



MONASH University

***Balancing ‘me’: Managing the self through  
bipolar disorder***

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## Abstract

Bipolar disorder affects a significant number of people world-wide, and due to its polarised characteristics, is difficult to diagnose and treat. When experiencing the manic side of the condition, people are often vulnerable as they enter into risk-taking adventures that are disruptive to life. The depressive side of the disorder is also an impediment because of its debilitating effect, sometimes resulting in suicide. While there has been more recent clinical research into improving diagnosis and management for people with bipolar disorder, there has been a paucity of sociological interest in the abilities of people affected by bipolar disorder to obtain diagnosis and manage the condition.

Addressing this lacuna, this Australian study sought to investigate how people with bipolar disorder are able to determine when to seek help, obtain diagnosis and engage in self-determining management practises, including the use of the internet. Since there has been a wide-spread and burgeoning public use of the internet for general health related information, the extent of the usefulness of the internet for people with bipolar disorder was also investigated.

The analytical framework for the study has drawn upon theoretical concepts of Michel Foucault and Nikolas Rose, specifically around ideas relating to biomedicine, individual autonomy, and the care of the self. Using a qualitative grounded methodological framework, data were collected from three different sources as a way of meeting rigour through triangulation. Data for the study were drawn from 10 face-to-face interviews with people who had been diagnosed with bipolar disorder, and were conducted within Melbourne, Australia. In addition, 12 online narrative testimonies about bipolar disorder were downloaded from the Black Dog Institute. The Black Dog Institute is a not-for-profit organisation, based in

Sydney, Australia that has clinical, research, and social interests in mood disorders. A third selection adding to the data sets comprised 3 conversation threads, bearing the largest contributor interest and most relevance to bipolar disorder, which were downloaded from the SANE Australia chat forum for mental health and illness. SANE Australia is a not-for-profit organisation with interests in mental health and illness promotion. The data was coded for analysis using the NVivo program for qualitative social research.

Results showed that the length of time it took to clinically diagnose bipolar disorder, shaped the way participants engaged with the internet which was found to be most useful for finding diagnostic information. Most participants were able to find internet sites that offered scientific descriptions of bipolar disorder, and they were confident that they could use the information to self-diagnose or present sufficient information about themselves to the clinic to assist with the diagnostic outcome. Participants were able to assess the internet site content based on their beliefs about authoritative scientific affiliation, such as the auspices of a university, or site claims about scientifically accredited information sourced. Information about treatment for bipolar disorder was more difficult to find and assess, and put into effect. While information about pharmaceutical treatment for bipolar disorder could be checked online, participants needed to engage with the clinic for medication balancing, largely due to the variation in individual experiences, and the unpredictability of the disorder associated with intermittent episodes. Engaging in the internet helped form rapport within the clinic between patient and doctor. 'Expertise' gained from the clinic remained the main source of information, the internet being a way of fact-checking clinical knowledge. Due to persistent difficulties with balancing moods in bipolar disorder, 'expertise' was also drawn upon through the use of alternative medicines and therapies. Such management choices made by participants were due to the need to maintain a balanced life, and depended upon engagement with the clinic and the care of the self. Where medication side-effects were serious, reliance

upon the care of the self, using self-disciplined management regimens, was possible, and a preferred method of maintaining the balance in life.

Experiential information was sought through the internet for help with management regimens, but because there is not a one-for-all type of medication or management regimen for bipolar disorder, this was difficult to find. Searching the World Wide Web was challenging as it was difficult for participants to locate another person with a closely matching symptomatic identity. However, experiential information about bipolar disorder was shared within the SANE Australia chat forum. The site also provided peer support and helped form in-group identity. Within group identities there was shared experience that helped people negotiate issues around being 'normal' and having a problem. Conversely, interview participants expressed more confidence in group support, obtained through meeting people in reality, rather than through the virtual experience of online chat.

Within a contemporary society, where individual autonomy is a part of life, responsibilities for taking care of the self are demanding, and sometimes impossible for people with bipolar disorder. Where diagnosis and treatment options are clinically difficult to determine, adding to the self-management difficulties, the internet was a valuable tool for information and support for people with bipolar disorder. Whether engaging with the clinic, using the internet or joining face-to-face groups, participants for this study expressed the importance of controlling mood swings and balancing their lives. Participants showed ability in being able to successfully engage with the internet, and also showed much understanding about, and determination for finding and maintaining a balanced life.

## **Declaration**

This thesis contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

A solid black rectangular box used to redact the signature of the author.

