I lacked agency to contribute to society.
because I did not have an active role in the economy. The disabled mentally ill are wards of the State.

Day eight – code switch

I wanted to limit my engagement with anything that would lead me to form an attachment with the ward experience.

At first, I was (passively) hostile to the nurses at Ward B (public), mirroring their hostility to me. Then I realised that I had to learn how to engage with the hierarchy of ward staff. They were my ticket out of here.

Mental health professionals say that they shy away from both strict diagnosis and one size fits all treatment. I have heard them say that mental health is a kaleidoscopic phenomenon to which there is no one answer or ‘truth’ in treatment. “Madness has in our age become some sort of lost truth” (Foucault 1967: vii). Ironic again that truth is relative to the socialised illness of the individual. Mental health is in fact perhaps the most postmodern of all Western medicines. There is not an exact method. There is not an exact truth, but fluid truths. It is relative to the pathology, the aetiology of the individual’s experience of the illness.
Day nine – pharmaceutical play time

I counted nine times when the nurses made mistakes with my medication. I questioned these mistakes, and I was quickly silenced. The head nurse assured me that the mistakes were harmless. Only four of these medication mishaps were documented in my medical notes.

On one occasion, the nurse was dispensing medication on her trolley with the drug charts open, I read on my medication chart that I was prescribed an injection used to calm the typical violent inpatient. I questioned this prescription, as completely unnecessary and totally out of character for me, I was told that it was protocol. All patients were assumed to be a threat to the ‘calm’ functioning of the ward. This prescription protocol defined the inpatient fundamentally and *a priori* as a threat, the focus being on the lacking and deficit of the patient, not the potential and strength to heal. Every measure was taken to guard and protect, not heal and support. I was so frustrated by the derogative and patronising manner of the nurse that I started crying in despair. The nurse then snapped at me, saying “For goodness sake Rachael, if you’re going to cry, go to your room! You’re upsetting people!” (Ironic, because we weren’t allowed to spend time in our rooms during the day.) Another nurse then spoke to me. I explained to him how this attitude is not empowering or therapeutic in the slightest, and that many of the nurses were burnt out and jaded. This nurse ignored the gravity of what I was saying, stating that all the nurses work here because they are nurturing and caring towards others. It was obvious that the nurses’ closed ranks around each other. Staff priorities are number one. The patient priority? Who cares?
On another occasion, the nurse distributing medication didn’t have my correct dosage of Quilonum. The nurse wrote in my notes, “During 2000hrs drug administration patient had an order of 900mg and I administered Quilonum modified release 250mg x 3 and patient refused the other half to make it to 875mg...” I would expect that a psychiatric ward would stock a common drug such as Quilonum. A following nursing note stated that I was ‘surly and sullen’ and difficult to engage with. When asked if I was okay I stated, “How could I be okay here? This place is horrible!” Apparently, I was mildly verbally abusive to the nurse administering the medication, who tried to give me Quilonum from the stock that she had. I was given the wrong medication. The smaller size Quilonum would have been acceptable, but this was important because I had always had it drummed into me that it was important to keep my Quilonum levels stable (as measured in blood tests). According to my medical notes, a risk assessment was completed, and the doctor was informed.

Another interesting note was that the psychiatrist clearly stated, and even underlined the order in my notes, that I was not be given diazepam (Valium). Yet that same day, I was given 10mg by a nurse, which I accepted, but not to my knowledge did I take Valium. A further medication mishap was that I was withheld my dose of Prothiaden as there was none in stock on the Ward. The impact of these medication mishaps meant that they played havoc with my self-confidence and self-belief. I was encouraged to believe that what the staff said was gospel. As such, I perpetuated my given label as stupid and lacking and unable to negotiate my own health. The mental health professionals assumed and reigned supreme.
It appears, from my medical notes, that some of the Ward B (public) nurses believed I exaggerated and exacerbated my psychotic signs and symptoms when I thought I was being watched. Below are some observations from some nurses:

“Has spent a lot of time talking on phone, paranoid at times, jerking bodily movements exacerbated when anxious or in view.”

“Jerking movements not visible when alone or with visitors, more exaggerated when being observed.”

“Body movements, left hand shaking, eyes darting suspiciously around, and jumped as if to get a fright displayed during discussion with Rachael, however writer observed her texting on her phone, watching TV for a long period of time with nil body movements seen.”

Stemming from my supposed exacerbated signs and symptoms, the nurses started to note how I was ‘staff splitting’. This means that I played the nurses off each other. Like a child who is not able to get what she wants from one parent, so they go to the other parent for better luck. A quote from the medical notes is below:

“Rachael became very teary and upset with the medication nurse this am after discussing prn medication. Rachael then stated that this space is not good for her mental health...staff splitting noted. Long discussion with Rachael about her medication and hospital policy.”
The reference to hospital policy was regarding my defiance to accept the medication prescriptions policy. Here I would like to note the power of bureaucracy and how the strength of the magical red tape, and the seemingly ritual practice of ward governance, supports hospital treatment. There is a schism between bureaucracy and what happens on the psychiatric ward. Often different languages are used. Often misrepresenting what is meant between Ward B (public) and hospital policy. For example, there is a hospital policy to rehabilitate Ward B (public) patients where possible, but I did not hear about any goals of rehabilitation until the day before I left.

*Day eleven – tensions over the fruit loops*

I was considered defiant by staff.

Here in this locked public psychiatric ward ‘management issues’ seemed to be a focal point. Note that the management issues are regarding behaviour not so much signs and symptoms. It seems, through reading my medical notes from the Ward B (public), that I displayed some of my own management issues.

One nurse noted, “She [Rachael] refused to participate in unit activities”. [Yet in the afternoon] “maintained a high profile in gym doing craft”.

One incident that was not written about in the notes occurred during breakfast on day eleven. I didn’t want to mingle or socialise with any other inpatients or staff, so I took my bowl of cereal outside into the courtyard. There I could get some quiet and peace. I found the plants calming
and helped me gain some stillness within this otherwise horrific experience. My solace was short lived. Again, what I thought could and should be promoted as a therapeutic environment was not the case. A nurse told me, quite roughly, that I had to eat my breakfast inside at the dining table. I asked “Why? I like it outside. It clears my head.” The nurse said, “You just have to!” I asked calmly, mainly because I didn’t understand and was curious as to her reasoning, “But why? It is obvious that eating in the courtyard makes me feel better, and this ward exists to make the mentally ill feel better.” The nurse responded, “You just have to eat in here. It is the rule and the policy!” I stated that I would like to see such policy. It was obvious that our banter wasn’t going anywhere, so once again I acquiesced and continued to play the game.

**Day twelve – rehabilitation?**

The only way I could retain some self-respect during my admission was to employ my skills as an anthropologist. As did DiGiacomo (1987), I started to unpack what I was seeing around me, what I was experiencing and how people were relating to each other. I observed negotiations of power, which defined the mentally ill as colonised (Smith 1999).

In Ward B (public), the colonialist parent State clearly confines and defines the inpatient as in need of prescribed direction. The patient cannot have agency. The only means for ‘recovery and rehabilitation’ is to play the game, pander to the nurses of note, don’t say anything that is in defiance to the biomedical model, be subservient. Once I accepted my subservient role and played the ‘game of recovery’, in complete compliance with the nursing staff, I began to be treated as more of a human. Seemly, good treatment is granted only if subservience is given.
At the end of my admission, I had an appointment with the rehabilitation nurse. I raised my perceptions of the ‘game of recovery’ to this specialist nurse. I told her that I felt disempowered rather than empowered by my experience in the ward. I went on to say that I hadn’t heard the word ‘empowerment’, ‘rehabilitation’, or any other such hopeful words in conversations in the ward. I explained how my time in the Ward B (public) was despairing. She was shocked, and started to say that it couldn’t be so, as if to say, “surely it couldn’t have been that bad?” I had to convince her of the reality of my experience of this culture shock rehabilitation? The resources I had to rehabilitate were my own, developed by me with support from loved ones and intelligent ones. If anything, Ward B (public) disarmed me.

_Discharge – thank God!_

On the day I was discharged from Ward B (public), I was released with a change in medication. I was back on olanzapine, 10mg in the morning, and 15mg at night. I had been weaned off the quetiapine and was still taking a little diazepam. (I was to be prescribed more drugs once I started taking Clozapine.)

The discharge notes summarised my reason for admission. Let me quote:

“Referred by GP after she presented with extreme distress, saying that she is not safe and that she cannot control her thoughts and the thoughts are taking over. Rachael tended to engage in repetitive movements in an effort to control the thoughts. She said she had auditory
hallucinations, only varying in intensity. They were critical and distressing. She presented to the Emergency Department today around 1535hrs. She had 10mg of olanzapine which she said helped her with the voices a little bit. She says she hasn’t been feeling well after her recent medication change post discharge from [Ward A (public)] (Admission in October 2012). The auditory hallucinations have increased and became more distressing over the last few days. On reviewing Rachael, she was very distressed and appeared to be responding to internal stimuli.”

My admission Mental State Examination was as follows:

“Appearance: 39-year-old Caucasian lady, appropriately dressed and groomed. Appeared very distressed and responding to internal stimuli.

Behaviour: No eye contact, was constantly hyper vigilant, looking towards the corners. Appeared paranoid and suspicious.

Speech: Normal tone and volume. Slightly pressured.

Thought form: No FTD (Formal Thought Disorder)

Thought content: Very distressed by the noises in the Emergency Department and voices of people talking to her over the last few days. Paranoid and distressed. Didn’t want to be admitted to Ward B (public) initially as she thinks it is a ‘scary madhouse’.

Perception: Admits to auditory hallucinations over the last few days, sometimes of people talking to her and making derogatory comments of ‘how much of a crappy person she is’. Says she’s been hypersensitive to noises and music as well. Says certain beats on radio music sounded like ‘codes’. Denies that the voices are telling her to harm herself or others.

Cognition: Grossly intact
Insight: Good insight into her illness and her medication changes. She’s aware that she needs to commence on a different anti-psychotic [medication].

Judgement: Reasonable.”

My progress whilst in hospital was as quoted below:

“Rachael was admitted and commenced on olanzapine again. Her quetiapine dose has also decreased gradually throughout the admission. She was kept on 2.5mg diazepam nocte. Her mental state improved throughout the admission. She wanted to be followed up by her GP and her private psychiatrist.”

**Conclusion**

My admission to Ward B (public) was more detrimental to me than being an outpatient. As an outpatient, I would have been managed without as high a degree of stigma. As an inpatient, I was treated and defined as a subhuman. Relationships I had were damaged from me being an inpatient at Ward B (public) - it was that much of a stigma. There was not a culture of rehabilitation in the ward. Instead, the care was somewhat punitive, addressing behaviour issues rather than treating the patient’s health holistically.

I had my last meeting with the registrar. I hadn’t forgiven him from lying to me about smoking and making me look even more crazy than what I was. He really didn’t get me. During my stay
at Ward B (public), I carried around a little green suitcase with me – a handbag. When he asked me why I carried my little green suitcase around with me, I told him that it was because we weren’t allowed in our rooms during the day, and I wanted to carry my books with me. The other patients didn’t seem to have the same need to carry their own little green suitcases of books. Obviously crazy behaviour!

Above is the panopticon version of Ward B - Jeremy Bentham’s panopticon (late 18h century). The sociological effect in the context of this thesis is that the mentally ill patients are aware of the presence of authority at all times, a system of control without knowing how they are being controlled (Mason 2019).
I returned to live and study in Town A in August 2014. It was about a year on.

Things just haven’t been good in the last few weeks. The noises are getting louder, unbearable! They keep saying things like, “You stupid idiot!”, “Who is ever going to like you, let along spend time with you?”, “You m’ose well die now and stop annoying everyone!”, “Die you stupid bitch die!” The noises talk over each, shouting coming from all directions. Different voices, penetrating. At least they don’t give me details of how I should degrade myself or die.

I’m super paranoid, not knowing what is real and what isn’t. I’ve been trying to hold it together. Damn it! I hate losing! My anxiety is through the roof! I’m having panic attack after panic attack. It is unbearable, intense. I am being crushed. I can’t breathe with the overwhelming panic that consumes me.
I had some good years, but these last two years have been terrible. All the tools and techniques I have developed over the years are no use to me now. I used to be able to control my anxiety with meditation, mindfulness, healthy lifestyle, breath awareness and control, cognitive behavioural therapy (although I’m not a big fan) and sometimes avoidance. Avoidance is not considered a useful technique to battle anxiety as it negates the cause and solution.

When I was not able to figure out what was real and what was not real, I could ask close friends and family – “Is that real?”, “Did you hear that?”, “Is that person looking at me?” Managing my psychosis was definitely made bearable by the support and feedback given to me by my loved ones. I could tell I was getting more unwell if I had stopped trusting my loved ones. Then the paranoia increased. My psychiatrist in Town A believes that my anxiety is linked to my psychosis.

I’ve rung the mental health team to make an emergency appointment with my psychiatrist. I have made an appointment for tomorrow.

Tomorrow has come and somehow, I manage to drive there okay. I lose it though once I get to the mental health service. “What?” “What was that?” “Who is that?” Screaming and blaring in my head, ear splitting, deafening me. “Who do I listen to?” “Who is real?” “What is real?” Again, when I get unwell, the world crashes in on me! I can just remember the seemingly loud noise of the elevator, and of people getting in. I could feel the penetrating eyes of the other people in the small elevator, looking at me, scrutinising and piercing their sight right through my to my soul with their powerful and terrifying eyes. I could tell who staff are and who are not. I
always try and make an effort to dress well and put on make-up – counteracting the possible visual stigma. This sometimes confuses people into thinking I am an employee not a client.

I am mostly insightful. When I am well, I can recognise my qualities and purpose. I am usually calm and even keeled – many years of taking Quilonum. I have a silly but mostly black sense of humour, coming from years of working in aged care. I have a strong sense of loyalty to family and friends and I would do anything for those I love. I am ambitious and meticulous, painstaking, fastidious, and thorough. I am also patient and tolerant, persistent and stubborn, and this is why I mostly win my battles.

Many people who meet me are shocked when I disclose to them about my schizoaffective disorder. Not that I tell people generally, but sometimes, rarely, it comes up. I actually hate disclosing. Often employers demand that I tell them. I’m not sure if this should be permitted, whether it is their right to know about something very private for me. I can understand the need for managers to be able to look out for the interests of their staff, but it is a basic human right to retain security. As per section 25, part I of the Universal Declaration of Human Rights Assembly 1948, “Everyone has the right to a standard of living adequate for the health and well-being of him/herself, including food, clothing, housing and medical care and necessary services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age, or other lack of likelihood in circumstances beyond his/her control” (My emphasis).

With regard to feeling secure with my disability, I need to feel safe and comfortable in living with a disability, in my case, a major psychotic disorder.
Doctor T, my psychiatrist, comes out to the waiting area. Hearing her voice “Rachael”, startles me away from the noises’ deadly repertoire, and my great efforts to silence them. I get up slowly, and timidly walk with the doctor, my head hung low. The doctor asks, “Do you mind if we have a student doctor sit in on us today?” This freaked me out! I fearfully started to ask the doctor about whether the student could look into and read my soul when she saw me. Doctor T knew not to push the matter, and when we arrived at her room, she asked the student to leave. I asked, “Is she angry with me? “She saw into my soul, didn’t she?!” “She’ll come after me now and punish me! That’s what they [the noises] say.”

I sat down on the chair. It had started again. I started cowering and trying to hide myself somehow within the limits of the chair. I was tapping again too, tapping my fingers against the chair arm, against my face, my head. The sense of touch was the only way I knew how to centre myself. Touch seemed real.

Shit! I hate losing it!
Bloody hell!

It seems that I am going through another psychotic episode.

Damn!! Usually I can handle the milder psychotic episodes, but this one is beyond my control. I have won the fight against many, many psychotic episodes over many, many years, but there are some I cannot manage. I cannot master this one. I need a hospital stay to get back on track: to control my anxiety, my psychosis causing anxiety; manage my paranoia; address my cognitive functioning disabilities; cement a healthy diet and exercise regime including meditation and yoga; and healthy; and to develop a sound work/life balance. Cognitive functioning is
paramount. I need to trust and believe in my thoughts and thought processes. If I don’t have control of my thoughts, I cannot be an academic or a policy advisor or even a giraffe breeder.

Doctor T asked me, “Has anything happened? What has changed?” “I don’t know, don’t know, don’t...” I said. Looking at me, seeing how fragile and unstable I was, Doctor T said that I needed to be in hospital.

I don’t know why I became unwell again. There isn’t always a reason. There was no apparent reason this time. However, now I was having a relapse, a psychotic episode, causing incredible anxiety. My psychiatrist wanted me to go to hospital. My medication needed adjusting. Doctor T started ringing the psychiatric wards in Town A. There were no beds available right away, so I was put on priority listing. The helpful thing was that I now had full private insurance which essentially increased my chances of receiving care.

My boyfriend at the time, with the help of the community mental health nurses, took me home, a safe place, to wait until we received notice of a spare bed in any hospital. John, my boyfriend, looked after me that night. A community nurse came by to check up on me and give me medication. It was a waiting game. I remember feeling disassociated, detached from reality, disconnected from the world and being in it. I was distant, not belonging anywhere, frightened of what lay ahead of me.
I think my boyfriend felt the same in many ways. He had never had a crazy girlfriend before, let alone one that had to be hospitalised. He didn’t know quite what to do with me or say to me. That makes two of us, although I’ve had twenty more years experience with it. I was very worried and concerned about John. He is very resilient and strong. He was at first supportive.

It is sometimes very difficult for people conversing with me to get any sense from me. When I talk it is tangential and all over the place, finding it almost impossible to follow a conversation with clarity and direction. For example, a group of friends could be talking seriously and clearly about buying motorbikes, when the next sentence from me will be about dentistry, a completed and unrelated topic, but seemingly logical to me. Sometimes I must explain my thought processes to friends because they are confused and don’t understand my flow of cognition and communication. My memory and my ability to contain knowledge has been diminished. I often have to ask the same questions half a dozen times in a few minutes. The chop and change in conversation makes it complicated, gruelling and confusing for others. Then there is the issue of me not hearing what is being said, partly because of the noises in my head taking up so much capacity adding to my confusion.

I remember feeling uncertain of how John might react. He hadn’t in the past understood when I tried to explain my schizoaffective disorder it to him. It is different to describe common mental health disorders, like depression, which seem easier for people to relate to, understand and therefore deal with. This makes it even more confusing and scary to describe uncommon and complex mental health disorders. I did my best to find a lay person’s book on schizoaffective
disorder, with very little luck. The book I found was directed at young children. The DSM-V would have been too confronting.

While waiting for a hospital admission, we decided to watch some movies, to bide the time away. John annoyingly banned me from watching horror films – just in case I get any ideas while I’m having a psychotic episode. As if I could be influenced by Jack Nicholson’s part in ‘The Shining’.

Somehow, I got to sleep that night... I’m not sure if John did.

In the morning, at about 9am, I received a call from Ward C (private), the administrative wing of the Ward C (private), stating that they had a spare bed for me, and could I please come in at 1300hrs. And so, we did.

I remember arriving at the private psychiatric ward, Ward C (private), at 1300hrs, as directed, and being given a pile of paperwork to fill out. It was a significant step in my relationship with John, as he wanted to be recorded as my emergency contact. I was pleased.

I was worried, however. John was a mental health virgin and had never been in a psychiatric ward, let alone helping to admit his girlfriend in to one. I was very anxious about him and I’m afraid the anxiety consumed me during this admission.
The walls are painted beige with green skirting boards. There were pot plants around the wall for aesthetics. There were cameras on the ceiling, in the corners. Also, the obligatory smoke alarms. Being a Catholic hospital, there was religious iconography around the ward, mostly in the forms of paintings and statues. Icons were displayed in the common areas, such as the dining room, group rooms and television/relaxation area. Being a patient in a Catholic hospital facility meant that I must take my own contraceptive pill, as contraception aids are forbidden in Catholic facilities. I have had friends refused vasectomies in the same hospital as it is against the teachings of the Catholic Church.

After a few days in a highly monitored room, I graduated and was allowed into a room of my own. I had my own bathroom, television, wardrobe, desk and bookshelves. The television was situated above the bed for easy viewing when lying down. A far cry from the graffitied insanities and punitive treatment in the Ward B (public). Ward C (private) also contrasted with Ward A (public) where I had to share a room, bathroom, television and everything else. Perhaps it is considered more therapeutic to have your own room.

The staff at Ward C (private) were amiable, understanding and patient. Not prerogative, patronising and superior, and considering themselves as privileged. The Ward C (private) staff respected me as an equal, appropriately suggesting advice when suited.
This ward is a private mental health ward. For the 17 days I spent there, it cost over $10,600 AUD. The care was very good. The nurses were supportive and understanding. It seems that only the privileged can afford good health care. Seventeen percent of my wage goes toward my mental health costs. And I receive free psychiatric, psychological and Clozapine care. If I was paying for all my mental health costs, I would conservatively spend 31% of my wage on my mental health. (I have not included the costs of my physical health, which involves yearly medical imaging decreed necessary by the medical profession’s need to measure, compartmentalise and evaluate.) There is a financial burden to having a mental illness. It is hard to reason that the chronically mentally ill, spending a third of their income on managing their disability, does not contribute to the economy of the community.