Signature:

Diana H. Murray

Date: 23<sup>rd</sup> March, 2018

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## **Praeludium**

Recently, I found an article posted online that revealed that a group of scientists, who had all suffered some form of mental disorder, had been investigating the possibility of a link between creativity and high intelligence, and the stereotypical idea of the ‘tortured genius’ or the ‘mad scientist’ (Hsu, 2012). As an example of these investigations, the article also gave mention to ‘bipolar sufferer’ Kay Redfield Jamison, a clinical psychologist and professor at Johns Hopkins University School of Medicine. Professor Jamison had stated that there had been some 20 to 30 scientific studies that confirmed the idea that ‘genius’ and ‘madness’ were linked (Hsu, 2012).

I found the article interesting as my own awareness of social discourses about such things had often caused me to wonder about the lives of people afflicted with more serious mental illnesses. I wondered about what they had to endure, but also thought about whether, in fact, they did relish certain parts of their illness that they believed served their creativity and intellect. In other words, in order to be possessed by their creativity, what must they experience in life that caused them to feel, as the article suggested, ‘tortured’?

Upon further perusal of the internet I found much argument about the differences between some serious mental illnesses, and whether certain celebrities, past or present, suffered from schizophrenia or bipolar disorder. Much of this debate and subsequent indecision had arisen due to the association of the disorders with psychosis, so often related to confused or ‘tormented’ minds. This caused me to remember artist Vincent Van Gogh, his prolific and extraordinary creativity, and its much discussed link to his madness. It would appear that whatever it is about the mind that is responsible for extraordinary creativity, it is also capable

of thoughts that often lead to extraordinary actions such as suicide. In the life of Vincent Van Gogh, there was much creativity, and yet, there was trauma and a short life ending in suicide. Through the imagery represented in his art, it could be argued, that Van Gogh did, in fact, suffer from a serious mental illness. For example, Van Gogh often painted wheat fields, and this picture could be interpreted to represent light from the sun and, therefore, life. In this picture, titled 'The Sower' (Kroller-Muller Museum, Otterlo), the sower is skipping across the field and the birds are reaping whatever they can get. In the distance, there is a ripe field ready for the pick. This whole picture has sun, warmth and light and life about it.



'The Sower', Google Images, Van Gogh paintings, accessed 20<sup>th</sup> November, 2017.

And yet, the gloomy mood of this second scene, titled 'Starry Night' (The Museum of Modern Art, New York), may well indicate that there was an opposite side, or pole, directing the thinking of Vincent Van Gogh. It is dark, somewhat chaotic, since the stars, along with the clouds are in abnormal flight; and the moon has a semi-abstract halo around it, possibly representing the shepherds' warning or the threatening storm of mania.



‘Starry Night’, Google Images, Van Gogh paintings, accessed 20<sup>th</sup> November, 2017.

Without any doubt, these two pictures represent very different moods where one might say the artist was thinking about the goodness of life and being on top of the world on the one hand, and reflecting his tormented or gloomy mind on the other. In any case, the online Van Gogh Gallery has claimed that the driving force for Van Gogh’s ‘extreme enthusiasm and dedication’ and the ‘pace of his art production’ was due to mania (Van Gogh Gallery, Van Gogh’s mental and physical health, para. 2). The claim that Van Gogh had bipolar disorder was also reinforced due to the fact that these manic characteristics were ‘always followed by exhaustion and depression and ultimately suicide’, confirming the mood swings associated with the disorder (Van Gogh Gallery, Van Gogh’s mental and physical health, para. 2).

Van Gogh died in Auvers-sur-Oise, France, from a self-inflicted gunshot wound, after a long period of physical and mental illness. His date of death was 29<sup>th</sup> July, 1890, having lived only a short life from his birth date, in Holland, of 30<sup>th</sup> March, 1853 (Purse 2017; also see Martin 2010b). Van Gogh never married although he was believed to have had two ‘serious relationships’ (Purse 2017, para. 1). His working life was also punctuated with uncertainty. First, he worked as an apprentice for his uncle in an art gallery in The Hague. He then worked

for an international art gallery until he was ‘fired’ (Purse 2017, para. 2). Van Gogh then became a preacher, a career he engaged in so zealously that his behavior brought about his dismissal (Purse 2017). It would seem that his temperament had not been suitable for carrying out his employers’ job prescriptions. Thus, reaching normal life expectations about maintaining personal relationships and employment could not be achieved for Van Gogh.

Van Gogh’s prolific and deeply considered artistry has caused some critiques of the genius and mental illness theory to argue that he did not have any serious mental disorder, but suffered from stress caused by Parisian life (Martin 2010b). However, in the same stroke of writing, the argument becomes spurious when Van Gogh’s psychiatric troubles are revealed in letters researched (for example, Martin 2010b). Soon after leaving Paris to seek a more relaxed environment in a country village, Van Gogh suffered his first mental breakdown when he cut off his lower ear lobe. He was admitted to the Hotel-Dieu Hospital. A year later he was admitted to Saint-Remy asylum. Van Gogh then moved to Auvers-sur-oise in the countryside where, he was under the care of the local physician, nevertheless ending his life (Martin 2010b).