Arguing from a Marxist perspective, I am committed to a position of servitude and dependence on the health system and the State, forced to surrender any true agency as I do not control the resources and health commodities, I need to survive. It is ironic that the path to my freedom is actually the path to my imprisonment. I need freedom, but I cannot be free without being defined by the language/s of being captured. These are the language/s of economy and the access to resources. The economic resources that I need to own to live a full life are controlled by politics and culture. I need these resources to function in society; I need these resources to survive.

Ward C (private) is seemingly the ward of the privileged, socially acceptable mentally ill. Most of the patients there are sick with first world illnesses such as anxiety and depression. There is not the degree of stigma with anxiety and depression as there is with a psychotic illness. There
were no overtly psychotic people in the ward. ‘Schizo’ patients are hidden from the social arena, even in this hospital.

The cultures between Ward B (public) and Ward C (private) cannot be more different. On my first day at Ward C (private), my allocated psychiatrist asked me, “What has it meant to you, having this illness for so many years? Has it changed you? Has it meant that you couldn’t live the life you wanted?” I couldn’t believe it! I was stunned! I said in shock, “No one has ever asked me that before!” I umm’d and ahhh’d a little. Then I began to sob. I was unsure, because I spend a lot of time trying not to think about what could have been. I don’t think I would ever get out of bed if that were the case. Then I said, through the tears that had started to flow down my cheeks, “It has changed my life fundamentally! I have lost relationships, my chosen career, my healthy body, my mind and intellect, my memory, my zest for life, my effervescence, zing and joyful demeanour, my hopes and dreams, my confidence, my self-esteem, my capacity and competency.”

My life without schizoaffective disorder. Wow!! I can’t comprehend that! More than half my life has been defined and confined by my mental health. I feel imprisoned by my diagnosis and prognosis. I am no longer in charge of my own life. I have limited or no agency. Having a mental illness can make you a ward of the State if you do not comply with the mandate of mental health professionals. I am empty with schizoaffective disorder, though I don’t know how to live without it.
My life has been turned around and spun on its head. I am not the young woman I was, with
dreams and aspirations and a thirst for an exciting future.

What I have left is the shell of a fat forty-year-old (odd) woman, who asks herself every day,
“How do I get out of this black hole?” I am imprisoned by a shield of anxiety and psychosis that
encases me tightly. I can see the outside world, and vaguely hear what a normal life sounds like,
but I am disabled and unable to reach, breath or smell normalcy. No one can hear my cries. No
one can feel my pain. Could this all be made up by me? Is this real? I am forever afraid that my
friends and family will have enough of me because I am so needy and demanding. I feel like a
shell of who I used to be. I am persistently worried that every relationship I begin will end
because I am crazy. I would break up with myself if I could. I also stay in relationships much
longer than I should because I am convinced that I cannot do any better.

At Ward C (private) we were encouraged to attend group sessions, though, happily, we were not
dishonoured by a decision not to attend. The staff explained why group work was important,
speaking to you as an equal. There was nothing punitive about my treatment. If we chose not to
socialise with others, we were not forced to socialise. Such luxury! Compared to Ward B
(public), it was a holiday resort! It was also a step up from the other Town A ward. We had
choices, and a degree of self-determination. It seems that not being forced to socialise with others
is therapeutic and less anxiety provoking, at least for me.

There were some things in Ward C (private) that reminded you that you were in a psychiatric
ward. You were regulated about when you could leave the ward. When you are first admitted,
you are not allowed out. Then after a couple of days you are allowed out for a walk with a sober adult. Leading to the ultimate leave, overnight leave, also with a responsible adult.

During my stay at Ward C (private), I had a brain MRI to better diagnose my anxiety. They found seven lesions in my brain. I waited for days for these results. I thought I may have a reason, a cause for my mental health condition. Finally, a doctor and a nurse came to speak with me in my room. Apparently, the lesions were insignificant and not related to my mental health. I went to the neurologist who claimed that the lesions were not the cause of anything. The condition was called “Radiological MS”. That is, I have the lesions someone with multiple sclerosis may have, but without symptoms. I must have a regular brain MRIs for a few years to see if there is any change. (Note that one year later, that is 2016, my ‘without symptoms’ developed into ‘symptoms’, with arm and leg spasms. As of 2019, the spasms are getting worse).

A typical day in Ward C (private) involved:

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>0700hrs</td>
<td>Get up, mindfulness, meditation, shower and dress</td>
</tr>
<tr>
<td>0800hrs</td>
<td>Breakfast</td>
</tr>
<tr>
<td>0830hrs</td>
<td>Reading</td>
</tr>
<tr>
<td>0900hrs</td>
<td>Walk – by myself</td>
</tr>
<tr>
<td>0945hrs</td>
<td>Reading mindfulness meditation</td>
</tr>
<tr>
<td>1000hrs</td>
<td>Group activities (I sometimes attended)</td>
</tr>
</tbody>
</table>
During the day, there was always time to see the doctors and to complete activities of daily living, such as washing clothes.

This admission was different to those in the other two psychiatric wards, completely different. It was almost like a hotel. The nurses wore normal respectful clothes, they were considerate and attentive to my needs. The staff normalised my position, speaking to me as if I was intelligent, not assuming I was a sub-human.

That was the primary difference between the three wards: the private psychiatric ward acknowledged my humanity. I was not subhuman; a sub-citizen. I had agency and a voice. Why should Ward C (private) have more empowerment for patients than Ward B (public) or Ward A (public)? Could the only reason be because it is privately funded?
The private ward had the typical mental health ward lay out, with the central hub housing all the sacred notes and policies. The hub was different to Ward B (public) in that there was not a glass pane separating patient from staff in Ward C (private), separating the misfits from the esteemed and protected staff. Despite this seemly common panoptic ward design-type, the allied health professionals, psychiatrists, pastoral carers, group coordinators, and the administrators all shared offices spread around the hub.

I was an inpatient on the ward for 16 days.

Above is the Ward C (private) version of the panopticon.
CHAPTER TEN

THE ART OF MEASUREMENT

SOCIAL CONSTRUCTION OF REALITY

“A point to consider: the space to produce knowledge and the way this space is or is not heard.”

(Field notes June 9th, 2014)

I agree with the concept that all things are born and understood from socio-cultural phenomena, and not solely understood through positivist natural sciences. Indeed, the label ‘schizophrenia’ only came about in texts in 1908 (Hacking 1999: 9). This is when the social sciences were developing. It goes to follow that what we know as schizoaffective disorder, pre social science and psychology, was mainly defined within the realms of hard science. The confusion between the old school of understanding of schizophrenia, which was born from the biomedical model, led to some confusion that stood to believe that schizophrenia is a scientific delusion (Hacking 1999: 112-114).
A factoid is a socially created fact, assumed by the powerful. The powerful factors surrounding the social construction of reality, as stated by Lea (2008), are numbers and graphs. Numbers and graphs are deemed honourable. Historically, the social-scientific facts and factoids are not as honourable as quantitative methods. Again, the biomedical realm has historically encompassed mental health, but mental health biomedical science cannot be understood separately from the social construction of reality. For example, during my admission in Ward B (public), I was desperate to have social contact. Social contact fuels me so that I have the courage to go on. It helps me to stay strong. However, admission to Ward B (public) was highly stigmatised in the Town B community. Due to this stigma and keeping my reputation in high regard, I had to be careful about who I told. For example, some of my friends were not told due to the stigma and shame they felt, and the consequent feeling of intense shame that I felt. I was dishonoured. I was made to feel like a social misfit and deranged then.

Mental health is commonly pathologised, but it is also socialised, creating a foundation in a social construction of reality. I am interested in looking at the examples of two assessments that best encapsulate my experience and relationship with measurement. These examples best capture the confounding factors in psycho-metric testing, and how potentially inaccurate they are in their representations of the mentally ill, and thus the tools accuracy altogether.

I was a subject for the Neuro-Psychological Assessment and the Personality Assessment Inventory (PAI). I'm interested in the ‘measurements’ of those living with schizoaffective disorder or major psychotic disorders and what that means for them. I am interested regarding my own contribution to the cultural archives (Foucault 2013), to know the perceived truth that comes from my own psychometric testing. These measurements have proven to be the most
significant anthropologically, that is, in context of my (dis)empowerment of the mentally ill. Which brings me to wonder, how was I categorised from these measurements?

I feel very strongly that my cognitive functioning has diminished substantively over the many years of living with my psychotic illness. I know that my memory is terrible, my concentration is lacking, and my ability to analyse data is stunted. I was hoping to get some constructive suggestions and tools to assist me to retain, or hopefully improve, my cognitive functioning, and I did. The person who administered the testing in Town A was a very intelligent and an experienced neuropsychologist.

Measurement and mental health

Measurement and assessment in mental health is vastly different from that performed in other arms of medicine. Exactly what is it that mental health assessments are trying to assess? Are the measurement technologies used in mental health different technologies than those used elsewhere in medicine? The measurements performed in psychiatry are subjective and esoteric in many ways. The brain, the organ most referred to in psychiatry, is an enigma. I must note, however, that psychiatry also has a hand in more holistic medicines. Treatment for psychiatric disorders are varied, and somewhat of a trial and error situation for each person living with mental health disorders.
From what I gather, psychometric testing is circumstantial. The tests are shady, giving a confounded result. Mental health professionals perform the usual assessments that other branches in medicine perform. However, the psychometric testing and other smaller assessments performed on mental health participants are unique. So, in becoming a consumer in a psychiatric ward, I am in some way enculturated into the inexact science, further becoming a subject to the culture precipitating the labels of subhumans, sub-citizen and social misfit. I am conflicted about whether I should participate in a subculture which disempowers me. Biomedical treatment is better treatment than none. Again, I am dependent on the system which disempowers me. Again, I am dependent on the State, with the hope that the testing will help me be okay.

The Neuro-Psychological Assessment I participated in illustrated how the factoid was given agency and, in some ways, has been anthromorphised. Through this tool, I was categorised and labelled. What I thought would be an empowering experience, learning about my strengths, in fact further inhibited me. It was official. The psychotic episodes I have had over the years have limited my cognitive capacity. Now I am being monitored and reviewed regularly by the State. Each month, and often more frequently, I am measured. Legitimised and given authority by these measurements, I am a part the institutional apparatus and infrastructure of these measurements, as a cultural artefact and product. As I was unwell, and needed treatment, I had little choice but to succumb to a system of disempowerment. The measurements develop from a technology of knowledge production to an object of governance (Foucault in O’Farrell 2007).
Excerpts from the neuropsychological report

Below is a passage of the neuropsychological report testing me:

“At the time of neuro-psychological assessment, Rachael was 40 years of age, in the fourth year of her PhD and working part time in a quality assurance role. [She was referred from her psychiatrist] to assist with perceived cognitive difficulties she was experiencing that were causing concern in relation to her studies. During these sessions, she requested to undergo a neuro-psychological assessment to assist further with her post-graduate study and her work.”

“Rachael currently reports memory difficulties with problems ‘retaining’ new ‘knowledge’, even if she re-reads information she has encountered only two hours earlier and can be repetitive in conversation. She felt her concentration is lacking and finds it difficult to focus on task. When reading, for example, it feels like her mind goes into a sort of ‘suspension’. She stated that she is unable to process the material, such that she seems ‘dissociated from my thinking’. She currently feels that her thinking lacks ‘clarity’ and feels limited in the quality of her ‘analysis’ skills such that she feels like a ‘below average student’ at present. This is against a diagnosis of schizoaffective disorder, which Rachael has been living with since her early 20s. Current assessment was timed to allow for recovery from a relapse in her condition.”

“On presentation, Rachael was a pleasure to work with and she appeared to apply her effort throughout, which was supported by the pattern of results across psychometric indicators of effort. On observation, she appeared to have difficulties sustaining her attention at times, with an impact of her general ability to process information (for example, instructions). She appeared
to have good insight into her health and communicated her lived experience of schizoaffective disorder in a way that demonstrated self-awareness and self-reflective capacities.”

“Results of formal cognitive testing demonstrated variability amongst Rachael’s current cognitive skills. Verbal intellectual skills were high average, congruent with expectation and Rachael had a particular strength in her general knowledge. Working memory capacities (that is, the capacity to hold and manipulate information in mind) were average and within expected limits. Speed of information processing was high average range and congruent with expectation. Perceptual problem-solving skills were low average, and whilst within normal limits for her age range, were considered low expectation, given Rachael’s other strong capacities.”

“Interesting to note was that when provided with additional time, Rachael demonstrated the capacity to complete one of these tasks as slightly stronger – average levels. Attentional skills were within the normal range, with some minor variability, ranging from the average-low average range up to the average range.”

“Memory performances were variable. New learning and recent memory of visual-spatial information was in the average range, and though normal for her age, was somewhat reduced as compared to her stronger verbal intellectual skills. Her new learning and recent memory for auditory-verbal information was variable. Immediate recall of pairs of words that were repeated was in the average-low average range and was average following a time delay. Recall of a story immediately after presentation was in the borderline to extremely low range and was in the low average-borderline range following delay.”
“Tests of executive functioning were performed in generally the average range as compared to age matched peers. Therefore, there were many which were well within normal limits (for example, average) for Rachael’s age, but possibly reflect departures from what is expected based on her educational achievements.”

I could not believe the results. I was hoping for some reassurance and validation. What I found out was that I have been affected terribly by my mental illness. Apparently, cognitive diminishment is common for people with my diagnosis. So, I am officially disabled; officially lacking full mental capacity. My capabilities were in fact diminished. I was sadly ‘handicapped’ according to some mental health professionals. In calling me ‘handicapped’ even though questionably a Freudian slip of the tongue, having said so, the professionals perpetuated the label they try hard to eradicate.

Below is an extract of some of the text of my personality assessment inventory (PAI) (assessment done October 2012):

“With respect to negative impression management, there are indications suggesting that the client intended to portray herself in an especially negative or pathological manner. Some deliberate distortion of the clinical picture may be present; evaluation of the critical items indicates she is not malingering. Also, such results often indicate a ‘cry of help’, or an extreme or exaggerated negative evaluation of oneself and one’s life. This exaggerated negative evaluation is consistent with how the respondent describes herself in interview. Regardless of the cause, THE TEST RESULTS POTENTIALLY INVOLVE CONSIDERABLE DISTORTION AND ARE UNLIKELY TO BE AN ACCURATE REFLECTION OF THE RESPONDENT’S OBJECTIVE STATUS – THE FOLLOWING
“Despite the general level of negative distortion noted above, there are some areas where the client described problems of great intensity... These areas could indicate core problems that stand out from the general level of distress and dysfunction reported by the client, such problems merit particular focus in further inquiry. These areas include disruptions in thought process; unusual ideas or believes; feelings of helplessness; tension and apprehension; heightened activity level; irrational fears; and compulsiveness or rigidity.”

“She likely questions and mistrusts the motives of those around her, despite the nature or history of her relationships with the following areas: antisocial behaviour; problems with empathy; unusually elevated mood or heightened activity.”

“A number of aspects of the client’s self-description suggest marked peculiarities in thinking and experience at a level of severity and usual even in clinical samples. These features are often associated with an active psychotic episode, with poor judgement and impairment in reality testing as hallmark characteristics. It is likely that she experiences unusual perceptual or sensory events as well as unusual ideas that may include enchanted thinking or delusional beliefs. Her thought processes are likely to be marked by confusion, distractibility, and difficulty concentrating, and she may experience her thoughts as blocked, withdrawn, or somehow influenced by others. She may have some difficulty establishing close interpersonal relationships.”
“The client reports a number of difficulties consistent with a significant depressive experience. She is likely to be plagued by thoughts of worthlessness, hopelessness, and personal failure. She admits openly to feelings of sadness, a loss of interest in normal activity, and a loss of sense of pleasure in things that were previously enjoyed. However, there appear to be relatively few physiological signs of depression. The symptom picture appears to be relatively free of changes in energy, appetite, weight, and sleep patterns.”

“The client indicates that she is experiencing specific fears or anxiety surrounding some situations. The patterns of responses reveal that she is likely to display a variety of maladaptive behaviour patterns aimed at controlling anxiety. For instance, phobic behaviours are likely to interfere in some significant way in her life, and it is probable that she monitors her environment in the vigilant fashion to avoid contact with the feared object or situation. She is more likely to have multiple phobias or a more distressing phobia such as agoraphobia, then to suffer from a simple phobia.”

The assessor goes on to say, “the respondent (me) displays core needs that need to be addressed. These include disruptions in thought processes; unusual ideas or beliefs; feelings of helplessness; tension and apprehension; heightened activity level; irrational fears; and compulsiveness of rigidity. The respondent is likely to be withdrawn and isolated, and she may have few if any close interpersonal relationships and may get quite anxious and threatened by such relationships. Her social judgement is probably fairly poor, and she has difficulty making decisions, even about matters of little apparent significance.”
My presentation during testing was affected and based on my psychotic state at the time during the hospital stay in Ward A (public) – October 2012 - where my perception or reality was eschewed and unreal. The testing did not represent who I am. This is not who I am. I was psychotic and dissociated from reality; at a time when I was nothing valued in society I am misunderstood, devalued and famed. The misrepresentation affected my life. The language and symbolic power used to adversely misrepresent my experience of living with schizoaffective disorder is based on biomedicine and science. I was represented by a testing which begets testing which begets misrepresentation, as well as stigma (Bourdieu 1991; Goffman 1963). An identification understood and measurable by biomedicine (DiGiacomo 1987). Suffering with schizoaffective disorder, and not knowing how to understand the disorder apart from biomedicine; I am pathologised.

The assessor went on to say, “The respondent indicates that she is experiencing a discomforting level of anxiety and tension. She is likely to be plagued by worry to the degree that her ability to concentrate and attend are significantly compromised. Associates are likely to comment about her over-concern regarding issues and events over which she has no control. Affectively, she feels a great deal of tension, has difficulty relaxing, and likely experienced fatigue as a result of high perceived stress. Overt physical signs of tension and stress, such as sweaty palms, trembling hands, complaints of irregular heartbeats, and shortness of breath are also present.”

Here I comment, again, because I am being defined and assessed by a priori assumption of madness. I’m defined by the assessment, by an assessment grounded in biomedicine and pathology. I lack agency. I am lacking. I am stigmatised and devalued and defamed.
The assessor follows on, “Her self-image may be largely influenced by a belief that she is handicapped by her mental illness. She is probably also seen by others as being something of a perfectionist. She is likely to be a rigid individual who follows her personal guidelines for conduct in an inflexible and unyielding manner. She ruminates about matters to the degree that she often has difficulty making decisions and perceiving the larger significance of decisions that are made. Change in routine, unexpected events, and contradictory information are likely to generate untoward stress. She may fear her own impulses and doubt her ability to control them.”

“Given this self-doubt, she tends to blame herself for setbacks and sees any prospects for the future as dependent upon the actions of others.”

For me, the assessment displays an unfathomable difference between my own self-perception and the PAI assessment of me. How is this difference defined and negotiated? How does this unfathomable difference between self and institutional measurement illustrate the significance and potency of relationships across the divide? What power dynamics are rife to craft an argument and identity around difference? It is these power dynamics that are fundamental to craft the critical theory stance of (post)colonialism. The purpose of (post)colonialism in this discussion highlights colonial existence, whereby the self is subjugated and disempowered under the powerful existing hegemony, in this case the PAI assessor and supporting paradigm of biomedicine (Said 1978). To associate with Smith (1999), the concept and process of mental illness service delivery can be likened to colonialism, whereby the dynamic between self and institutional measurement are unpacked. (Post)colonialism implies a step away from colonialism, whereby there is a difference between self and institutional measurement.
A concept that epitomises the difference and power negotiations across the board is the Silenced Manifesto. The Silenced Manifesto allows for a space, a ‘(post)colonial space’, admitting and permitting a possible commensurability between the heard (colonisers) and the silenced (the colonised). These advances coalesce as (post)colonial logic (Kowal 2008: 341). The language used in such as analysis forms to make the manifesto discourse. The language used coalesces between my own self-perception and the PAI assessment of me.

To continue, the assessor goes on, “The respondent’s interpersonal style seems best characterised as self-effacing and lacking confidence in social interactions. She is likely to have difficulty in having her needs met in personal relationships and instead will subordinate her own interests to those of others in a manner that may seem self-punitive. Her failure to assert herself may result in mistreatment or exploitation by others, although at this point, it appears that the strategy has been effective in maintaining her important relationships.”

When reading the above report from my PAI, I was amazed. Yet, nowhere in my medical notes is there evidence to show that I am empowered to define my own identity. I am defined by the hierarchy of mental health professionals as fundamentally lacking and without the means or resources to participate fully in society. There is somewhat of an assumed a priori knowledge that the psychiatric participants are lacking or in deficit in some way, and in need of intervention and support. I lack the capacity to make my own friends and to develop a social and fruitful life (according to the Personality Assessment Inventory – PAI). I am the consumer, the inmate, the social misfit. What’s more, in other spheres, more broadly defined in society, in economics and politics, I am the subhuman, the sub-citizen.
It appeared and felt to me that I was reading about an entirely different person. I didn’t relate to anything the psychologist said. It made me wonder what on earth the assessor was hearing, because in reading her report, I didn’t recognise myself at all. I felt divorced from my assessment. This assessment is a good example of miscommunication between health professional and consumer.

This miscommunication also illustrates power differentiations between the health professional and consumer. The language used between health professional and consumer whilst both speaking English, was seemly incommensurable. The cultural clash becomes a strong imbalance between the health professional and me. Miscommunication and misrepresentation are commonplace in medicine. For example, the “Sharing the True Stories Report” (Cass et al 2002) based in Darwin, Northern Territory, showed an example of the significance of miscommunication between cross-cultural groups.

Measurements and assessments become cultural artefacts in the world of the (post)colonialist medical science and specifically (post)colonialist psychiatry. Cultural artefacts are socio-political objects which aid in the governmentality of (post)colonial power structures. In reaction to exploring and negating, the nature of (post)colonialism is known by deconstructing it. Social power play is rife, which brings to light the nuances of the social in practice and the social in theory if there is an actual difference between the two. Note that (post)colonial power structures negotiate power in whichever name you give the paradigm, such as the science of biomedicine. Foucault’s concept of pastoral power contributes to the construct of the State and governmentality, both of which are socio-structural constructs, operating, validating, justifying and making accountable them institutions (Foucault 2007).
There are assumptions made *a priori* in the factoid assessments. The individual needs to be empowered and in charge of their own agency and future – the individual is the central focus and values the factoid. The factoid assumes that the power of the individual reigns. However, Foucault argues that the power really belongs to the social pathways and social structures which define and confine the agency of the individual. According to Foucault (2007), the individual is not something that needs to be liberated, rather the individual is the closely monitored product of relations between power and knowledge. Power dynamics are profound in the case of the mental health consumer and the services provided to them. The psychological measurements in these testings have significance to anthropology; they come to life as a series of statistics, cultural artefacts and factoids. They can also raise the question of what the measurements represent, and indeed who owns the knowledge of the crazy? (Lea 2008) Psychometric measurements are a socio-political technology which aid in the governmentality of current power structures.

I later received clarification and explanation of the neuropsychological assessment and the PAI. An expert in the field, a neuropsychologist, assured me that these tests are not necessarily completely accurate. There are masses of bewildering and puzzling factors. I had a lot riding on the tests. I wanted to prove that, despite my disability, I was absolutely capable, competent and clever enough to get exceptional marks on these tests; to prove that I am proficient and qualified enough to complete my PhD, and that I can live a full life. Instead I received average marks with average indicators. However, as the excerpt stated, I applied great effort and commitment to my study if nothing else.

I was worried, indeed petrified, that this test proved that I was inept, and I lacked aptitude to complete my PhD. Although the neuropsychologist noted that there are a lot of impermeable factors which meant that such a negative conclusion was expected. I have been told by mental
health professionals that I am capable of completing my PhD, though it may just take me three times longer. The truth of the matter is that my quality of life has diminished permanently.

**Proximity of measurement**

Measurements, assessments and diagnostic tools are historical and cultural artefacts used in the proximity (Kowal 2006) of medical science, specifically psychiatry. An example used in psychiatry is the cultural medical practice of having regular set blood tests. First, the blood test results have a numerical value - certain levels of certain medications must be present in the blood, at therapeutic levels defined by medical science. Second, the process of having monthly blood tests can be seen as a cultural regime, where the mental health participant is drawn into the rhetoric of psychiatry and becomes defined and dependent on the medical system, fixed in a paternal relationship with mental health services.

The blood tests are anthropological symbols of servitude – that is related to symbolic and interpretive anthropology (Wikipedia 2014), from the consumer and ‘protection’ for the mental health professionals. The measurement, in this case the blood test, precipitates in an Us and Other dynamic where power play is rife (Derrida 1966). The mental health professionals - the Us - use techniques of measurement, diagnosis and treatment, to stake a claim on the way the mentally ill should live. The mentally ill – Other – not being privy to the sanctity of medical knowledge, have little choice but to trust the deified mental health professionals. As per Smith (1999: 52), “What makes ideas real is the system of knowledge, the formations of culture and the relations of power in which these concepts are located…[A] major sociological concern becomes
a struggle over the extent to which individual consciousness and reality shapes or is shaped by social structure.”

In an analysis of diagnosis and the utilisation of measurement tools to legitimise the cultural labelling of the mentally ill, the roles of the subhuman/sub-citizen/social misfit are bantered and negotiated and ultimately legitimised. Diagnoses are defined and perpetuated by the culture of madness and predicated by the scientific fairy-tale statistics of evaluation (Lea 2008). This is a seemingly impossible venture, especially considering the anecdotal cultural evidence that ultimately measures the unmeasurable.

Nevertheless, psychiatric science with its measurements cannot be ignored. In trying to find a sound measurement tool; to bring to life the magical proof of numbers in a diagnosis – psychiatry relies on measurement - statistics, pie graphs and bar graphs. The magic of digits and quantitative methods cannot be ignored. These digits and graphs can be understood as cultural artefacts or factoids. Statistics actually represent the kaleidoscopic phenomena of mental illness. The illuminations of measurement factoids enable the mental health facts to develop a social life. (Lea: 2008: 128)

Measurements legitimising diagnosis seem to create a space of proximity where it is possible to negotiate and exchange between and within the socio-cultural structure, and this is embedded in the many persuasions of power control and comprehension from which they came. This space for legitimising measurements is important as it provides some cognition, some proximity, for negotiation between cultural artefacts and factoids (Kowal 2006; Lea 2008). To make this space workable, there must be some proximity in the connection between what is the phenomena of the
measured and the un-measured. What is defined as within the realms of the measurable and the
un-measurable? That is, discovering an understanding between what is science and how this
relates to non-science. For example, considering the cultural artefact, and if or how there is space
for an understanding of science, one can ask if and how and why it is significant. Thus, some
space is available in the proximity to measure the unmeasurable.

If there is space for proximity and measurement between the measurable and the unmeasurable
there is also space for proximity and analysis. What if there is a misrepresentation in the
proximity? One can argue that in trying to define and assess the diagnostic process, the mental
health professionals can categorise and misrepresent the mentally ill. As such, mental health
measurements may perpetuate a culture which ultimately leads to a crisis of representation (Smith
1999). The ultimate power of the physician, in this case the psychiatrist, reigns as a demi-god in
medical science. In an effort to make commensurable the incommensurable, there is a call for
university students of today to study the anthropology of medical science and/or medical
anthropology (Kleinman 1988).

Mental health has become part of dinner party conversations, corridor talk, seminars and political
enquiries. As part of my experience, immersed in the context and texts of a major psychotic
illness, there exists an idea of what is an acceptable form of mental illness. It certainly isn’t
schizophrenia or schizoaffective disorder. There is a ‘right’ kind of madness, which is somewhat
more accepted and respected. It is not uncommon today to have highly esteemed personalities,
whether they be politicians or musicians, living with depression or anxiety or even more
complicated disorders, pay homage to their diagnosis to add to their common respect and appeal
(Lea 2008).
There exists a concept called ‘ethnographic capital’. It is perhaps more of a reality than a concept. Ethnography, according to ethnographers, equips the researcher with the power and commodity of knowledge. The ‘capital’ of ethnography relates to how knowledge comes to be owned through its development and creation. Socio-cultural structures or perhaps institutions such as governments, have a vested interest in owning knowledge which produces cultural artefacts, because owning knowledge empowers institutions/structures. Ownership of knowledge, accumulated as capital, becomes a commodity because it can be defined, understood, exchanged and given value. These commodities, for example cultural commodities of art and discourse, have made capital out of the ethnography (Lea 2008: 84).

What is ethnographic capital in this study? I have found that autoethnographic methods of measurement build autoethnographic capital. The cultural phenomenon of measurement supports the power of the psychiatrist’s diagnosis. Measurements are part of the cultural phenomenon that supply the ‘truth’ for the science of psychiatry. Measurements also supply the truth supporting the ‘right kind of mental illness’. Like what Lea (2008: 84) describes as the ‘right kind of white’.

Discourse
‘Discourse’, as defined by Foucault, refers to the ways of constituting knowledge through text. Together with the social practices, the subjectivity and power relations of discourse adhere to such knowledges and relations between them. Discourses are more than ways of thinking and producing meaning (Massey University – University of New Zealand 2020).

The language used in texts, which has developed for the mentally ill, is potent. For example, the texts available for the consumer are mostly to do with their rights and responsibilities. The walls at my psychiatrist’s rooms, covered in mental health advocacy brochures, used the powerful words of psychiatric jargon. The ‘Charter of Consumer Rights’; ‘Do You Know your Rights as a Consumer?’; ‘Your Rights and Responsibilities as a Consumer’ and brochures about the right to give feedback about services received. The brochures are aimed to empower the mental health participant. As well, the brochures could be seen as propaganda for mental health service provision, though I didn’t understand the significance at the time. Once, when I was waiting at my doctor’s rooms, and somewhat manic, I completely reorganised the mental health brochures to my liking. This act empowered me in a sense, to make order the significant texts to my liking. I organised and structured the brochures first in topic, then chronologically, then alphabetically. If there were any misfit brochures, I would order them in the colours of the rainbow. So, it seems that the efficacy of the brochures was questionable in my case.

These information resources are based on the broader documents of state/territory and national mandates of mental health in Australia. For example, the Northern Territory’s overarching document is called the ‘Northern Territory of Australia Mental Health and Related Services Act’ (28th July 2016). The governing document for the Australia Capital Territory is the ‘Mental
Health Act 2015’. And national governance in mental health is led by the ‘National Standard of Mental Health Practices’ (2010).

All these texts combined and analysed together form cultural and discourse phenomena. Mental health is in some ways an art form that negotiates the language complexities between cultural meaning, natural sciences, social sciences and esoteric, existential and holistic care.

The effective words of mental health language, used by mental health professionals, often have underlying meaning attached to them. For example, the question ‘How are you feeling?’ has extra underlying meaning. Not only is the mental health professional interested in your physical feelings due to physical reactions to medication, the consumer is also supposed to describe other non-physical symptoms. Here the question ‘How are you feeling?’ also conveys the meaning of an insightful nature, especially regarding psychotic symptoms, which affects all phenomena. Reporting on the esoteric factors ‘I am feeling’ requires me to have a sense, an insight to the degree and the depth of my feelings.

I must be careful here. If I use the wrong words or expression, I may give the mental health professional the wrong impression and wrongly reflect my condition and what label I should be classed under. Usually with diagnostic labelling, mysterious and obscure feelings are defined and labelled into diagnostic categories. Psychiatry itself is defined as profound and perplexing (Szasz 1970). Extrapolating from Lea, psychiatry attempts to ‘intellectualise’ crazy (Lea 2008: 137).
Disempowerment

I get caught in an extreme and intense storm of madness, seemingly engulfed in a turbulent whirlwind of insanity. I am suffocating in the wiles of the storm of lunacy. I am helpless, with no site of freedom ahead of me. I am imprisoned by my label and my diagnosis, reliant on the science of psychiatry to grant me freedom, because it doesn’t seem like I can do it on my own.

Measurement can be liberating for some and disempowering for others. Coming from the camp of disempowerment, where I am defined and confined by my diagnosis and categorisation of subhuman, sub-citizen and social misfit, these questions are important. How am I labelled as a subhuman, sub-citizen, social misfit? How is this defined and enacted? What are the tools of diagnosis, the tools that measure sanity? And what is the broader significance of these measurements?

There is a sacredness about measurement, about culture, about representation and meaning. Each measurement utilises a tool of some sort. These measurements are objectified to define and identify the properties according to the modern science of medicine. Medical science of the masses comes under the realm of public health.

Public health studies make it clear that health is reliant on cultural constructs, arguing that there are social determinants to health. For example, Australian Indigenous peoples’ health is affected by socialisation into the racist and colonisers’ culture. (Carson et al 2007; Paradies 2006; Thomas 2004; Smith 1999). Here we step into the realm of the social sciences. I mention this to
emphasise the point that measurements have a subjective element, or whole. The factoids support and create cultural products, or artefacts, which add depth to the original biomedical scientific assessments (Lea 2008).

**The State and the silenced**

Then there is the phenomenon of silenced reports on shelves. Here I place the concept of the Silenced Manifesto, with the silenced becoming part of the hidden mental health discourse. (To be detailed in chapters 12 and 13.) The sciences of the brain (including psychiatry, psychology, neurology and neuropsychology) produce and utilise methods for authorising, legitimising, validating and treating mental illness. These psychometric tests have cultural significance and produce artefacts. These measurements are highly esteemed in biomedicine (McMahon 2013). They situate the individual in question in accordance to a pre-determined definition of ‘normality’. This information substantiates the diagnosis and treatment of such.

Policy is central to governance infrastructure, linking together and forming foundations of the capital and substance of the socio-cultural, political and economic. National quality frameworks, part of the backbone of policy, form objects of governance, and produce objects of knowledge. These political objects of knowledge produce further knowledge. Health professionals forge and define programs through power banter, for example, between themselves the governing bodies, the Us, and mental health clients, the Other. The bureaucracy decrees that psychometric measurements are necessary tools for knowledge production, an extension of the biomedical model and scientific measurement which defines and justifies national policy and governance. Today, in Australia, there is a political commitment to deal with the ‘mental health issue’. 

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There are seemingly no absolute and completely reliable and valid measures to assess mental health participants, and there are certainly not reliable and exact measures to direct treatment. My experience with schizoaffective disorder, for instance, would be contextualised by the many variants in my life. Diagnosis and subsequent treatment need to be individually assessed, and not be declared for an assumed homogenised group, combining pathological mechanisms in to one disorder. Psychiatry needs to be careful not to simply generalise or categorise too swiftly, especially not at the at the expense of the individual’s health (Szasz 1970).

Foucault argues, when looking at the agency of the individual, power really belongs to the social pathways and social structures with which the individual is defined and confined. According to Foucault, “the individual is not something that needs to be liberated, rather the individual is the closely monitored product of relations between power and knowledge” (Farrell 2020). Foucault also argues that power play exists in all interactions, including measurement processes, which are essentially part of a production of knowledge based somewhat on socio-cultural and political factoids (Foucault in Appignanesi et al 2005). Information alone assumes an independent universal and highly potent ability to change people’s lives and behaviours (Lea 2008:127). The prevailing assumption is that scientised facts have a considerable capacity to engender sorts of behaviour change (Lea & Wilson 2005). As such, data itself has developed to being inherently powerful (Lea 2008: 132).

Many different capabilities exist in the utilising and conceptual analysis of measurement. Foucault (1969) argues that power is not a thing but a relation, and that power is exercised
throughout the social body, operating at even the most micro levels of social relations. Power is omnipresent (O’Farrell 2005). Dynamics of factoids include giving agency to and anthromorphising the factoid; empowering the individual narrative; and empowering the State and the various institutional apparatus and infrastructure of which the factoids are a product.

Cuthbert (2013) states that it is essential to treat the various and mostly complex symptoms, rather than concentrate on categorising people into definitional diagnosis. A system of measurement is essential. A system of measuring brain science is essential. A system of incorporating the heterogeneous and multi-faceted phenomena into psychiatry and brain science is essential. This includes incorporating the factors of experiential, environmental, and behavioural measures, as well as observable, neurobiological, neuropsychological and genetic measures. A system of assessing and treating psychiatric symptoms is essential. Some scholars argue that a grouped definition of schizophrenia does not exist. Other scholars argue that we need valid and reliable ways to measure. Others argue that the cultural phenomena of mental health cannot be negated. We need rigorous research to decipher rigorous ways of measuring psychiatry, in all areas of assessment, diagnosis and treatment (Szasz 2008).

Conclusion

My goal for now is to prove to myself that I am intelligent. For over half my life I have been mentally ill and have managed competing, confusing, baffling and bewildering noises in my head. With these noisy thoughts, I have limited capacity to decipher rival knowledge. I cannot trust the version of reality my mind gives me. I want to feel that my thoughts and perceptions
are valid and true. That I don’t have to constantly second guess myself and annoy people by my constant need for reassurance and validation. With psychosis, I hear things that (I hope) are not true. I am constantly in a state of distrust and confusion about the version of truth in my head.

Measurement may be likened to a tool of (post)colonialism (Smith 1999: 6; 23). Many distinct populations, including the mentally ill, have experienced colonialism, in various ways (Smith 1999: 26). Diagnosis and labelling are (post)colonial actions (Smith 1999: 26). Those labelled as mentally ill, or non-white, or female are historically not granted the status of fully human. Some of us are not even considered partially human (Smith 1999: 26).

The psychometric measurement tools are empowered as entities of their own and generate or adversely define structure and agency for those who engage or disengage with the tool. For example, an individual could have his/her voice heard within the institutional bounds of the service provided. Further analysis could portray how institutions can use the ‘science’ of measurement.

Outside the walls of positivist medical science lay the social foundations of mental health. These foundations include facets such as: taking account of the complex nature of human interaction, socialisation of science, and the power dynamics bantered in the potent, and cogent exchange of what is socio-cultural capital. Health factoids circulate as authoritative accounts of success (Lea 2008: 150-1). For it is a fact of bureaucratic logic that the full sweep of human experience and meaning can be distilled into categories of assumed wider impact (such as economics, politics, and colonisation).
CHAPTER ELEVEN

7 LESIONS: 7 VOICES: 7 DRUGS: 7 STORIES: 7 CONCLUSIONS

MY CRAZINESS IS PERPETUAL: 7 STORIES OF BEING LABELLED AND EMBEDDED IN CULTURE

Seven stories of my craziness follow, although there are many more.

1. My perspective of the self: who am I?

Who am I?

Am I the inpatient in a psychiatric ward that got lost in the foyer of the hospital trying to find a toilet? Or am I the inpatient who was trying to get in another patient’s bed, apparently not wanting to be removed. Or am I the person whose potential employer ran away from, until she realised it was not a dignified thing to do?
Who am I? Am I the subject: the mental health subject?

Am I the loved and cherished daughter, sister, friend, colleague, cousin, or partner I’ve always wanted to be?

Who am I? Or am I the crazy girl, disabled by the noises she hears, or the paranoia that plagues her, or the panic that suffocates her, or the incredible depression that bestows her?

Who am I? Am I the label that people mark me with, the stigma, the disempowered human misfit that is ostracised from society?

Who am I? What have I got to offer? What is my space? Where am I placed?

I am stuck in the paradigm of mental health science provision. Lacking the agency to live a full life. My life is not my own. I am stuck. I am within the space of disablement, where I am silenced and shelved via diagnosis and in relation to the deity of mental health professionals, who decree my appropriate care. And the care providers have the best intentions. It is the culture that labels, not individuals.
2. The highs and lows of living with schizoaffective disorder

How has living with schizoaffective disorder changed me? What are the symptoms? For one, and an obvious one: the noises – I prefer to call them noises, as mentioned previously. There are about seven of them. They are always chattering, never giving me any peace. When I am well, they are just a whisper. When I am unwell, they are shouting and wailing. They say things like: “You’re hopeless”, “You’re stupid and worthless”, “You won’t amount anything”, “You’re fat and ugly – no one will want you”, “You are a burden to your family and friends, if you even have any”, “You are a social misfit, a sub-human and a sub-citizen, sapping resources from society for your sorry arse”. The noises are all different ages and of different sexes. About seven of them rule my head.

It is very hard to negotiate these noises. Everything gets so blaring. My senses are magnified. The noises can be all consuming. It seems that they fight for my attention. I also try not to listen to them because I feel it empowers them. This whole process smothers me more, making me question my perceptions. I become paranoid, as the noises challenge all my senses, and all the ways that I can decipher reality.

I am silenced. Once known that I have a major psychotic illness, I am assumed a priori to be stupid and disabled, therefore, not to be listened to. I am labelled, I am stigmatised, I am Othered, including by myself.
I am fighting the labels and culture by embarking on this PhD. I want to prove everyone wrong, especially myself, for I think I am fundamentally stupid - an assumption that has been embedded in my psychology over the many years of subjugation from the persistent noises. I am fighting this uphill battle because I have been told by a neurologist that my brain does not function properly. Also, in some other testing, the measurements rightly or wrongly have shown that my cognition is lacking. I am determined to show medical science wrong. I hope I am wrong.

I feel an intense shame about how I act while I am unwell. I am a mess. One day, when I hadn’t been to work for three days, my supervisor came to my house. Apparently, I was passed out on the couch. There was an empty bottle of gin on the floor beside me. I was in the depths of despair, hardly able to get up. There was nothing in the fridge, no food in the house at all. My supervisor brought me some food. I hadn’t eaten in days.

In a matter of a week, I had jumped out of my depression. I was buzzing with energy. I was overactive and unstoppable. I had just been given a class to teach. I threw myself into the job. So much so that my supervisor pulled me aside and told me to calm down and slow down. I was smoking incessantly, spending a ridiculous amount, all on a multitude of credit cards. I scrubbed my house clean and clean and clean again. My supervisor paid me to clean her house. I scrubbed her whole house, polishing all wooden floors and furniture with orange oil, putting everything in neat order. I remembered having the conflict in my logic. I had difficulty deciphering what was real and what wasn’t. My friends were carrying me. I relied on them for my dignity.
3. The significance of coffee

In a recent job in Town C my supervisor pulled me aside to go and have a coffee. I knew that when you are pulled aside for a coffee something is wrong. So, my supervisor pulled me aside, halfway through my contract.

What he then said was devastating and shocked me to my core.

He stated that I have not got the skills for my job. That my resume and referees’ reports were vastly different from the person here in front of him. He also said that there is no way that my contract would be extended, as I had hoped.

My supervisor stated that the severity of my mental illness was to blame for not being suitable for the job. This seemed incredulous, mainly because the organisation prided itself on accommodating and supporting those with mental health issues. They seemed to support people with minor mental health issues, but any illness more complicated or volatile, is too much to understand and too much to fathom.

Considering that I do have a disability, as affirmed by my supervisor, an option was to give me a two day a week job; a tokenistic gesture created to show the mental health sector that this
organisation does support people with mental health disabilities. I would be the token disabled employee, though my supervisor would not phrase it that way.

I thought at the time that my supervisor could give me a lifeline. I asked him if he could possibly support me in being a referee. He refused. He said that he can’t be honest and true to himself in being a referee for me.

My supervisor stated that they will advertise for my position. When I asked if I should apply, he stated that I could apply, but I won’t get the job. I asked him whether they would re-advertise if they couldn’t find someone suitable. He said yes. And still I will not get the job. I can apply for the job, but I will not get it. But do apply! It reminded me of being sectioned. I was totally disempowered and paralysed. Whatever I choose as an option, I lose out.

My supervisor otherwise displayed supportive and empathetic behaviour, holding my hand and crying, offering his services. Though when it came to employment - to really support and empower me, the help that would mean something to me, he was unable to give. Again, I could not be truly supported because I, in his sight, lack the skills. The skills they need are apparently those of a well person.

I was good at what I do yet was not valued for my skills – I was effectively sectioned by my boss. I’m not sure what skills are valued? A previous supervisor once gave me a reference stating that my main issue is my massive lack of self-confidence.
So, my supervisor thought he could ‘help me’. What does this mean exactly? It seemed to me that the help my supervisor was offering was absolutely from a kind heart, but at the same time, also paternalistic. I am being extremely supported yet fundamentally and ironically suppressed and discriminated against - stigmatised.

4. The dynamic of needing the disability support pension

My psychiatrist believed I should apply for the disability support pension as a safety net. As it now stands, losing my job, I am definitely in need of it. Even succumbing to needing the disability support pension is a slap in the face. I remembered being on the pension before, how shameful it was. I felt like I wasn’t part of society, like I wasn’t contributing.

Below are snippets from a letter written by my supervisor (the one who could not support me) to help support my application for the disability support pension. The comments are very harsh, yet sometimes, frustratingly very true:

“...the magnitude of Rachael’s mental illness has resulted in her having a significant psychosocial disability, which makes it extremely challenging for Rachael to function effectively in the workplace”
“I am now able to recognise that this was not just a case of regular ‘interview nerves’, but a manifestation of Rachael’s psychosocial disability”

“It impedes her ability to process clearly with any speed what has been asked of her, and the more she realises that she has missed the point of the request, the more rattled she becomes and the more difficulty she has in understanding what has been asked of her. It becomes a great impediment to Rachael in interview situations and in the workplace. It is also very clear that this sequence of events causes Rachael great humiliation and distress.”

“We have many examples from her period of employment with us of Rachael apparently understanding what she has been asked to do and how to go about undertaking the task – but in reality, producing something very different from what we intended. Rachael requires a period of time and additional support to absorb information that we are unable to accommodate. She has difficulty processing instructions and managing more than one task at a time. Rachael appears to suffer functional memory problems and gets easily confused. When this happens, she gets very stressed and this further exacerbates the problems to an extent where even basic tasks can be a struggle. This is not just my experience working with Rachael, but also that of my colleagues. We see in Rachael, intellect, determination and goodwill, but an inability to complete the tasks appropriate to her job description.”

(My supervisor’s emphasis)
Physically, emotionally, intellectually. It’s suffocating. I cannot move. It’s shameful. I want to scream, yet I have no voice.

5. I feel so ashamed

There are so many emotions tied up in living with schizoaffective disorder. So many feelings involved in the pain of life. These range from: humiliation, devastation, anguish, feeling deeply remorseful and crippled, guilt, suffocation, desperation, a feeling of drowning, and being lost.

Of particular note is the feeling of shame.

Along with this, I feel like a subhuman, a sub-citizen.

I am ashamed of it all. It is official. I am stupid. I don’t belong. I make stuff up so that I seem to fit in, but I really don’t fit in. I am ashamed that I was dependent on my boss and friends. I was a liability, sapping whatever I could, drawing out whenever I could. I do not fit in even in my culture.

The shame I feel, and still feel... I drown in it. I know that it is silly of me to invest time in even thinking about the stigma that infects me. I don’t seem to have a choice. No matter how much people try and encourage me, my society – with all my progressive friends – cannot grant me a
complete and empowered identity. It is too soon for our society to do away with the titles of subhuman, sub-citizen and social misfit, although all power is claimed and people living with schizoaffective disorder are declared equal.

Expressed feelings from the mentally ill are not important. They are only a compilation of random, meaningless and empty words. My feelings are obsolete, as I’d imagine would be the case for many of the mentally ill.

6. The inevitable powerlessness

I am punished and powerless for having a major mental illness. It seems that only minor mental illnesses are tolerated. My mental illness is the reason I am classed, or labelled, as unskilled. This really hurts. Diplomatically phrased by the Executive Officer of my (aforehand) supervisor, ‘I have a different skill set’ – one not needed. In the same breath of announcing to the staff that my contract was not going to be extended, the Executive Officer emphasised that there will now be a commitment to the implementation of the organisation’s vision of evaluation, measurement and quality assurance – all skills that I possess and are known to possess. This was ignored, while I sat, my heart breaking, and no one knew, cared or understood. I’m invisible and silenced. No one sees me or hears me. The rules of human resources management from my aforementioned position provided the glass ceiling of discourse, which I could not break through.
Whose voice is being heard? What are the implicit or explicit silences in this discourse? Which noises are empowered (Hanisch 1969)? I am silenced. Once known that I have schizoaffective disorder, I am assumed a priori to be stupid and disabled, therefore, not to be listened to. I am labelled, I am stigmatised, I am Othered. With every voice heard, there is/are noises silenced. For every voice empowered there is/are noises disempowered. Again, which noises are heard? What social structure manifests the noises and makes them clear? The Silenced Manifesto provides the social structure of governance, manipulates the vernacular and shelves the silenced.

I have such skills, demonstrated skills, but I am silenced in this space. Those also labelled as mentally ill are also silenced, just for being in the community space. The silenced, those labelled as inadequate, or perhaps more commonly labelled as disabled, the seriously mentally ill lack power. As labelled and disabled, I am powerless. I have not the power to take what I need from society, my own authority and self-determination. The powerful allow the distribution of command to the disabled, with supremacy. Disabled, suffocated, silenced. Not fully human; not a full citizen.

Because of this, I am overwhelmed. I am drowning. I cannot understand why I am being treated this way. The whole point of working is to retain some sense of self-worth and dignity. By working I am contributing to society, paying taxes and being an active member of the politico-economy. Yet somehow and someway I have been marked as incompetent and incapable.
My mental health status becomes the fault of everything going wrong in my life. I go to the doctor with a physical ailment and come out petrified and defeated that my physical health has actually turned into a mental health issue. I had lost another battle.

As an act of pity, or perhaps good will, my supervisor offered his help for me to get a job. The main way he would support me would be by attending interviews with me, translating questions as the interview went along, because I apparently get confused about what is being asked of me. I should note that I am very, very bad at interviews. With that in mind, I cannot figure out if this gesture is meant to be significantly kind, or significantly insulting. My boss said he will be my advocate because I am disabled and need help. Despite the sugar-coated insult, I accepted his offer. My supervisor then stated that he will write an email to my psychiatrist to explain his benevolent gesture, buying into the cultural vernacular that my actions and presumptive allegiances are determined and sanctioned by the greater good, a macro-narrative of society, for example the medical professional. My micro-narrative, an autoethnography of society just doesn’t cut it.

7. The phenomenal meta-narrative

Through living with schizoaffective disorder, I have noted that I am in a constant dialogue, sometimes even a fight, competing with bioscience. Science is a meta-narrative that consumes the culture of health.
Being labelled in a stigmatised culture comes with self-loathing, and a belief that I lack dignity, personhood and agency. This label of fundamentally lacking impinges on the basic human rights for those with disabilities. Specifically, Articles 5 and 12 of the United Nations Convention of the Rights of People with Disabilities (UNCRPD 2014). To add, the WHO has developed a comprehensive mental health action plan (2013-2020). It calls for a change in the attitudes that perpetuate stigma and discrimination that have isolated people since ancient times, and it calls for an expansion of services in order to promote greater efficiency in the use of resources (WHO 2013).

What is it like to live with a disability? How am I disabled? As per the United Nations (UNCRPD - Department of Economic and Social Affairs Disability 2014), disability should not impinge on the quality of life and agency awarded to those living without a mental illness. How has my disability affected my life? I lack the discourses and resources, the social, cultural, economic, political resources that can potentially enable me to live a full life. Being disabled, I am regarded as a social misfit and deranged, identities constructed for me as a lesser human being. I am forever labelled. That branding will scar me forever.
CHAPTER TWELVE

THE SILENCED MANIFESTO

“The Silenced Manifesto, being likened to the exposition of a religion, through its commanding language and discourse, mandates the governance and placement of the silenced.”

(Field notes April 8th, 2018)

“[There is] no need to hear your voice, when I can talk about you better than you can speak about yourself. No need to hear your voice. Only tell me about your pain. I want to know your story. And then I will tell it back to you in a new way. Tell it back to you in such a way that it has become mine, my own. Re-writing you, I write myself anew. I am still
author, authority. I am still [the] colonizer, the speaking subject, and you are now at the center of my talk”

(bell hooks, 1989).

My goal is to prove to myself that I am intelligent. I am paranoid about it. For almost half my life I have been mentally ill, and have in turn heard competing, confusing, baffling and bewildering ‘noises’ in my head. Describing them simply as ‘noises’ takes away the agency and power that the ‘voices’ try to claim. With these noises, I have limited capacity to decipher rival knowledge. I cannot trust the version of reality my mind gives me. I want to feel that my thoughts and perceptions are valid and true, that I don’t have to constantly second guess myself and annoy people by my incessant need for reassurance and validation. With psychosis, I hear things that (I hope) are not true. I am in a constant state of distrust and confusion about the version of truth in my head.

This chapter expands on my concept of the Silenced Manifesto. The Silenced Manifesto is a powerful concept that I have developed as part of my original contribution. It describes the position of the marginalised and what Foucault (1961) calls the ‘underdog’ and how they have been and are being silenced. It encompasses the discourse that perpetuates the labelling of the subhuman, sub-citizen and social misfits.

The focus of the Silenced Manifesto as a concept is to give a voice to those whose voice is not or has not been heard. This concept may be reappropriated to many situations where there is disempowerment, discrimination, and discernment of a group, or indeed regarding an individual. In this case, giving a voice to those living with a mental illness, specifically schizoaffective
disorder. We have been silenced by our diagnoses and labelling, both historically and now. We are/have been silenced, suffocated, and disabled in more compounding ways than living with the original disability. The labelling and silencing have perpetuated and enhanced the position of lacking for the disabled; it has a snowball effect. The silenced become more silent. And the disempowering discourse becomes more entrenched. Thus, the Silenced Manifesto imprisons the marginalised.

In my lived experience of having schizoaffective disorder, my quality of life has diminished - permanently. I have been stuck, categorised and hence silenced by my diagnosis and the perceived appropriate treatment I need to have, as per mental health professionals decree. The silencing and suffocating of my expression, my thoughts, my essence is perhaps the most disabling, disempowering and de-humanising experience of my life. And I wish I could say that it happened only once. Rather, I argue that such silencing and suffocation is embedded in psychiatry. This is compounded by the added marginalisation and subjugation that mental health participants receive when they are an already marginalised and subjugated group, namely the disabled as labelled, in this instance. My story is one embedded in the definably unjust world of psychiatry.

The ‘silenced’ part of the Silenced Manifesto refers to the complex of narratives where the marginalised are silenced. They are simply not heard. The silenced, I argue, lack the resources to be heard. They lack the language of governance to be heard. They lack the power to be heard. Their silenced narrative; their plight, their voice, their language; their politics, their power; are shelved, along with the many texts and discourses that are subject to the disempowerment of the
marginalised. Their true representation is in crisis (Smith 1999; Rabinow in Clifford & Marcus 1986).

The ‘manifesto’ of the Silenced Manifesto unlocks the incredible chest of knowledge, the language, the symbols, the narratives, the texts and the discourses which decree who has power over the structure of society. The manifesto is the part of culture that culminates and represents the discourse which has power over the underdog (Foucault 1961), the colonisers having control of the colonised.

I have separated the discussion of the Silenced Manifesto into sub-headings:

- An anthropological paradigm – the Silenced Manifesto
- Methodology and the Silence Manifesto
- The Silenced Manifesto – its application to all narratives
- My narrative, language and the Silenced Manifesto
- Reality and the Silenced Manifesto
- Labelling theory and measurement and the Silenced Manifesto
- Social theory and the Silenced Manifesto
- (Post)colonialism and the Silenced Manifesto
- The Communist Manifesto and the Silenced Manifesto
- Governance, politics, policy and the Silenced Manifesto
- The space of commensurability and the Silenced Manifesto
- The Silenced Manifesto and stigma
  - The Silenced Manifesto and the stigmatised self
- Discourse and the Silenced Manifesto
As discussed in earlier in this thesis, at times my logic and expression are fragmented, as my mind is fragmented. I have tried to explain the concept of the Silenced Manifesto with the best logic that I know how. Though my expression may be spasmodic and somewhat ‘fruitful’.

**An Anthropological Paradigm – the Silenced Manifesto**

The Silenced Manifesto is also an anthropological paradigm, tied to culture by its spoken and written word. Culture, the learned behaviours and ideas that are characteristic of a social group, exists to support society; that is its function. Just like the heart's function is to maintain blood to the body, culture functions to maintain society. Individual need is still important, but it is succumbed to maintaining the structure of society. Foucault argues that the power really belongs to the social pathways and social structures which define and confine the agency of the individual (in Rabinow 1984).

Foucault (in Saar 2002) also spoke about the ‘genealogy of subjectivity’ where we think we are free agents in our society, but we are defined by our historical development over time. This historical definition process is covert. It has meant that notably, power intersubjectivities and processes have been embedded in the cultural values and social fabric. Over the last few centuries, the pillars of science have been naturalised, that is science as supreme is considered an assumption before any other knowledge or perspective. Scientific fact has an *a priori* assumption. This version of reality is *the* version of reality with its’ accompanying meta-narratives. All analyses come after this fact (Foucault in O’Farrell 2007).
Following on and situating the discussion, regarding Indigenous Australians, there is the ‘Closing the Gap’ discourse; and economies of scale built on ‘Closing the Gap’ (Kowal 2006). There is an assumed remedialism here (Kowal 2006) that may be associated with the historical construction of sub-citizen policy, and the identity structure and manufacture of subhumanity, all to influence the power negotiations that make the social misfit. All this is developed and precipitated by the culture which supplies the space, the sustenance, the life blood and the resources for these underdog categories to survive (Foucault 1961). The Silenced Manifesto helps define and express these categories of survival; finding a structural means which allows for survival separate from the hegemony; a way of fighting through the glass ceiling of the Silenced Manifesto.

An anthropological perspective of the Silenced Manifesto, regarding this thesis, entails enculturating the silenced and the hidden into an imprisoning discourse and reality from the perspective of my lived experience of having a psychotic illness. I have been labelled, and these labels have been perpetuated by a culture and a corresponding narrative which upholds Otherhood and colonisation. Here the labels of subhuman, sub-citizen and social misfit are perpetuated by a culture that values the disempowerment and inequality of the underdog, albeit covertly and perhaps unknowingly. An analysis of culture and the discourse it pertains serves to unpack the values held by the micro/macrometanarratives.

Kleinman (1980: 178) comments that culture affects the way we perceive, label and cope with somatic symptoms as well as psychological ones. All illness is normative (that is at least in part socially learned and guided by cultural norms) and culture shapes illness behaviour principally by cognitive processes.
Methodology and the Silenced Manifesto

The Silenced Manifesto is also a methodology, which piggybacks on emancipatory methodologies, for example and in this case, autoethnography. The methodology of an autoethnography, unpacks the plight and perspective of the underdog, in this case the subhuman, sub-citizen and the social misfit. The Silenced Manifesto describes the way that these subordinates are hidden. As well as describing how and why the underdog is stigmatised and labelled as such.

An autoethnography, such as mine, is used as a methodology to illustrate and expose the broader meta-cultural phenomena as well as the more micro cultural phenomena; both being universal underpinnings of the Silenced Manifesto. A sample of one is not egotistical or narcissistic. The singular sample size enriches the study and analysis by depicting a different alternative viewpoint – amplifying the whisper of the disabled, or the ‘handicapped’ as I have been labelled and defined. Again, through the labelling and the culture labelling, here is a strong reference to the Silenced Manifesto.

The Silenced Manifesto – its application to all narratives

The universality of the Silenced Manifesto can be expressed by the concept/s of colonisation and discrimination, where the marginalised are ultimately disempowered, by not having the resources necessary for agency, not knowing the language of the powerful and as such, not being able to have a voice. The universality of the Silenced Manifesto may be described by all
micro/macro/and metanarratives where agency and structure suffocate and limit the freedom of everyone, but most importantly in this case, the mentally ill.

The universal narratives as part of the Silenced Manifesto include those related to tangible textualized objects such as discourse, text, language, historical accounts, stories, policies, rules and regulations, government acts, and measurement. The Silenced Manifesto illustrates the silenced’s position. For example, where there is an imbalance of power, this imbalance is hidden and silenced both overtly and definitely covertly. The silence in its overt form is omnipresent and ubiquitous, and more covertly, unseen, unheard or unheeded.

The silence permeates all narratives, universally, to various degrees. Examples of how the Silenced Manifesto is perpetuated as a universal concept include categorising the underdog as lacking and part of a crisis of representation, as per (post)colonisation (Smith 1999). The universal application of the Silenced Manifesto can be related to the system of governance and politics which has contributed to the discourse separating Us and Other, colonisers and colonised. This discourse infiltrates the macro narrative where the structure of the health system is pieced together by policies and bureaucracy (Lea 2008). The Silenced Manifesto, with its universal and suffocating discourse developed through history, describes how the marginalised cry out to be heard. Yet their voice is stifled by the weight of colonising labels such as stigma. They live with a perpetual and invisible limit that confines and defines their freedom to succeed in ways that they wish. This is similar to the metaphor of the glass ceiling associated with the struggle of feminism to achieve in their career goals (Shade 2018). Foucault (1961; 1976) advocates for basing concepts of power imbalance in their historical situatedness, such as those socially identified with women, race, LBGTQI+ or the disabled, where marginalised groups are defined
and confined by a historical development of governance and politics that essentially labels the Other into a dynamic of socially crafted reality (Hacking 1999; Lea 2008).

The meta narrative of national and international governance is streamed down into the macro narrative of the health system, which in turn is streamed down to an individual, a micro narrative, where internal struggles of power play with relationships and knowledge are negotiated and textualized into a discourse that can be situated universally. The individual narrative reappropriates into a great internal struggle. This internal struggle is navigated within forced boundaries, succumbing to power negotiates of narratives, of the Silenced Manifesto.

Another universal application of the Silenced Manifesto can be related to class actions against the Catholic Church from then abused children, or even the stolen generation amongst Australian Indigenous peoples where these disempowered people have had their worlds classified and categorised as per their dominant and decriminalised discourse. The institutionalised are good examples of how discourse and silencing are infiltrated by a culture that fundamentally, yet covertly, endorses inequality, as power is negotiated between Us and Other and knowledge production.

This culture perpetuates a system that inadvertently and covertly and mostly unknowingly endorses and supports discrimination and disparity. The universal application of the Silenced Manifesto situates the universal narrative of a culture into a socialised dynamic, albeit a culture set by international civilisation and hegemony, that structures and defines the marginalised.
At times subhumans, sub-citizens and social misfits fall into the realms and traps and labelling of each of the narratives, that is micro/macro/meta narratives. It is not unusual for there to be miscommunication between the three narratives. At times, through the dynamics of different narratives, one questions the extent and precipitation to which the culture perpetuates the existence of the subhumans, sub-citizens and social misfits. Considering this, one should question who is silenced and not silenced in the politics of the narratives. I question who is marginalised and disempowered by this process. Which characters have gained and/or lost power? And considering the process and development of narratives, looking outside the square, the mentally ill can and should craft their own narrative, to try and empower and demystify, and to unpack the stigma that exists so pervasively in culture. Here the Silenced Manifesto is anthromorphised, where the manifesto can personify narrative/s. Through the narrative/s, and its system of organisation of language and symbols the disempowered are given a voice. The silenced have come alive.

**My Narrative, Language and the Silenced Manifesto**

“Here the underdog are not heard. They speak another language. There is little commensurable space to communicate and understand. Who are the silenced? Who are the noisy?”

(Field notes June 12\textsuperscript{th}, 2018)

I hope my narrative will assist to emancipate those living with a psychotic illness. By revealing in text my hidden world of being dehumanised and disabled, being forced into an identity of subhuman, sub-citizen, social misfit, this thesis creates a discourse and methodology which aims
to empower those living with schizoaffective disorder, and indeed potentially other mental illnesses. The discourse revealed by my narrative.

This narrative explores some of the dynamics between the self, the production of knowledge (the factoids generated), the technologies of governance, and the compilation of the use of measurement into a system of governmentality, to be used to validate, justify and make accountable the position of the service implementers. I am still trying to reconcile or find some commensurability between the motive of the service provider, the rigour of the methodology which makes the service provision valid and accountable, the ultimate governance of services, and the self-determination and agency of the service recipient.

Language is the site of social organisation, within which power is exercised and contested. To the present time, reality consists of many narratives and discourses. As a site of exploration and struggle, language is constantly an area where there are competing meanings and related practices, and discourses (Foucault 1978; 1979). Discourses represent the negotiations of power between groups and individuals to determine what is ‘true’ in relation to each other. What something means to an individual is dependent on the discourses available to them (Grant 2010: 581). The Silenced Manifesto utilises the worth of language and communication to negotiate powerplay in discussion of self within the space of commensurability.

The sick person encounters difficult medical languages as s/he moves through the health care system (Kleinman 1980: 53). Sickness is to be understood and explained by semantic networks. For instance, culturally articulate systems interrelate and cognitively categorise personal
experience, psychological states and social relationships. Healing viewed from that perspective involves the same semantic networks (Kleinman 1980: 364). The social is intertwined by symbols, and to language it is a necessity to communicate internally and externally in the social landscape. Symbols and thereby language, are fundamental and pivotal to all functions social and otherwise.

Language is the system that permits structured thinking. Thinking is the ‘system output’ that occurs in the interactions between subjects (situated within culture) and the environment (nature). These interactions, social, cultural or otherwise, are the objects of thinking. Language allows us to communicate in social relationships; and to categorise our environment as represented symbols (Appignanesi 2004). Language, a symbolic tool supporting the connections within the social, can be likened to a social entity, a cultural artefact. In its operations, sometimes illicit, language may (dis)empower, silence and control, as per the Silenced Manifesto. Language connects medicine as it connects and translates the experience of madness and its negotiation of power.

Foucault explains how power is a relationship not an object (Foucault in Rabinow 2002). Our identity, experience and stories are intertwined with the identities, experience and stories of the Other; our writing must be both faithful to experience and respectful of relationships. Sometimes these narratives show that individual experience does not fit theory (Richard 2008: 1720 in Ellis & Bochner; Muncey 2005).

Richards (2008: 1720) argues that narratives are often treated as data for a researcher. They do not, however, come into existence as data, but instead as a process of identification formation that has significance for the narrator. They are formed as individual stories that are generalisable. All narratives address several key theoretical debates. For instance, with micro and macro
linkages, there is structure and agency and their intersection, then colonisers and colonised, and social reproduction and social change (Laslett 1999: 392 in Wall 2008: 39).

Narratives are created and maintained by social phenomena, which also creates and maintains individual phenomena. Like all stories, narratives are a way of making sense of things, in this case, mental health. Mental health narratives are often presented with culturally embedded symbols that reveal personal and social beliefs (Sharf & Vanderford 2003). Indeed, in analysing the phenomena of narratives, the concept of socially constructed facts is precipitated. The cycle of deviance and mental health turns again and again. In this cycle, the mentally ill remain squashed into a medicalised narrative.

The biomedical model can be described as a cultural system, which precipitates the political, economic, social and environmental narratives of mental health. DiGiacomo (Senior et al 2006) argues that the position of biomedicine as a cultural system focuses on the symbolic structures, events, and relationships involved in biomedicine (Kleinman 1987: 341), including micro, macro and meta narratives. DiGiacomo describes the power dynamics of biomedicine between the positions of micro (the individual doctor) and macro (the national medical system) and meta (the broader international health system) and how it negotiates and compares to the individual micro system of symbolic structures, events, and relationships in the cultural system of the dynamics of the micro self. The cultural dynamic in the micro/macro/meta biomedicine narrative is exemplified by the example of DiGiacomo. Her experience of biomedicine illustrates the cultural complexities of her battle to be involved in the decision-making process of her treatment, and to obtain enough and clear information about options (Senior et al 2006; 2009).
Mental health patients, the mental health professionals and government bodies upholding policies form the institution of mental health service delivery. The culture embedding and centring mental health service delivery has traditionally been borne from the positivist macro-narrative of medical science. With the advent of social sciences, other narratives were introduced into the mental health vernacular. What is of great importance is the new emphasis of new types of measurements, thus new ways of delivering assessments, diagnosis and treatments. I am interested in unpacking and repacking the foundation and the contents of the social structure of mental health service delivery, which I believe creates a sound basis for culture analysis, illustrating and highlighting the grounded values and norms.

Reality here is viewed as textual and understood within the parameters of language. Reality consists of many micro, macro and meta narratives and discourses, which are all reliant on the structure and utilisation of language, encompassing the values of the Silenced Manifesto. The social world is structured, covertly, by our means of understanding and communicating in the world, which is through the prism of symbols and language. Narratives and discourses, directed by language, control us but we are not overtly aware as we are so engulfed in them. In our everyday lives we are blinded by this power play as we are so accustomed to it. Derrida (1978) argued that we must deconstruct and make less natural or real the meta-narrative at hand. The micro/macro/metanarrative can be any discourse which is utilised to overpower the Other.
“What makes ideas real is the system of knowledge, the formations of culture and the relations of power in which these concepts are located...a major sociological concern becomes a struggle over the extent to which individual consciousness and reality shapes or is shaped by social structure”

(Smith 1999)

Socially crafted reality, a relatively new developed concept, in the last fifty years or so, is part of a re-arrangement of views of science and rationalisation, creates a whole new gamut of cultural artefacts (Lea 2008). These cultural artefacts, developed from a self-reflective social construction of reality, act to construct madness. As an anthropologist, I am consumed by the social construction of reality. I cannot separate the cerebral from the social. Neither can I separate reality from other social phenomena like culture, politics, spirituality and economics.

Now the question lies, how is reality constructed, albeit socially constructed, by someone with a psychotic illness that fundamentally skews all perceptions of reality? Psychosis is a social construction in the sense that its ramifications and the magnitude of its true meaning are very much defined in the social phenomena. If psychosis were not such a stigma those suffering from this mental illness would not be so ostracised, demoralised and stereotyped as subhuman, sub-citizens and social denigrates.

Then there is another factor in the socially crafted concept – verisimilitude – the feeling or illusion of reality (Adams, Jones & Ellis 2015: 85). Hacking (1999: 33) argues that the world
does not come quietly wrapped in facts. Facts are the consequences of the ways in which we represent. Latour (1991: 21) states the philosophers of science and historians of ideas would like to avoid the world of the laboratory.

Health care systems are socially and culturally constructed. They are a form of a social construction of reality. A social construction of reality signifies the world of human interaction existing outside the individual and between individuals (Kleinman: 1980: 25). At the same time, something can be both biomedically real and a social construct.

In each case, the chaotic repetition and heterogeneous iteration and absorption of health facts has its own specific density of encounter (Hacking 1999), but at the same time each moment forms part of a wider patterning. They both draw on and reify historical classifications (the agreed consolations of phenomena that warrants sombre measurement) and a culturally established “trust in numbers” (Porter 1990). That is, each iteration embeds and is embedded within a deep socio-cultural underpinning that imbues statistical representation with a logic and comprehensibility they would not otherwise have given their highly abstracted character. This heritage enables first the authoring of factual research within health (and ordains the institutional resources such authoring relies upon) and second the widespread acceptance is that such cultural artefacts are transparent representations of a more serious underlying social construction of reality they purpose purport to explain (Lea 2008: 145).

Regarding the Silenced Manifesto and its place in the dialogue between what creates reality, there is a covert, at times overt, cry from the camp of the silenced. Reality, in this case for those
living with a psychotic illness, is understood both as biomedical and social. Each perspective has its own discourse that seeks to find a space of commensurability to understand the language of each other. Communication, text, discourse, language of the silenced is more about the realm of the social sciences than the biomedical sciences. The social construction of reality for the silenced is about those who are silenced just as much as those who are already granted a clear voice. It is a discourse between the silenced – the subhuman, sub-citizen and social misfit – and the powerful - the greater debate of governance. The Silenced Manifesto depicts a space for reality construction that lives within the boundaries of discourse, albeit a quiet discourse. Considering a socially constructed reality, which cannot be negated, there is little conceptual space for a reality to exist in isolation from its discourse. The reality of biomedicine also cannot exist in isolation from its discourse. Again, reality relies on a space of commensurability between sociality, in this case culture, and medical science.

The biomedical realm has historically encompassed mental health, but mental health biomedical science cannot be understood separately from the social construction of reality. For example, during my admission to Ward B (public), I was desperate to have social contact. For me, social contact re-fuels me so that I have the courage to go on. It helps me to stay strong. However, Ward B (public)was highly stigmatised within the Town B community. It limited my visitors due to the stigma and poor reputation it has. I was shamed, gutted. I was made to feel a social misfit and downcast. Not only silenced but invisible.
Labelling Theory and Measurement and the Silenced Manifesto

“It should be noted that it is ironic to label what we state we should not label.”

(Field notes January 5th, 2014)

I have difficulty in being labelled. To be called ‘handicapped’ by progressive health professionals today is disempowering, although it may well be true. Who do I trust now? ‘My own ‘questionable’ and ‘lacking’ perception of reality, social construction of reality or supposedly named positivist reality? Or should I perhaps trust the scientific and rigorous cognitive functioning test performed on me by an experienced neuropsychologist? Do I trust the cultural artefacts of the testing over my own perspective? Which perspective reigns with the most power? Should I trust my individuality over categorisation? What does all this mean in the context of the social construction of reality, the reality formed through social dynamics, the neuro-psychological assessment, and the cultural artefact? Does the artefact legitimise madness?

I think that I have less capacity and capability in my cognition. With the example of my emotional investment in psychometric testing, it makes me feel defeated, depressed, conquered and crushed. Even with testing that is supposed to empower me by discovering my strengths, I am still defined as lacking. I have let down my family, my friends and myself. I feel great shame, it encompasses me still... I drown in it. I know that it is silly of me to invest time in even thinking about the stigma that infects me. I don’t seem to have a choice.

The internalisation of the label develops into a self-fulfilling prophecy: if the individual is indoctrinated so much by the powerful, they will actualise and become the label they are given.
For example, if a teacher praises and encourages a student, the student is more likely to succeed (Scheff 1974).

As discussed, measurement has become a tool, depicting a kaleidoscopic, dynamic and socio-cultural production of knowledge. The assessment process creates a space of knowledge production, a formation of political technology where the act of ‘measurement’, also narrative development, forms a type of discovery which has political and governmental significance. The measurements produce knowledge: transforming the numbers into factoids (Lea 2008). The factoids become more structured conceptually as the language and symbols of knowledge production. As part of the language of scientific knowledge, these factoids/objects of knowledge become validations for governance, to ‘measure the unmeasurable’. (Lea 2008) Similarly, the Silenced Manifesto represents a concept where a hegemonic discourse stifles the heard, so its becomes a negotiation of ‘to hear the unhearable’.

Psychometric measurements, embodied as factoids, are socio-political technologies which aid in the governmentality of modern power structures. There are no completely reliable and valid measures to assess mental health patients, and there are certainly not reliable and exact measures to direct treatment.

Broadly speaking, in this thesis, tools for measurement are classified as socially created defences and weaponry to justify mistreatment and misrepresentation and the disempowerment of people living with a major psychotic illness, and perhaps all people living with a mental illness. There is a sacredness about measurement, about culture, about representation and meaning. Each measurement utilises a tool of some sort. These measurements are objectified to define and identify the properties according to the modern science of medicine.
Having schizoaffective disorder immediately categorises you as a social misfit, deviant, subhuman, sub-citizen. These underdogs are unable to experience full quality of life. Some of this negative labelling can be blamed on, quite ironically, measurement. Measurement is assumed to be liberating as it is presumed to define and provide answers to troubling questions. How am I de-humanised? How is this defined? What are the tools of diagnosis, the tools that measure sanity? And what is the broader significance of these measurements? How do the mental health professionals measure the seemingly unmeasurable?

In exploring the anthropology of evaluation and measurement, one must consider the anthropology of accountability (Lea 2008), including validation and justification. Lea (2008: 120) argues for the “persuasive power of the pie charts”. A pie chart is an artefact of evaluations, and an artefact of medical science – to me, evidence of tunnel vision and science bias. What are the power dynamics involved in evaluation, measurement and accountability? What are the social constructions of facts – ‘factoids’ (Lea 2008), and the cultural/statistical artefacts geared to justify reproduction of cultural institutions/phenomena, such as bureaucracies? Then there are the phenomena of silenced reports on shelves, representational evidence of the Silenced Manifesto.

Latour (1991: 241) states that today, those who are labelled as mentally ill are society’s stigmatised scapegoats, officially and in principle. Historically, for example, both the medieval witch and the modern mentally ill patient have been the scapegoats of society. Latour goes on to describe the dehumanisation and degradation that is caused by mental illness. The alcoholic,
the addict, the homosexual – all and many more are said to have a mental illness (Latour 1991: 122-123).

The labelling of downcast and social misfit came about as defined categories through a dominant culture which highly values economic, social and political classes. For example, during times when I have been very unwell, I have been unable to work. My economic class thus changed. I received the disability pension. I had become a dependent on the State. I was not value-adding to the economy. I felt great shame as I could not contribute. I even felt shame in front of my family and friends. They did not judge me – they felt sorry for me. This perpetuated my shame. The cause of this, arguably, is the culture that perpetuates being subhuman, sub-citizen and/or a social misfit. I was labelled, and I could not do anything about it. As a young woman when I was diagnosed, it was through the culture of medical science that my identity was set, and this identity has been perpetuated via stigma.

**Social theory and the Silenced Manifesto**

Theory can help to make sense of this. Theory enables us to make assumptions and predictions about the world in which we live. Research and theories that follow have a great significance for [subhumans] that are embedded in our history under the gaze of Western imperialism and Western science. Social science is based upon ideas, beliefs and theories about the social world (Smith 1999: 40, 41, 49).
People always live in some form of structure. Subhumans and sub-citizens, as categories are a part of structure, as are colonialism and the rights of citizenship [or lack of] in ways that produced the underdog discourse, related to the underclass. Goldberg (1993) shows how this process is being extended and renewed by categories dominant in present day social societies, for example the ‘West’; ‘underclass’; and the ‘primitive’.

Poststructuralism is mentioned here as being closely aligned to postmodernism, but perhaps also reactive to it by negating the importance of all social theorising, not limiting social analysis just to multiple truths. In reaction to exploring and negating, the nature of structuralism is known by deconstructing it. There are no macro-universal truths, nor micro nor nano-truths. Social power play is rife, which brings to light the nuances of the social in practice and the social in theory, if there is an actual difference between the two. For a short time, Foucault claimed to be a poststructuralist (Foucault in O’Farrell 2007)

Poststructuralism can be understood as measurements, assessments and diagnostic tools that become cultural artefacts in the world of poststructuralist medical science and specifically poststructuralist psychiatry. In this case, they form part of the vernacular of psychiatric language, from culture and structure. The mental health workers use techniques of measurement, diagnosis and treatment, a structure of poststructuralist medical knowledge, to stake a claim on the way the mentally ill should live. The mentally ill – Other – not being privy to the sanctity of poststructuralist medical knowledge, have little choice than to trust the deified mental health professionals.
(Post)colonialism and the Silenced Manifesto

The discourse of solidarity and political reconstruction has retreated into the academy, where it is theorized as ‘(post)colonialism’. Here we find the critical theorizing of scholars like Edward Said and Gayatri Spivak, both of whom construct analyses of the colonial Self and the colonized Other. (Or ‘Us’ and ‘Other’ as I have been naming it.) As Edward Said (in Smith 1999: 38) asked: “Who writes? For whom is the writing being done? In what circumstances?”

The only way I could retain some self-respect during my hospital admissions was to employ my skills as an anthropologist. As did DiGiacomo (1987), I started to unpack what I was seeing around me, what I was experiencing and how people were relating to each other. I observed negotiations of power, which defined the mentally ill as colonised (Smith 1999).

“At some point there has to be dialogue across the boundaries of oppositions.” (Smith 1999: 40). As Smith (1999) argues, human nature, that is the essential characteristics of the person, is an overarching concern for Western philosophy even though the concepts of ‘human’ and ‘nature’ seem to be in opposition to each other. The separation between mind and body, the investing of a human person with a sole psyche and consciousness, the distinction between sense and reason, definitions of human virtue and morality, are all cultural constructs. While the workings of the mind may be associated in Western thinking, primarily with the human brain, the mind itself is a concept or an idea.

The struggle to assert and claim humanity has been a consistent thread of anti-colonial discourses on colonialism and oppression. We are a first world country full of (post)colonial guilt that we’re
content to [let people suffer] with a benign refusal to attribute blame and locate responsibility accurately (Smith 1999: 27; 144). There remains pervasive gaps between the colonisers and the (post)colonised. There is the income gap, the education gap, the class gap, and the gap between privileged and deprived neighborhoods (Kowal 2006)

Historically situated, the European powers had by the nineteenth century already established systems of rules and forms of social relations which governed interaction with the Indigenous people being colonised. The same can be said of the mentally ill. The principal of humanity was one way in which the mentally ill, or peoples seen as not fully human, enabled and justified various policies of social control (Smith 1999: 28). You cannot look at colonised relationships without addressing the complex problem of power relations (Smith 1999: 23).

Ethnographers turning into autoethnographers, came to realize that stories were complex, constitutive, meaningful phenomena that taught morals and ethics, introduced unique ways of thinking and feeling, and helped people make sense of themselves and others (Adams 2008; Bochner 2001; Bochner & Ellis 2002; Fisher 1984). Furthermore, there was an increasing need to resist colonialist and sterile research impulses of authoritatively entering a culture, exploiting cultural members, and then recklessly leaving to write about the culture for monetary and/or professional gain, while disregarding relational ties to cultural members (Conquergood 1991; Riedmann 1993; Ellis 2007).

Ellis (2011) posits that autoethnography may be associated with a type called Indigenous or native ethnographies, where the autoethnography is developed from colonised or economically subordinated people and are used to address and disrupt power in research. An example is the
reaction of cultural guilt expressed by white Australians to Australia’s Indigenous citizens (Denzin and Lincoln 2005: 773). Once at the service of the (White, masculine, heterosexual, middle/upper-classed, Christian, able-bodied) autoethnographer Indigenous/native ethnographers now work to construct their own personal and cultural stories; they no longer find (forced) subjugation excusable (see Denzin, Lincoln & Smith 2008). The Indigenous social structures which Western anthropologists purport to study may in fact be artefacts of the colonial era (Layton 1997: 190). And these cultural artefacts have histories within the colonial era.

‘Archaeology’ was the term Foucault used during the 1960s to describe his approach to writing history. Archaeology is about examining the discursive traces and orders left by the past to write a 'history of the present'. In other words, archaeology is about looking at history as a way of understanding the processes that have led to what we are today (Foucault in O'Farrell 2007).

Madness is associated with a break in historic structure, our historic hegemonic structure of White, masculine, heterosexual, middle/upper-classed, Christian, able-bodied perspective. All ideas have histories, and they have different types of histories, including social histories (Hacking 1999: 30). Anything worth calling a construction has a history (Hacking 1999: 50). To understand the character of certain issues means to examine their history (Latour 1991: 113).

Over the last centuries, both the study and treatment of the mentally ill has been captured by the natural and social sciences. Mental health studies have been leaking out of the tight grasp of the
natural sciences and spread into the realms of the social sciences. We can now claim that mental health was pathologised in its conception, borne from biomedicine. More recently mental health has been socialised. What is socialised and ostracised, the social sub-citizen, is also pathologised. DiGiacomo (1992) states that anthropologists fear clinicians will not take them seriously unless they accept the concept of biomedical diseases as the gold standard. There is a hierarchy in mental health care, historically, classing the biomedical model above all else.

*Governance, Politics, Policy and the Silenced Manifesto*

“How is madness bureaucratised and made a part of social policy? And how is madness governed if not by measurement and science? The stigma of the mentally ill is protected and authorised by the government bureaucracy.”

(Field notes 16th, 2017)
Hanisch argued that the political is embodied in the personal, and vice versa (Hanisch 1969; 1970; Richards 2008: 1724). It is about giving a voice, empowering the silenced, the social outcasts, and recognising the cultural meaning and significance that the outcasts are confined to (Butler 2000). Living with schizoaffective disorder, I feel conflicted. I feel conflicted and confused as if my world is falling in around me. It is about an assault of the mind as well as culture. I question the culture that suffocates me as such, often without my input or true representation. It is about recognising the importance of the foundations of knowledge in the broader system of politics and economics. Such is the task of the Silenced Manifesto, removing the silenced reports off the shelves and putting mental health experience and discourse into the vernacular. The vernacular being the language of the powerful in mental health, that is simply put, the governance and bureaucratisation of biomedicine.
Considering the ’manifesto’ part of the concept of the ‘Silenced Manifesto’, is the discourse that the hegemonic culture covertly/overtly uses, via its texts, to claim power over the marginalised in society. For example, the discourse developed over Australian history and used by Australian governments to covertly have power over the mentally ill, and at the same time disempower the mentally ill, becomes the Silenced Manifesto. Continuing, the manifesto becomes a cultural artefact, the sentiment of which is entrenched firmly in the tools of governance. The use of language covertly and/or overtly entrenches the strategy of governance. Its (mis)representation of the marginalised in government policy cements the imbalanced power relations between government and the mentally ill. Unequal access to and influence on policy, especially the language of policy representing the true needs of the mentally ill, demonstrates a significant misappropriation of power. Control over the government texts, that is the government’s cultural artefacts in the form of policies, demonstrates the power of State and its political use of language. Language becomes texts, texts become cultural discourses, discourses become enculturated manifesto, the manifesto covertly and overtly identified and empowered in governance and policy - the silenced manifesto breathes, it breaks through and comes to life. The suppressed voices of the mentally ill are silenced and situated within the cultural discourse of governance.

Latour (1991: 213) argues that the State owns everything, people included. People are at once an investment and a product. Which makes their identity...what?

Governmentality as a strategy and rationale, Foucault claims, has dominated political power in Western countries since the eighteenth century (Lupton 2013: 115). “For some scholars drawing upon Foucault’s writings, ‘dispositif’ is a term used to encompass the governing of the social body, configuring a heterogeneous assemblage of discursive, administrative, technical, legal, institutional and material elements (Aradau and van Muster 2007: 91). A dispositif relates to the
bringing together of these heterogeneous elements, or knowledge structures, which enhance and maintain the exercise of power within the social body” (Lupton 2013: 118). According to Lupton (2013: 118-119), some suggest in the form of neo-liberalism, maintaining social order and governance relies on productive and dispersed forms of authority. Citizens are cultivated to govern themselves and to focus on self-actualisation rather than emancipation.

Measurement is empowered, seemingly by scientists, to be a socio-cultural entity with its own agency. It is empowered to define service delivery implementation as a form of political technology. As well, measurement is seen as an object of governance; empowered to play a significant part in knowledge production and as an object of knowledge. Foucault argues that the individual is not something that needs to be liberated, rather the individual is the closely monitored product of relations between power and knowledge (O’Farrell 2007). Foucault uses the word to refer to the fact that it is not just the object of knowledge which is constructed but also the knower (O’Farrell 2005). Knowledge is decreed acceptable if the governing body declares it as such. Knowledge constructions are not produced in sterile and stoic vacuums. Human volatility is considered, as well as the significance of cultural constructs.

Freedom is a cultural construct. Foucault notes that he “believes solidly in human freedom”. He also argues against nineteenth century existentialist views of an abstract freedom and a ‘free’ subject and says that freedom is a practice rather than a goal to be achieved. Knowledge starts with rules and constraints, not freedom. Freedom is also a condition for the exercise of power (Foucault in O’Farrell (2007).

The medical factoids, as well as being objects of governance by the health professionals, have also become a subject of governance by the mental health patients, illustrating a comprehensive,
complex, and dynamic, socio-cultural production of knowledge. Factoids become more structured conceptually as objects of knowledge. These objects support governance. The factoids thus can become objects that support the biomedical truth; the truth that is supported and validated by medical science, including psychiatry. According to Foucault (2007), “the individual is not something that needs to be liberated rather, the individual is the closely monitored product of relations between power and knowledge”. Foucault argues that power play exists in all interactions including the measurement process which is essentially a production of knowledge based on socio-cultural and political factoids. (Foucault 2007). For example, the mental health professionals, to varying degrees, retain a position of power over the mentally ill, perpetuated by a system of dependence. To illustrate, despite my apparent independence and functionality, I am forced into a dynamic of dependence to get my medication. And I have in the past have had to get this in a public place at a set time, with no regard to the fact that I might have a job and other things to do. “Always, there is monitoring, measuring and medicating. Always.” (McMahon 2017: 26)

Lea (2008) argues that white men, middle class, able bodied, and non LGBTIQA+ develop and empower bureaucracies and policy magic, enabling the inner sanctum of policy a life and value of their own. Policy is central to governance infrastructure, linking together the substance of socio-cultural, political and economic foundations. Good medicine would be given status and legal protection by the State; it would be the task of the State to make sure that a true art of curing does exist (Foucault 1973: 20). Medicine and the health care system in Australia are mostly supported by the State. The first task of the doctor is therefore political (Foucault 1973: 33).
The National Mental Health Strategy is a commitment by Australian governments to improve the lives of people living with a mental illness (Department of Health 2014). National quality frameworks, part of the backbone of mental health policy, form objects of governance. These policy objects of governance define objects of knowledge, which in turn and cyclically, produce objects of governance (Johnstone 2001; Jenkins 2002). The bureaucracy decrees psychometric measurements as a necessary tool for knowledge production, an extension of the biomedical model and scientific measurement which defines and justifies national policy and governance (Lea 2008).

“Today’s mental health institutions and hospitals are all about measuring and judging and surveillance.”

(Field notes November 22nd, 2015)

The mental health assessment tools and medical observations, cultural artefacts of modern psychiatry, are all about measuring and judging deviance. Measurement tools are negotiated as tools of governance. They are promoted and supplied with a price. They are commodified. Policy is commodified. Governmentality is commodified. Psychiatric care is commodified. Wellness is commodified. The Silenced Manifesto, incorporating all these things, is also commodified. There is a glass ceiling of oppression and subjugation when being commodified and defined in a society where economy is valued highly.
The Space of Commensurability and the Silenced Manifesto

Part of the role of the rehabilitation nurse in Ward B (public) was to find some space of commensurability between wellness and unwellness, to improve communication and understanding and preparedness, and thus to minimise the time spent in hospital. Although this didn’t happen in my case. Efforts for rehabilitation were a piece meal gesture, with little agency or effect. In this instance the space of commensurability can appear to be tokenistic or even false.

The space of the Silenced Manifesto has historical roots. Foucault’s concept of historical situatedness describes the factors that have been instrumental in the development of the space of commensurability, related to the paradigm of the Silenced Manifesto. In his book, Madness and Civilisation (1961), Foucault studied the sub-citizens or deviants in society, including prisoners, homosexuals and the mentally ill. Foucault here discussed the ways that our identities are historically produced and situated.

As discussed in chapter three, in the Middles Ages the mentally ill were an accepted part of public life, but by 1650, the mentally ill were burnt as witches. In the eighteenth century, the mentally ill were classed as abnormal and removed from society. Then with George III’s delirious descent in 1788, satirists and cartoonists were given a golden opportunity. Madness had become a sort of entertainment. The mentally ill were re-categorised again, this time as entertainment, freaks. In the twentieth century, the mentally ill were medicalised, pathologised and became patients and experiments of medical science and institutionalisation. So, the terms of what have defined mental illness and its association with deviancy have changed. In modern times, according to Foucault, the mentally ill are subject to more measuring and surveillance and judgement as is
relative to the recent legacy of medical science. The silenced are gagged again. The hegemonic
culture perpetuates the discourse. Yet this is the space where social change can happen; through
a shared space where language and power can be negotiated.

“Mental health, as a socio-cultural phenomenon, has developed over hundreds of years,
with foundations in superstition and growing into medical science and positivism, and then
becoming more relatable to the social sciences”.

(Field notes May 11th, 2015)

The concept of power negotiation has been a strong theme in this thesis. Mental health services
have long been influenced by landscapes of power. We are also confronting geographics of
power within the acute care experiences (Liggins, Kearns & Adams 2013: 108). The landscape
for those living with a mental illness, as decreed by Foucault (1973: 188-189), states that disease
exists in space before it exists in sight. The landscape of the disease is also immediately a causal
space.

As for the landscapes of power, as recently as 1860, it was not necessary to be mentally ill to be
incarcerated in an American mental institution. It was enough to be a married woman.
“Married women...may be entered or detained in the hospital at the request of the husband of the
woman or the guardian...without the evidence of insanity required with other cases” (Szasz 1970:
15).

To clarify, institutionalisation refers to the process of embedding some cultural conception (for
example, a belief, a norm, social role, value or mode of behaviour) within the control of an
organisations’ structure of science and politics. Latour (1991: 127) argues that an example of
the institution is a prison – structures for the confinement of socially undesirable persons, that is subhuman, sub-citizen and social misfits. Foucault (1961; 1963) declares that in the eighteenth century, institutional spatialisation of disease makes its appearance. There grows space for interrelations and power play between each micro and macro conception.

Hacking (1999: 58) argues that categories of knowledge are used to empower relationships. As a fundamental statement that Foucault generated and supported, power is intrinsically linked with knowledge. Whoever has knowledge has power and vice versa. Whoever has knowledge, then power, has the resources to disempower or empower themselves and Others. When the discourses of power are in the hands of the underdog, the power distribution shifts, even if only briefly (Foucault 1961, 1975; Richard 2008: 1724). To expand, being known about is interrelated to knowability. According to Hobbes, [creating a language] which understands power to equal knowledge, there is an equation that is at the root of the entire modern (Latour 1991: 26).

The Silenced Manifesto can here be noted as having created a commensurable cultural space from which a discourse of mental health, from all perspectives, including policy, can be defined. I want the mentally ill to have their voice heard and to create a discourse platform from which they/we can obtain strength. In this context, I ask the questions: how can I break through the cultural divide, break through the disempowerment and misrepresentation bestowed on me because of culture? How am I labelled and defined? Who is granted a voice in this cultural space? Stigma – the ‘why’ of the Silenced Manifesto.
Stigma comes from the Greek, to mark or brand. Stigma refers to marks that publicly disgrace the person (Kleinman 1988: 158). Goffman (1963: 2) notes that in more recent times, stigma has come to refer more to the disgrace then to the actual bodily mark. “The normal and the stigmatised are not persons but rather perspectives” (Goffman: 1963: 138). The changed meaning is an instance of the more general process of the psychologising of experience in the West, through which metaphors of distress and other human problems that were once bodily have become mental. Even amongst those living with disease, there is a social hierarchy of health.

Lack of social support and feelings of stigmatisation can hinder health care utilisation (Wohl et al 2011 in Spieldenner 2014). Those first stigmatised were associated with their religious beliefs. Later, the association shifted. Meaning was then related as a person to be a slave, a criminal, or a traitor – deformed, ugly, blemished, ritually polluted and to be avoided. The unwell are also associated as social misfits - especially in public places behaviour clashes with social norms. It is questionable where the space of commensurability is, and who has the louder voice when conducting or considering a shared space with the stigmatised - they become part of the Silenced Manifesto.

The Silenced Manifesto and the stigmatised self

My self-image is largely dominated by a belief that I am handicapped by my mental illness. The consequence of being labelled mentally ill includes such penalties of personal degradation, loss of employment, loss of the right to drive, to vote, to make valid contracts, or to stand trial – and
last, but not least, involuntary incarceration in a mental hospital, possibly for life (Szasz 1970: xxxi).

Grant (2010: 581) argues that there are various types of self in relation to society, with various types of stigma. Firstly, the cultural self informs and influences our experience of ourselves, Others and the world. In a modern theoretical landscape, having many different ‘selves’ to draw on, in a constantly shifting interior landscape, the boundaries between self and Other, mediated by language, are often blurred.

A type of social self, according to Grant (2010: 581) is the stigmatised, Othered self. Goffman (1963) has contributed much to the discussion of stigma. His book, *Stigma: Notes on the Management of Spoiled Identity* (1963), is summarised by examining those who are considered less than human, that is subhuman. For example, the woman, the disfigured person, the blind, the homosexual, the mentally ill patient and the member of a racial or religious minority, all identities that can be considered areas of judgement, judged potentially as socially ‘abnormal’, and therefore in danger of being considered less than human, a subhuman.

For the human predator in society, the rule is to stigmatise or be stigmatised (Latour 1991: 260). How and why are some people treated more humanely while others are met with silence, disgust and abuse (Adams, Jones & Ellis 2015: 14)? What about the silenced? The silences in mental health governance and the mental health lived experience? What are the often-silenced voices of the stigmatised saying (Liggins, Kearns & Adams 2013: 106)? Here the Silenced Manifesto can be concomitant and concurrent, helping to explain the stigmatised position of the silenced.
The discourse mandating and officiating the colonising reality described here, and the perpetuating culture that situates and brings meaning to the plight of the mentally ill, creates the ‘manifesto’. The manifesto can be described as today’s mental health discourse, borne from a histology in medical science, and developed in time to dominate those who are lacking, the mentally ill. The manifesto is the offspring of governmentality, its economics and its culmination in the policies which feed the health bureaucracy, which is in turn a cultural artefact (Lea 2008). The development and nurturing of the health bureaucracy is fed by the validating measurements of psychiatry.

There is both a covert and an overt relation between discourse and inclusion in histology and its supposed and declared empowering of the mentally ill (Foucault in Goldstein & Cascaito 1991). The policies, crafted by what one would expect from a manifesto, are grounded in language and the complexities of mental health semantics, the relationship between governance and economics, and a system of class that labels the mentally ill and their place within the structure of society. Thus, the labels of sub-citizen and social misfit. The term, the Silenced Manifesto, is used to describe the mentally ill, although it can be widely used in other arenas. In this case, the Silenced Manifesto depicts the mentally ill as lacking. However, the term is a whispered voice, whispering the covert disempowerment of the mentally ill.

The written word, the texts, discourses, are representations of culture. It doesn’t have to be written as such. Discourse, in this case of the Silenced Manifesto, could mean oral history, the
products of the arts, the sciences, and any form of transfer of knowledge. The manifesto is a representation of cultural significance, a fluid space, transferable from one to another. It is fundamentally essential to all parts of socio-cultural significance.

The Silenced Manifesto identifies and/or develops a discourse, a vernacular that represents the plight of the ‘disabled’ in some way, in this case my living with a major psychotic illness. The notion of the silenced is included in that these often marginalised groups are not heard. They are shackled, disempowered and disallowed in the vernacular. They do not possess roles that are significant to the order of society. They are smothered, suppressed, and shushed out of the culture – silenced and hidden.

**The Communist Manifesto and the Silenced Manifesto**

Who are the classes today? The intelligentsia, industrialist, the politician, the economist, the religious? (Foucault 1972). The mentally ill being neither producer or consumer, have no class: idle, vagabond, unemployed, belonging only to confinement, a measure by which he/she is exiled and as it was abstract for society (Foucault 1961: 218-19). Having no class creates a limited space of commensurability, communication and translatability. As per the Silenced Manifesto, a non-class situation creates a glass ceiling, or similarly a straight jacket that confines and restrains and restricts the means of agency for those living with schizoaffective disorder.

Who are the classes today? The class struggle isn’t Marx’s invention. In medieval Rome there were knights and slaves. In the Middle Ages, feudal lords, artisans and serfs existed. The modern
bourgeois society that has sprouted from the ruins of feudal society, has not done away with class antagonism. It has established new classes, new conditions of oppression, new forms of struggle. Australian society is more and more splitting into two great Australian camps: bourgeoisie and proletariat (Martin 2016; Ponzanesi 2014). The worker exchanges his commodity, labour power, for an equivalent wage, so the boss says, to purchase what he needs to survive: light, food, roof, clothes (Martin 2016; Ponzanesi 2014). Patriarchy is revived with madness in the bourgeois family (Foucault 1961: 240). The Silenced Manifesto blocks the degree of movement between classes, both by confining the space to be heard, and also by confining the avenue for the discourse to be navigated, as per all power negotiations.

It seems that tools and objects utilised in the mental health arena can be called commodities, and the processes in developing and using these commodities should be called commodification. I was not given any ownership of the commodification of knowledge production, and hence I was not granted access to the power bestowed in such a production of knowledge. Following on, and as Brenner (1974 in Kleinman 1980: 48) has demonstrated, mental illness is strongly influenced by our society via socioeconomic changes.

Regarding the Silenced Manifesto, the process of commodification silences the voices of those living with a psychotic illness by commodifying the underdog, thereby limiting the space of commensurability into a relationship between economy and social misfit. The main accolade of the underdog and economy is the labelling of class. The labelling of commodity perpetuates the culture which places boundaries on the underdog. The labelling silences the mentally ill by limiting spaces from which commensurability operates.
The economic wealth of mental health services is not solely based on measurements and numerals. I hope that the psychometric results from assessments themselves are meaningless, due to their negative reporting and misrepresentation of myself. Are they true? Do they really represent me? Socialisation, socio-cultural capital, the kaleidoscopic nature of human interaction, and the power dynamics bartered in the potent and cogent exchange, become the non-numerical wealth. Social relationships become economic wealth. The socialised stories behind the numbers enrich the data. Although the stories alone are not substantial for the discerning eyes of those with a positivist perspective.

In the psychiatric wards, I did not have control over my own resources when admitted. Everything was taken from me; my own resources were manipulated by the medical staff. As my admitting nurse in the Ward B (public) said to me, “You cannot have in your possession materials which place you at risk, that is at risk of self, others or reputation.” At risk objects that were taken from me included chocolate. I could not argue for threat of being sectioned. Thus, the Silenced Manifesto. My voice and word was and is imprisoned.

Biehl (2005: 23) argues that from the perspective of one human life...deemed mad and intractable, one comes to understand how economic globalisation, State and medical reform, and the acceleration of claims to human rights and citizenship, coincide with and impinge on a local production of social death, albeit being silenced and textualised, as per the notion of the Silenced Manifesto. The negotiation over the human and nonhuman forms part of a complex set of relations through which individuals are linked to each other and to the political body. The Other’s dying makes it possible for one to belong to a family like institution, to a new population and subjective economy. The ethnographic challenge is to find these empirical relations and linkages – technical, political, conceptual, and affective – and to bring them out of thoughtlessness.
The Communist Manifesto stressed the social need to produce an interior space that coexists with the exterior practices of citizenship. The manifesto, related to Foucauldian or Deleuzian language and logic, introduced the question of subjectivity as a matter of counter-governance: all spheres of government should influence the ways in which individuals and groups constitute themselves as subjects so that citizens may elude both established forms of knowledge and dominant forms of power (Biehl 2005: 137).

Biehl (2005: 316) states, “That is not to say that mental disorders are basically a matter of social construction, but rather that such disorders do take form in the most personal junction between the subject, his or her biology, and the intersubjective and technical re-coding of ‘normal’ ways of being in local worlds.” “Indeed, it’s a mystery!” (Biehl 2005: 236)

Whatever the cause of my last relapse and hospitalisation my experience in the Ward C (private) was relatively pleasant, although expensive. The main difference between the other two wards was capital. In anthropological terms, for instance, the difference was cultural capital, ethnographic capital and discourse capital, to name a few. Conversations about power support such capital/s. Though it is not as simple as that. Having the means to control the resources in your life enables your recovery. Access to more resources is needed if one must consider recovering in a different culture with a different language. Ward B (public) and Ward A (public) and Ward C (private) all have different cultures. The Ward B (public) is somewhat colonialist. Ward A (public) is somewhat paternalist, but more supportive of rehabilitation. Ward C (private) is somewhat empowering and focussed on rehabilitation. These cultures, some may argue, fall in different spectrums of the Australian Mental Health values and politics. The values of the
Australian Mental Health system include: coordinating treatment and supports for people with severe and complex mental illness; improving Aboriginal and Torres Strait Islander mental health and suicide prevention; and reducing stigma and discrimination (Australian Government, The Fifth National Mental Health and Suicide Prevention Plan, August 2017: 4).

The Silenced Manifesto can be included here as a relation to the Communist Manifesto where a space of commensurability between the interior and exterior spheres of personhood are created. So, it is possible to create social power, empowering the marginalised and providing a platform to make themselves heard, to equip the silenced with the semantic tools to be understood, to make the personal political. The text, embedded, creates a newfound ‘discourse’. The newly heard and marginalised are heeded, a commensurable space is created, their consequent power is precipitated by the culture that it envelopes, and the marginalised, that is the colonised, now have the hope of becoming full humans and citizens, and definitely not social misfits.

**Conclusion**

My identity is not my own. This sentiment is typical of people living with a psychotic disorder. Many, including me, are defined as dependents of the State, with prescribed agency or freedom, without the freedom to live as desired. Is it possible for me to regain my freedom? For this to happen, a broader mind may be necessary, as some people living with major psychotic illnesses act oddly at times. They are social misfits. Am I also a social misfit?
Considering all that I am, who am I? Am I defined purely by my sociality? To what extent is my identity influenced by my understanding of self? My mental health journey is neither linear or predictable. Who am I? Who am I regarding all the factors involved in personal and social construction?

In this thesis, the subhuman, sub-citizen and social misfit are described as having been forced into a position of disempowerment, being disabled, disengaged, and detached because of the hegemonic government macro-narrative. This macro-narrative dictates the historical construction of sub-citizen policy in Australia, where the dynamic political landscape is changing. There is the deconstruction of current self-determination/post self-determination policies, and the politics of implementing these (Kowal 2006).

Since I was 23, I have been suffocated by my experiences of living with schizoaffective disorder. Over time, I have swayed, and I have fought to and fro, back and forward, through each experience, remembering some, forgetting much. My sense of self, my identity as a person, these fundamental, unique and distinctive facets of my self-concept, my agency in this regard is limited. My fundamental and basic human right, to be free from unwarranted prejudice, has been robbed of me in many ways (OHCHR n.d).

My quality of life has diminished permanently. I have difficulty in being labelled. To be called ‘handicapped’ by progressive health professionals currently is disempowering, although seemingly true (from their bio medical perspective and validated by their measurements of me).
There are many questions that have been explored in this autoethnography. How has my disability affected my life? Why is my story significant? How does my autoethnographic methodology succeed with this topic? How do my experiences contribute to an anthropology of mental health? How has my psychosis and forthcoming thesis been enculturated and situated in space and history? How does stigma work? How do language and narratives encapsulate the meaning, identity and purpose of the underdog? How do politics and policies wield power over the marginalised, and strengthen and support such power? How do measurement and labelling provide insight into the experience of living with schizoaffective disorder? How significant is the social creation of reality to this thesis? What does the phenomena of (post)colonialism add to the analysis presented here? What structure and function is there, and how is this concept fluid, flexible, waxing and waning, blown to and fro in the winds of influence and power? And I ask, how are the silenced made silent, and how does discourse perpetuate the labelling of the silenced?

All these questions can be answered in some way with the Silenced Manifesto.

Considering, the PAI assessment absolutely disempowered me. I had no power left to fight with, no power. It was a battle of the wits, a battle of the minds, albeit between the knowledge of the sane and the knowledge of insane. I had no chance at winning. There is a presumption that the social misfit is stupid, lacking. The assessing psychologist was sheltered from criticism because of the deified position that an esteemed mental health professional is bestowed. There were many influences that swayed the psychologist’s assessment. Power is swayed to the value of the measurer who trumps the resource lacking and knowledge poor psychotic person. Psychosis is
related to the tangible individual, which equals fear, uncertainty and chaos. Psychology as related to tangible science equals certainty and hegemony.

I am silenced. I am ignored. I am hidden. I do not share a commensurable space with the government and its politics and policies, the processes of labelling and measurement, and the means of silencing and cementing the underdog in discourse. I do not have access to freedom. Indeed, I am excluded and imprisoned in many ways from society. The Silenced Manifesto reappropriates and encapsulates all opportunities to exert, resist and influence power. It creates and builds a foundation compassing the commensurable causal space, language and narratives, the production of knowledge, all governance and policy, the construction of reality, the processing of labelling and measurement, the paradigm of (post)colonialism, stigma and social theory.

I would like to be known as someone who is independent, who controls the circumstances influencing her life, and has power to own my own knowledge. Though actually, I am vulnerable. I have long periods of being unwell. I always will. It is difficult to live past that, knowing what may come. I must do things like get income insurance and full health cover and to keep my affairs in order, that is when I can afford it, which to be honest, hasn’t happened now and will probably never happen. In many ways, I am commodified.

My experience of living with schizoaffective disorder is described by the Silenced Manifesto. I am silenced and imprisoned often by a straitjacket of oppressive governance. I have been
excluded: by language; by power; by politics and policies; by inaccessibility of services; by discrimination. Ultimately, I am silenced: by being hidden; by being choked; by the limits of the manifesto.
CHAPTER THIRTEEN

CONCLUSION

7 LESIONS: 7 VOICES: 7 DRUGS: 7 STORIES: 7 CONCLUSIONS

Seven conclusions

In this concluding chapter I will extrapolate and compile seven conclusions from this thesis. These follow on and develop from the five questions/statements posited in the introduction chapter.

I have learnt over the twenty plus years of living with a major psychotic illness, that people do not expect much from me. My psychiatrist in Town B tried to make me work part time for years, and definitely not to have me study on top of that. A nurse I spoke to recently during one of my monthly Clozapine clinic assessments, stated that she is astounded by what I do, by what I have achieved. She describes me to her friends and colleagues as a ‘real achiever’, despite the ‘pain life has caused me’. I find it a little disconcerting to be labelled as ‘successful’, as someone who
fights the labels of ‘disabled’ and ‘handicapped’ (terms used by health professionals I have seen), as if I am not capable of living an enjoyable and full life.

The discipline of my intellectual (de)construction is anthropology, and stemming on from that, this ethnography is an autoethnography. The day that anthropologists give up their attempt to ground meanings in politics and economics will be a sad day (Douglas 1992: ix). As per my perspective, in this autoethnography, I have addressed with raw insight the issues of a culture of schizoaffective disorder. In this case, the culture of mental health, exemplified by my experience of living with schizoaffective disorder.

As Kowal (2006) states, anthropology is concerned with culture and discourse. Mental health discourse has historically been defined by and developed and supported by the biomedical model. It is this dominating medical culture, the structured perpetuating narrative, connecting the doctor (the scientist) and the patient (the lacking), that cements the roles of the powerful doctor and the powerless patient in their allocated and respected constitutes. A culture change dissipating the tower of strength of the scientific foundation has proven difficult to conquer.

Western knowledges, philosophies and definitions of human nature are what Foucault has referred to as archives. Some people might refer as a storehouse of historic artefacts, ideas, texts and/or images which are classified, preserved, ranged and represented back to the West. Foucault also suggests that the archive reveals practice from which the West itself cannot necessarily describe because it operates within the rules and they take it for granted (Kleinman 1988: 43). Clinicians (and researchers too) need to unpack their own interpretive schemes, which are filled with personal and cultural biases (Kleinman 1988: 53).
Autoethnography is a valued methodology with which I was able to realise the minutia and intricacies of what it is like to live with schizoaffective disorder. I have examined and unearthed the culture of my world, and the world of culture. This perceptiveness helps me to paint a picture and provide an in-depth analysis of the culture of the mental health experience. It would be difficult to find a methodology other than autoethnography that could provide such depth of detail, richness, thick description (Geertz 1973) and insight into the detail of life experiences of schizoaffective disorder.

1. Labelling

When considering the cultural identities of subhumans, sub-citizens and social misfits, I cannot ignore the importance of labelling theory. The essence of labelling theory is that individuals are crafted by society and given identity by society. This is done via the labels that individuals are given by the society. Some labels result in harmful effects, such as the perpetuation of deviance, and the creation of stigma. This label is perpetuated by the society. The negative effects of labelling, the naming and assumptions, are internalised by the individual so that they adopt the negative influence of the labelling. Importantly, the individuals self-actualise and learn to accept and identify as a subhuman, sub-citizen, social misfit. The internalisation of the label develops into a self-fulfilling prophecy: if the individual is indoctrinated so much by the powerful, they will actualise and become the label they are given. For example, if a teacher praises and encourages a student, the student is more likely to succeed (Scheff 1974).
Regarding mental illness, labelling can lead to negative outcomes. The more the person living with a mental illness believes and internalises the labelling of subhuman, sub-citizen, social misfit, the more they will believe they are devalued and lacking. And so is the self-fulfilling prophecy. The individual living with a mental illness internalises the language and culture and politics and psychology and economy, and the interpersonal relationships. All these factors are given space, a possible commensurable space, to flourish. In this commensurable space the labels have been cemented and developed and have been self-actualised. And so is the self-fulfilling prophecy. The culture that labels those living with a mental illness perpetuates and the individuals become part of the culture defined as the lacking (Scheff 1974).

“The university and in a general way, all teaching systems, which appear simply to disseminate knowledge, are made to maintain a certain social class in power; and to exclude the instruments of power of another social class.” (Foucault & Chomsky 1974)

A mental illness diagnosis can label you for life. Once painted with the brush of mental illness, in this case schizoaffective disorder, it is hard to break that association. In measuring the
unmeasurable, there exists a crisis of representation (Said 1978). Diagnosis can precipitate such a crisis of representation, in being the ‘esteemed’ scientific phenomenon of labelling and categorisation. It relies on the ethnographic capital of measurement.

It makes me sick to know that I am being known about, by others, who themselves perpetuate the labelling of those living with a major psychotic illness. The main difference is that in my situation I have somewhat of an insightful ability to question the capability of those with power over me.

Those who I am close to, most gently always ask me how I am going with my study, eager for me to complete. Many find my symptoms to be annoying. They do not realise that my memory and cognition problems are symptoms, albeit permanent, and not innately part of my personality. They are not conscious choices. I have no power over these annoying aspects of my illness. I feel like I am judged. To live with me, I feel judged. I live within the boundaries of a priori knowledge from others. I am bounded by what is defined for me, not what is true to me. Here, again I am defined by others. Though, I should not be patronised because of it; again, treated as a child. Living with a major psychotic illness, I am often treated as a child.

Labelling is an activity that predisposes the fundamental subject of this thesis. Put another way, the culture of mental health and its associated labelling precipitates the stigma of both the system and personal phenomena of living with a major psychotic illness. In sociology, labelling theory is the view of deviance according to which being labelled as a ‘deviant’ leads a person to engage in deviant behaviour (The Chegg Study n.d.). The mentally ill patient is viewed as a deviant, defined by those disassociated and detached from the labelled group of society.
I obviously do not belong, especially not in this workplace, but also in study and in relationships. In fact, I don’t know of any area of my life that has not been plagued by my mental illness. I have been labelled in every manner. How can I break through the cultural divide, break through the disempowerment and misrepresentation bestowed on me because of culture?

Szasz (1970: xvii) argues against the practice of psychiatry, saying that “the result is the dehumanising, oppression and persecution of the citizens branded mentally ill.” One may also argue that the labelling of the mentally ill is precipitated in the functioning of culture. The functioning of culture, with its foundations of values and meaning, plays into the need for culture to empower or disempower its subjects of participants, and whether this system/society supports them or inhibits them.

2. Subhuman, sub-citizen, social misfit

The subhuman, sub-citizen, and social misfit are lacking. The subhuman, sub-citizen, and social misfit lack the power and agency to participate fully in society. Biomedicine measures what is mostly the scientific ways the person is lacking. In this instance, we are looking at my lived experience of having schizoaffective disorder. The culture that affects me and perpetuates the existence of the subhuman, sub-citizen, and social misfit also limits the power that I may attain.

From my experience, I am most emancipated when my own voice is heard and heeded. In this analysis, one must ask, what are the implicit or explicit silences in this discourse? Whose noises are (dis)empowered? (Butler 1990). What culture precipitates the subhuman, sub-citizen and social misfit? These questions are addressed by the concept of the Silenced Manifesto where the
person living with schizoaffective disorder, me, has not the empowerment of being heard let alone the platform, or space, to speak from. To follow, Foucault stated (in Zolatova 2010), “There is not one but many silences, and they are an integral part of the strategies that underlie and permeate discourses.”

According to Marx and to a lesser extent Foucault, the workers do not own any of the modes of production or modes of information which will contribute to their quality of life (Poster 1992; Nussbaum & Sen 1993). One may think that it is the workers who are at the bottom of the class struggle. But it is those who do not even make it to the class of worker that concerns me. They belong to the figurative class of stigma. They are subhumans and sub-citizens, who do not play an active role in society other than a dichotomous comparison between normalcy and whatever deviance is. Being a social misfit and deranged means that you do not even participate in any economic equation, let alone be included in any sort of societal evaluation (Appignanesi 2012: 99). There seems to be no room for the subhuman, sub-citizen and social misfit, the anti-social, with what Foucault (1973: 74) called the revitalised ‘enlightened bourgeois’.

Foucault (1967: 65) notes that in England, the hospital later called Bedlam, exhibited their “lunatics” for a penny every Sunday...madness itself... which put on a show. The mentally ill created entertainment for the society. They were an exhibit, commodifying and sensualising the stigmatised, disempowering the subhuman, the sub-citizen and socially marginalised. In analysing the ‘space’ which encompasses and allows for major psychotic illnesses, there is an a priori, an already assumed knowledge, that the mentally ill person is disabled; lacking. It is assumed that the person hasn’t the capacity to function intelligently, or to negotiate their own health.
3. **Culture**

Culture helps people to understand phenomena. “All cultural classification systems have anomalies, things that do not fit, and ambiguities, things that may fit in more than one category” (Lupton 2013: 62, 67). Moreover, “...cultural concepts concerning labelling, boundaries, classifications and categories, the violation of which confounds cultural values and expectations... these polluting people are culturally positioned on the margins of society...Certain classes of people are singled out...requiring control to bring them back to conforming with moral values” (Lupton 2013: 74). This is the way in which dominant groups have reacted against those who are deviant (Lupton 1999: 54; Lupton 2013: 61). Of most importance is how this autoethnography and relevant literature depicts the dominant culture, that is how the dominant culture perpetuates the labelling of subhumans, sub-citizens, and social deviants.

I argue that mental health is a social phenomenon, just as much as a scientific phenomenon. Outside the walls of positivist science lay the social foundations of the concept of mental health. Mental health facets include taking account of the kaleidoscopic nature of human interaction; socialisation from science; and how the power dynamics are bartered in the potent and cogent exchange of socio-cultural capital. The constructs of knowledge become cultural artefacts. And the uses of these tools form together to support a system of governmentality. They work to validate to justify and make accountable the positions of the service implementers.

From the perspective of an anthropological decree, considering socio-cultural capital, there is a reappropriation into the textualized version, ethnographic capital. From this, the Silenced Manifesto endorses and adopts ‘discourse capital’, which can be comprehended as using and
understanding the wealth presented in language and culture. The Silenced Manifesto engulfs discourse capital. It utilises the capital presented in text, in language and culture.

Such discourse is also precipitated in stigma. It is absolutely a socialised phenomenon (Kleinman 1988), connected with culture and everything there is about how one person can affect another. Also, it builds into how a society affects an individual, and how an individual is barred by the social. Historically the stigmatised are labelled as shameful and outcasts, not wanted or tolerated by the mentally well. Kleinman refers to stigma as the socialised “shame of illness” (1988: 158). The shame is inextricably connected to culture and its applications in society. One can connect and relate the social to its misrepresentations.

Goffman states, “Social misrepresentation is to be distinguished from personal misrepresentation” (1963: 82). Social misrepresentation and the related socially stigmatised are greater strangers to themselves (1963: 48). The personally stigmatised live in terror of their mental health status being thrown in the face (1963: 109). Such is the turbulent identity construction of the stigmatised, those with a major psychotic illness in this case.

4. Measurement

The power of measurements and consequent numbers and pie graphs are quite profound (Lea 2008).

Measurement is an outcome with the use of its tools, depicting a kaleidoscopic, dynamic and socio-cultural production of knowledge. The assessment process creates a space of knowledge
production, a formation of political technology where the act of measurement, also narrative development, forms a type of discovery which has political and governmental significance. The measurements produce knowledge: transforming the numbers into factoids (Lea 2008). The factoids become more structured conceptually as the language and symbols of knowledge production. As part of the language of scientific knowledge, these factoids/objects of knowledge become validations for governance, to measure the unmeasurable. (Lea 2008)

The power of measurements and consequent numbers and pie graphs are quite profound. In the beginning I was wary and very sceptical but open to learning more about the possibilities of psycho-measurements. In retrospect, I see that in adopting the neuropsychological tool, I was perhaps over-zealous, projecting too much hope into ‘measurement’, too eager to believe in the answers that I thought the measurement would bring. The psychometric factoids, although hoped to bring good news for me, can demonstrably also generate bad news. The measurements inadvertently create a schism of (dis)empowerment and labelling between those who use the tool on the ‘Other’, and the ‘Other’ themselves (McMahon 2013).

Nevertheless, psychiatric science and its magical digits and quantitative methods cannot be ignored. In trying to find a sound measurement tool; to bring to life the magical proof of numbers in diagnosis – psychiatry relies on measurement, statistics, pie graphs, and bar graphs. These digits and graphs can be understood as cultural artefacts or factoids. Statistics illustrate the kaleidoscopic phenomena of mental illness. The illuminations of measurement facts enable the mental health facts to develop a social life (Lea: 2008: 128).
Measurements legitimising diagnosis seem to create a space of proximity where it is possible to negotiate and exchange between and within the socio-cultural structure, and this is embedded in the many persuasions of power control and comprehension from which they came. This space for legitimising measurements is important as it provides some cognition, some proximity, for negotiation between cultural artefacts and factoids and scientific relics (Kowal 2006; Lea 2008). To make this space workable, there must be some proximity in the connection between what is the phenomena of the measured and the unmeasurable. What is defined as within the realms of the measurable and the unmeasurable? That is, discovering an understanding between what is science and how this relates to non-science? For example, looking at the cultural artefact, and if or how there is space for an understanding of science, and how and why it is significant. Thus, some space is possibly available to measure the unmeasurable.

5. **Critical theory**

The main theory covered by this thesis is critical theory involving (post)colonialism. Other theories briefly discussed in this thesis are structural-functionalism, Marxism, postmodernism and poststructuralism. An important theorist used in this analysis is Michel Foucault (1926-1984).
Critical theory is more emancipatory than the explanatory postmodernism and poststructuralism. As well, critical theory aims to understand the social construction of reality. Other theories, apart from (post)colonialism, classified as critical theory are feminist theory, queer theory and possibly neo-Marxism. Foucault argues, each of these theories work to empower the Other through analyses of the historical production of prejudice and their social-cultural-political *a priori* assumptions. The awareness of present-day madness as a part of its theoretical basis in today’s modern social science, is accomplished by a certain analysis of modernity, which is situated from the start in the temporal, historical and social context (Foucault 1967: 201).

The main theorist I have used to analyse my thesis is Michel Foucault. Studying his work, gave me a heightened perception and conception for a study such as this. His insight helped me to understand better power relations, knowledge production and archiving, histology, critical theory
and (post)colonial theory. The labelling marked in this study can be explained via the negotiations of cultural artefacts, and how they are utilised to silence or amplify the voices of those consumed in the powerful cultural windmill of cultural infrastructure. Again, the Silenced Manifesto is placed here, that is by giving a voice to the disempowered within the discourse of the cultural infrastructure.

6. (Post)colonialism

To explore the anthropology of (post)colonialism, and the culture that precipitates the labeling and definition of the mentally ill as social misfit and deranged, as lacking or in deficit, also precipitates and holds high the values of paternalism and colonialism. Spivak explains how those confined are not fully human. Those living with a major psychotic disorder are essentially bantered around between being colonised, decolonised and then re-colonised (Spivak 1990, 1998; Smith 1999). To extrapolate from Kowal’s argument (2006; 2008), the banter between the colonised and the colonisers in Indigenous health can be likened to the banter between the mentally ill and the mental health professionals and the politics engaged.

For the most part, those who advocate and insist on canonical forms of doing and writing research are advocating a White, masculine, heterosexual, middle/upper-classed, Christian, able-bodied perspective. Following these conventions, a researcher not only disregards other ways of knowing but also implies that other ways necessarily are unsatisfactory and invalid. Autoethnography, on the other hand, expands and opens a wider lens on the world, eschewing
rigid definitions of what constitutes meaningful and useful research. As such, writing personal stories can also be therapeutic for participants and readers.

Measurement may be likened to a tool of (post)colonialism (Smith 1999: 6, 23). Many distinct populations, including the mentally ill, have experienced colonialism in various ways (Smith 1999: 144). Diagnosis and labelling are (post)colonialist actions (Smith 1999: 26). Those labelled as mentally ill, or non-white, or female are historically not granted the status of fully human. Some of us are not even considered partially human. Ideas about what counted as human in association with the power to define people as human or not human were already encoded in imperialism and called colonial discourses (Smith 1999: 27). As Audre Lorde stated, “[The] Master’s tools cannot bring down the master’s house” (Smith 1999).

The practice of measuring the mentally unwell can be likened to (post)colonial practice (Smith 1999). How do the mental health professionals measure the seemingly unmeasurable? Some perspectives on these are addressed in my medical notes. There are no completely reliable and valid measures to assess mental health participants, and there are certainly not reliable and exact measures to direct treatment. Due to being so uncertain, I must question whether my illness is valid in its assessment and diagnosis.

The concept of the Silenced Manifesto depicts a relationship between the colonised and coloniser. This relationship is covert and surreptitious, and hidden from the public societal vernacular. This is very much part of the relationship between those living with a major psychotic disorder and those who govern them. The coloniser, Us, have assumed power and/or
have negotiated power over the mentally ill, the colonised Other. The Other are dependent on the coloniser. Data begets knowledge which begets power, which begets knowledge, which begets data. The coloniser’s agenda is to use tools of measurement, psychometric tools in this case, as political technologies and artefacts which are entwined and essential to governance. Us work to further enable cultural artefacts to become commodified, another avenue where power can be won. The Silenced Manifesto connects the Us and Other, strongly, firmly yet in privacy and silence. The measurements developed from a technology of knowledge production to object of governance (O’Farrell 2005), may be used by Us to have power and colonise the Other.

7. **Silenced Manifesto**

The negotiations between the colonisers and the colonised may also be understood by engaging with the concept of the ‘Silenced Manifesto’. The ‘silenced’, the colonised, are disempowered and stifled by the coloniser, be it through education, policy and politics, economics, and the power play precipitated in the (post)colonial culture and space between the coloniser and the colonised. The colonised are governed by the manifesto discourse and mandates of the colonisers, in this case, biomedical science.
The Silenced Manifesto allows for a space, a (post)colonial space, constructed by the colonised. It is a space where there is a possible commensurability between the heard and the silenced. A space that acknowledges the relationship between coloniser/colonised, and the production of coloniser resources, knowledge and power, that is conceding according to the colonisers manifesto. The Silenced Manifesto allows for the development of such a space. These advances coalesce as (post)colonial logic (Kowal 2006).

I have negated a traditional detailed discourse analysis, but in turn have provided an insight into the culture of mental health, the labelling of the mentally ill and societal norms with the concept of the Silenced Manifesto. The Silenced Manifesto positions the discussion in the (post)colonial space using (post)colonial logic (Kowal 2006) which can supply a more complex and profound analysis and perspective. The manifesto perpetuates the cultures of politics, economics, histology and science. I have included the concept of the Silenced Manifesto, to make more apparent the powered narrative between coloniser and colonised.
An Australian national health policy and program, the NDIS, holds the values of individual choice and control in high regard. The NDIS, also used in mental health, mandates person centred and directed care, creating a discourse which develops a manifesto, which in turn fuels an arm of governance. Along with the sustenance that the manifesto gains from governance, it secures solidarity and power from bureaucracy. Bureaucracy as such becomes a cultural artefact, which further feeds into the vernacular and again, the drive of the manifesto.

In this case, the power of the manifesto doesn’t always corroborate and substantiate the disempowered, that is those living with a psychotic illness. The voice of the mentally ill are silenced by governance, its cultural artefacts for instance bureaucracy, and its discourse. They do not speak the same language. The voice of the mentally ill are overpowered and disempowered; it is hidden; it is silenced.

I have created an anthropological study of living with a mental illness. Specifically, an autoethnography of living with schizoaffective disorder, looking at the way I have been labelled as a lesser human, with an understanding that labelling is part of the culture which encompasses it.
It seems ironic that although I fight being labelled and stigmatised, I have developed habits of buying into the disempowerment bestowed on me. Today, I negotiated with a nurse about my need to be admitted to a psychiatric ward – the Ward C (private) mentioned in chapter eight. The psychiatrist was keen for me to be admitted so that my medications may be tweaked, two medications. The first medication I am taking is of a high dose and needs to be reduced. Similarly, my psychiatrist states that my cognitive functioning would improve if I am taken off the second drug. These medication changes I am told will have little cost or effect to my mental health. The nurse stated that I will most probably be in hospital for two weeks.

I spoke about this probable hospitalisation with a friend. He suggested that I am allowing myself to be disempowered by the bio-medical model. He stated that I should do what is therapeutic for me, possibly minimising the time spent in the hospital and more time in the more therapeutic environment as my community – with my friends and family. This cannot be avoided. But without realising it, I have disempowered myself. Indeed, the culture that perpetuates everything bad as depicted in this thesis: the labelling, measuring, and stigma, is the same culture that has caught me up, in the name of bio-medicine and science, of which I am subject to. Even though I fight against being part of the disempowering discourse, there is a strong sense in me that finds peace, solace and safety in being admitted to the Ward C (private).

In my experience, I have been a pawn in the power game of mental health service delivery and have not always been able to negotiate my freedom. If the overarching structure is the culture of a society, then I am a slave to our culture. In this thesis, I have carefully explored the enigma of living with schizoaffective disorder, and being labelled a subhuman, sub-citizen and/or a social
misfit. Then I explored the culture that precipitates the labelling. I hoped to explore this mysterious and unfathomable culture. Like a true anthropologist, I was most interested in culture.

Partly due to my own undoing, I feel conflicted. I feel crushed. Can’t I be a whole person? Although with what the noises say and what I hear others say, real or not, with all the pressure, I am now convinced I am disabled. I am coming to believe that I am all the labels people are bestowing on me. I am lacking. I am stupid. I am powerless. I am silenced. And I am blind - “There are eyes everywhere. No blind spots left. What shall we dream of when everything becomes visible? We'll dream of being blind” (Virilio 1977)

How and why has living with schizoaffective disorder affected my life? Perhaps because my diagnosis has de-railed what is important to me. Living with schizoaffective disorder has disempowered me as my values are based on social justice - individual agency, virtue and equality for all. My agency is now severely limited. I can be detained if I am deemed to be unwell, or not in my right mind. Whilst I can understand the hegemonic logic, it still does not feel decent or moral to me. Under such a regime, I feel it is unjust, unequal, and even paternalistic in the governance of ‘caring’ for someone living with a major psychotic illness. So, my life expectancy, quality of life, agency, and self-determination are all questionable, disputed, and dubious. Whereas, my profound feelings of personal shame and inadequacy are intensely impenetrable for me.

There must also be more room for a more thorough analysis of the data sourced from Foucault or Marx. For instance, as per Foucault (c. 1977), “from the idea that the self is not given to us, I
think there is only one practical consequence: we must create ourselves as a work of art.” We must embrace the art of autoethnography. One issue that needs exploring is Foucault’s historical situatedness.

Avenues of analysis must be explored within the combination of culture and economics and politics and governance – and how these phenomena become commodities. However, there must be more depth to the analysis than concluding that commodities and resources are the major causes for all ramifications and difficulties in the theory and practice of mental health. (Post)colonialism must be explored further.

I suppose in many ways my focus should be to communicate well the cultural issues involved in schizoaffective disorder, between the individual experience and the broader socio-cultural terrain, including the situatedness of ideas and experience. Then the (post)colonial condition may be able to offer hope for peaceful coexistence in the post-colony (Kowal 2006).

I am stupid!

I am disabled!

The mental health professionals use techniques of measurement, diagnosis and treatment to stake a claim on the way the mentally ill should live. The mentally ill – Other – not always privy to the sanctity of medical knowledge, have little choice than to trust the deified mental health professionals. Factoids are socio-political technologies which aid, for instance, in the
governmentality of power structures. Note, however, that power structures negotiate, command and influence in whichever name you give the paradigm. For example, the paradigm of (post)colonialism may be extrapolated here. So much is riding on the use of measurement. Measurement therefore benefits service providers, or colonisers, to give power to and sanction the socio-cultural, political and economically produced entity. Some may say that the purpose of measurement is its validation of (post)colonialism.

I cannot separate my mental illness from my person, despite my every effort. I am absolutely pathologised! My measurements support this dependence. I am handicapped. I am disempowered. I am named and determined by the colonisers. The biomedical colonisers associate with the richness and power of the cultural artefacts, factoids. Biomedical agents are colonisers, identified with the spectrum of what is mental health, such as governance and bureaucracy, and the various mental health professionals. Yet I cry for help from the colonisers when I am unwell and desperate.

I will always live with schizoaffective disorder.

I would rather live a shorter life than live in the hell of insanity.

The only reaction I must have is that I am absolutely gutted. Thoroughly. Completely.

I am branded by the Silenced Manifesto.
CHAPTER FOURTEEN

GLOSSARY

Agency: Within Sociology, self-determination or free will (Denzin & Lincoln 2015: 340).

Alienation: As identified by Karl Marx, the condition of workers who feel estranged from themselves or society due to lack of power, control, fulfilment, and satisfaction. Marx attributed this to capitalist society, where the means of production are privately owned (Denzin & Lincoln 2015: 340).

Autoethnography: A young Anthropological methodology that focuses on the self (‘auto’) and ethnography’ the study of culture. There is a sample size of one. All interchanges and interrelations, including notes on power relations, are performed through the eyes of the researcher (Adams, Jones & Ellis 2015).

Biomedicine: A conceptual body of illness that excludes psychology and social factors, while focusing on the scientific of biology scientific factors (Free Dictionary 2020).

Bourgeoisie: In Marxist theory, the social class of people that owns the means of production (Denzin & Lincoln 2015: 340).

Brain: The objective bodily organ that is in control of all cerebral functioning such as processing rationality, thoughts and senses.
Bureaucracy: Defined by Max Weber as a system of organisation that is characterised by a hierarchy of rule-bound officials. Bureaucracies are arguably socialised entities that create a structure of people. According to Lea (2008), government bureaucracies are cultural manifestations which create their own facts, or ‘cultural artefacts’ to legitimate and validate their position. For example, the work that bureaucrats do can arguably create and actually perpetuate and strengthen the meta policy of ‘Close the Gap’ rather than emancipating those the policy was designed for. This can be called the ‘magic of bureaucracy’ (Simonton 2015: 340).

Confinement: In Madness and Civilisation (1961) Foucault describes a movement across Europe in the seventeenth century which saw the establishment of institutions which locked up people who were deemed to be ‘unreasonable’. This included not only mad people, but the unemployed, single mothers, defrocked priests, failed suicides, heretics, prostitutes, debauchees in short anyone who was deemed to be socially unproductive or disruptive. He labels this movement the ‘Great Confinement’. He continues his study of confinement in his history of the birth of the prison, Discipline and Punish (1982) (Foucault in Farrell, C. 2020).

Crazy/craziness: A term made in jest for the mentally ill to introduce and provoke and request another level of understanding of what it is like living with a major psychotic disorder. I use this term to invite poetic quip into the discussion. The liberty of using poetic licence through humour, as permitted with the methodology of autoethnography, provides a more complex and multifaceted understanding of the experience of living with schizoaffective disorder. Indeed, by using the term ‘crazy’, I am also labelling the mentally ill as with the terms sub-human, sub-citizen and social misfit. A premise of this autoethnography is that it is a reappropriation.

Critical theory: Which includes queer theory and feminism, critical theory encompasses theories that seek to deconstruct the hegemonic theories, and in doing so disempower the powerful (often
referred to as and colonisers) and empower the powerless (often referred to as colonised). Critical theory is an emancipatory theory (Bronner 2011).

**Culture:** The languages, customs, knowledge, beliefs and norms that combine to make up the way of society. May also refer to the arts (such as music, theatre, literature and so on) (Geertz 1973).

**Discourse:** In general use, communication in speech or writing; in sociological use, a framework or system of ideas that provides a perspective on life and governs the way it can be discussed. Discourse imparts a meaning to events, and varies in different eras, geographical areas, and within social groups (Simonton 2015: 340-241). Discourse is a rather slippery notion in Foucault’s work but at the most basic level he uses the term to refer to the material verbal traces left by history. He also uses it to describe a certain ‘way of speaking’ (Foucault 1972).

**Discourse analysis:** Discourse analysis (DA) is a type of discourse analytical research that primarily studies the social power dynamics of culture through text and talk. The power dynamics are enacted, reproduced, and resisted by text and talk in the social and political context. DA represents the analysis of the social structure (Dunn & Eble 2015).

**Economic determinism:** A materialistic view of history which claims that economic forces cause all social phenomena and the evolution of human society (Simonton 2015: 341).

**Episteme:** This term, which Foucault introduces in his book *The Order of Things* (1966), refers to the orderly ‘unconsciousness’ structures underlying the production of scientific knowledge in a particular time and place. It is the ‘epistemological field’ which forms the conditions of possibility for knowledge in a given time and place. It has often been compared to T.S. Kuhn’s notion of paradigm (Kuhn 1962).
**Feminism:** A social movement that advocates the social, political and economic equality of the sexes. Feminism is recognised as having had several ‘waves’, or eras, each with a different agenda of issues (Simonton 2015: 341).

**Foucauldian power:**

- Power is not a thing but a relation

- Power is not simply repressive, but it is productive

- Power is not simply a property of the State. Power is not something that is exclusively localised in government and the State (which is not an universal essence). Rather, power is exercised throughout the social body.

- Power operates at the most micro levels of social relations. In fact, power is omnipresent at every level of the social body

- The exercise of power is strategic and war-like. (Foucault 1983) (Simonton 2015).

**Full citizen:** For an individual to be able to participate fully, in sound mind and body, in the political and economic spheres of society, so that the individual may have control or influence over the resources that affect his/her own life.

**Full human:** For an individual to be in full capacity of themselves, including of sound mind and body, to take control of the resources that affect his/her life. This includes full capacity within an individual’s existential, cultural, social and spiritual context.

**Gaze:** Foucault uses the word to refer to the fact that it is not just the object of knowledge, the person gazed upon, which is constructed, but also the knower. Clinical medicine at the end of
the eighteenth century set much more on visibility – on looking and seeing and on visible symptoms (Jennifer Reinhardt 2020).

“If thou gaze long into an abyss, the abyss will also gaze into thee” (Nietzsche: 1886 “Beyond Good and Evil”).

**Governmentality:** Foucault originally used the term ‘governmentality’ to describe a particular way of administering populations in modern European history with the context of the rise of the idea of the State. He later expanded his definition to encompass the techniques and procedures which are designed to govern the conduct of both individuals and populations at every level not just the administrative or political level. In consideration of history and politics, measurement can go on to deliberate the issue of governmentality (Foucault in Farrell, C. 2020).

**History:** Foucault’s entire philosophy assumes that human knowledge and existence are situated and profoundly linked in history. He argues that what is most human about man is his history. He discusses the notions of history, change and historical method at some length at various points in his career. He uses history as a means of demonstrating that there is no such thing as historical necessity, that things could have been and could be otherwise (Foucault 1961, 1963, 1969).

**Historical a priori:** This is the order underlying any given culture at any given period of history. Foucault also uses the phrase the ‘positive unconscious of knowledge’ to refer to the same idea. The episteme which describes scientific forms of knowledge is a subset of this (Foucault in Farrell, C. 2020).

**History and historiography:** Foucault’s entire philosophy assumes that human knowledge and existence are profoundly historical. He argues that what is most human about man is his history. He discusses the notions of history, change and historical method at some length at various points in his career (Foucault in Farrell, C. 2020).
**Homo economicus**: In relation to the individual’s structural and functional position within the economy (Chen 2019).

**Insanity**: Doing the same thing over and over again and expecting different results (Albert Einstein).

**Madness**: The state of having a serious mental illness; extremely foolish behaviour; a state of wild or chaotic activity. More of a historical term that developed over the last century and a half. A value-laden term, a cultural term with prejudice undertones for the mentally ill.

**Marxism**: A structural theory of society...[where] social change arises out of conflict between social classes, that is, the owners of the means of production, and the exploited working classes (Simonton 2015: 342). There is a strong correlation between Marxism and *homo economicus*, where the individual’s identity is bound by economics and the politico-cultural principles it is structured by. Foucault is well known for his controversial statements in 1966 that “Marxism exists in nineteenth century thought like a fish in water: that is unable to breathe anywhere else” and that it was a mere “storm...in a children’s paddling pool” (Foucault’s *The Order of Things* 1966: 262). For a brief period of time after 1968 Foucault’s comments on Marxism as a form of political activity became more favourable. He subsequently returned to his earlier views on the historical specificity of Marxism and to criticisms of the inflated claims made by Marxists in relation to Marxists in relation to Marx’s work. As Simonton (2015: 29) states, “Modern society has two great classes: the industry-owning bourgeoisie and the proletariat”.

**Measurement**: An act that explores, validates and seeks to gain reliability for an outcome. In this context, the significance of measurement in psychiatry aims to qualify and quantify the validation and accountability of services. It is also a way of gauging the individual’s mental health status and changes that treatment may or may not have instigated. In this discussion, measurement may be related to mental health to other forms of prejudice like racism and sexism.
**Mental illness:** A mental illness is a health problem that significantly affects how a person thinks, behaves and interacts with other people. It is diagnosed according to standardised criteria. Mental illnesses are of different types and degrees of severity. Some of the major types are:

- anxiety
- schizophrenia
- schizoaffective disorder
- bipolar mood disorder
- personality disorder
- eating disorders
- depression
- psycho-social disorder
- post traumatic stress disorder.

**Mind:** the philosophic and socialised subjective entity that encompasses all functions just like the brain. This includes rationality, thoughts and processing of the senses. The mind has a cultural entity where it is subject to judgements of values and norms.

**Othering/Us:** to view or treat (a person or group of people) as intrinsically different from and alien to oneself. The difference is a power dynamic between ‘us’, the economical and political powerful, and the ‘other’, definably the disempowered, somewhat dependent on ‘us’. In the instance of this thesis, the “othered” are the mentally ill, and “us” are those representatives of the cultural schema that perpetuates the view of ‘Otheredness’. The ‘us’ in this case are primarily the mental health professionals (Said 1978).

**Politics:** the structure which encompasses the systems, laws, culture, discourse, internal and external power plays, influencing the actions and policies of a government or getting and keeping
power in a government. The work or jobs of people within the political sphere are included, such as elected officials, who are part of a government. Also, the opinions that an individual or group has about what should be done by governments. Finally, politics is about person’s political thoughts and opinions (Merriam Webster 2020).

**Positivism:** Within sociology, the idea pioneered by Auguste Comte, that it is possible to observe social life in a measurable, verifiable and scientific way to establish truth about society. This belief gave rise to the ‘positivist’ opinion that science could build a better world (Simonton 2015: 342).

**(Post)colonialism:** Colonial existence which entails the taking over of the governance of the State, whereby the citizens are subjugated and disempowered under the powerful existing hegemony (Said 1978). The concept and process of mental illness service delivery can be likened to colonialism (Smith 1999). (Post)colonialism implies an end to colonialism. As Aboriginal activist Bobbi Sykes has asked “What? Post colonialism? Have they left?” (Smith 1999: 25)

**Postmodernism:** A perspective that denies there can be a defining “truth” about anything, instead suggesting that a text, person or society can be deconstructed according to many different ‘truths’. By its nature, postmodern social theory rejects being defined and is difficult to define Appignanesi, et al (2005).

**Poststructuralism:** Closely aligned to postmodernism, but perhaps also reactive to it by negating the importance of all social theorising, not limiting social analysis just to multiple truths. In reaction to exploring and negating, the nature of structuralism is known by deconstructing it. There are no macro-universal truths, nor micro nor nano-truths. Social power play is rife, which brings to light the nuances of the social in practice and the social in theory, if there is an actual
difference between the two. For a short time, Foucault claimed to be a post structuralist (Foucault in O’Farrell 2007).

**Power – knowledge:** One of the most important features of Foucault’s view is that mechanisms of power produce different types of knowledge which collate information of people’s activities and existence. The knowledge gathered in this way further reinforces exercises of power. Foucault refutes the idea that he makes the claim ‘knowledge is power’ and says that he is interested in studying the complex relations between power and knowledge without saying they are the same thing (Foucault in O’Farrell 2007).

**Psychiatry** - a specialist form of bio-medicine. A scientific bio-medical model of the workings of the brain. Treatment prescribed by psychiatrists tends to be bio-chemical, with inclusion of talking therapies and allied health.

**Psychologist** – the psychologist works with the functioning of the mind/brain, commonly those with psycho-social disorders. In Australia, to become a psychologist it is customary to hold a Masters degree in a related subject to psychology. Also, a psychologist often claims to be scientific stemming from the bio-medical model which relies heavily on behaviour change and development through talking therapies, and in conglomeration with other allied health professionals, for a more holistic treatment. Sometimes psychologists working closely with psychiatrists, other times they do not work so closely. (The Australian Psychological Society 2020).

**Psychosis** – thoughts, feelings, behaviours that distort reality.

**Relationship:** a connection, association, or involvement (Cambridge Dictionary 2020).
Rigour – a term to indicate that the issues raised by the concepts of validity and reliability are important in qualitative research. The onus is on the researcher to deal with their participants with integrity, honesty and fairness (Liamputtong & Ezzy: 1999: 38, 43).

Queer theory: A cultural theory that challenging binary notions of sexuality and instead suggests that sexualities are in part cultural constructs influenced by time and space (Simonton 2015: 343).

Science: The observation, identification, description, experimental investigation, and theoretical explanation of phenomena (Free Dictionary 2020).

Sectioning: involuntary admission when it is likely for the individual to cause harm of self-harm to the others because of the illness or be of mental or physical deterioration (The Australian Human Rights Commission 1992).

Self: the evaluation by oneself of one's worth as an individual in distinction from one's interpersonal or social roles (Simonton 2015: 343).

Silenced Manifesto: I have founded, established, created and built the concept of the Silenced Manifesto.

Social misfit/deviant: a behaviour or type aof person deemed ‘rule breaking’ in terms of the norms of a particular society or social group (Kleinman 1980). A social misfit is a person who does not fit into society. There is no room for them. They do not adhere to the public values and behaviour of the socially kept and powerful. They are rejected and not tolerated. Their behaviour is labelled as anti-social. They are outcasts of society. It is not uncommon that people living with a mental illness, with their anti-social behaviour are homeless – and thus rather public. Those who do not want to have their space infiltrated by anti-social behaviour do not want to see the mentally ill homeless person in their public. They label such people as social misfits, and
commonly the social misfits are admitted to psychiatric wards. They are silenced and hidden by the mental health system. Where else are they to go?

**Social Structure:** The social institutions and relationships that form the framework of a society (Simonton 2015: 343).

**Society:** the structure and functioning that brings a group together making a meaningful group of individuals. “Society is not a mere sum of individuals. Rather, the system formed by their association represents a specific reality which has its own characteristics” (Simonton 2015: 37).

**State:** Foucault argues that the State is a codification of relations of power at all level across the social body. It is a concept which provides a “scheme of intelligibility of whole group of already established institutions and realities”. Further, “the State is a practice not a thing”. Foucault emphasises that the State is not the primary sources of power (Foucault 2004: 282).

**Stigma:** A mark of disgrace or an undesirable characteristic, physical or social, that disqualifies an individual from being fully accepted by society. The marginalising of individuals in society, because they evoke negative responses from others, have been attributed (Goffman 1963).

**Structuralism:** The idea that we must understand – such as a text, human mind or society – by examining the elements, or pattern of relationships, in its structure (Dreyfus & Rabinow 1982).

**Sub-citizen:** Sub-citizens, very similar to sub-humans, who do not participate fully as citizens of the state, for example, sub-citizens do not fully contribute to society politically or economically. The notion of sub-citizen is in relation to the state or nation.

**Sub-human:** Sub-humans are defined as those not granted full human status in society in that they are deemed to lack the capacity to participate in society. They display behaviour that is antisocial, going against what is the norm of social behaviour.
**Systems:** The socio-cultural, political, economic, religious and/or environmental structures all connected by language in some sense of the word.

**Theory:** Framework, or ‘lens’ through which to understand phenomena.

**Us/Othering:** to view or treat (a person or group of people) as intrinsically different from and alien to oneself. The difference is a power dynamic between “us”, the economic and political powerful, and the ‘other’, definably the disempowered, somewhat dependent on ‘us’. In the instance of this thesis, the ‘othered’ are the mentally ill, and ‘us’ are those representatives of the cultural schema that perpetuates the view of ‘otheredness’. The ‘us’ in this case are primarily the mental health professionals (Said 1978).
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