Van Gogh only had ten years in which to accomplish all of his art works. Due to his insomnia, he claimed to have slept with camphor under his pillow, possibly with no relief. In fact, it was most likely that the insomnia was associated with bipolar disorder, and that enabled him to complete 200 paintings and 100 works on paper within the space of fourteen months (see Martin 2010b). Van Gogh only sold one art work in his life, but he is now one of the most popular artists of all time (The Art Story, an online educational art site for the general public). Van Gogh’s work has been described as ‘emotionally evocative’ and has

been accredited to have influenced artists and movements during the last century and continuing today. The artist's sensitivity has been claimed by critics to be captured within each painting, as a result of having been created through his 'eyes, mind and heart' (The Art Story). As Van Gogh summed it up himself, written in a letter to his brother that was found in his pocket after his death, 'Ah, well, I risk my life for my own work and my reason has half foundered in it' (Martin 2010b, p. 630).

## Chapter 1 Introduction

When I started my PhD in February 2015, I knew very little about bipolar disorder, but my previous interest in serious mental illness and its possible association with creativity and intelligence had inspired me to learn more. Rediscovering the life of Van Gogh, through the internet, has confirmed for me that discourse linking serious mental illness with creativity and ‘genius’ is still in circulation. Speculation continues about what kind of mental disorder Van Gogh did suffer from. Attempts to scientifically analyse the available historical evidence around Van Gogh’s genius and mental illness may be found in academic articles published as a result of the work of some psychiatrists. Since around the early 1960s (see for example, Hemphill (1961) Monroe (1978) and Strik (1997)), psychiatrists were already arguing for a diagnosis for Van Gogh of cycloid psychosis, episodic psychotic reactions, or manic depression. The argument for Van Gogh’s unstable life and his creativity are more recently being associated with the possibility that he did, in fact, suffer from bipolar disorder (see Hsu 2012).

Apart from the very much acclaimed link to creativity and ‘genius’, bipolar disorder is a mental illness that bears negative consequences in terms of social and economic losses. People with bipolar disorder have given descriptions of their mania as being ‘mortifying’ after the event, since they are prone to personally uncharacteristic behaviours such as ‘one night stands’, engaging with prostitution, over spending, being dictatorial towards people – all characteristics defined as being responsible for putting reputation at risk (Parker 2007, p. 240). Such descriptions of bipolar disorder that outlined the very different perspectives of living with the condition aroused my interest and I embarked upon this study. I wanted to know how people with the condition may learn to manage the part of it that is uncharacteristic of themselves, and continue to pursue beneficial traits such as creativity.

I therefore, began my investigation by acquiring some facts and figures about bipolar disorder, which I give due attention herein. Further contemplation moved me towards considering a study paradigm that would allow me to gain some insight into the lives of people with bipolar disorder. The analyses from data collected about the social interactions and personal challenges for people with bipolar disorder then formed the core chapters for this thesis.

### **1.1. What is bipolar disorder?**

Bipolar disorder is a category of mental disorder that has a life-long chronicity, and is life-impairing (Inder et al. 2011, p. 428). According to Phillips & Kupfer (2013), bipolar disorder is usually noted in early adulthood and is persistent throughout a life time. Its ‘abnormal cognitions, beliefs and experiences’ were first categorised by one founder of modern psychiatry, Emil Kraepelin, as ‘manic-depressive psychosis’ (Phillips & Kupfer 2013, p. 1663). The condition may be described as having two poles which are in opposition and consist of episodes of mania at one end and depression at the other (Mitchell 2013). The Diagnostic and Statistical Manual, version 5 (DSM-V, 2013), the most widely used manual for psychiatric classifications and diagnosis, describes bipolar disorder as two typologies – Bipolar I and Bipolar II. According to Parker (2007), to make a distinction between Bipolar I and II disorders, the intensity of the manic ‘highs’ must be greater for Bipolar I, to the point where they may include psychotic features. These ‘highs’ tend to last longer and may even need hospitalisation (Parker 2007). For Bipolar II, the hypomanic ‘highs’ are less severe and are not associated with psychosis. These ‘highs’ are not necessarily impairing and may be experienced as enjoyable (Parker 2007). The depressive side to the disorder is severe and impairing, increasing the risk of suicide for both Bipolar I and II; however, for Bipolar I there

is the tendency to develop psychotic depression (Parker 2007). The oscillation periods for Bipolar I tend to be longer-lasting but with longer intermission between episodes, whilst for Bipolar II the mood changes are swifter and more frequently occurring (Parker 2007).

Merikangas, Jin and He (2011) found that there was a need to emphasise the importance of detecting bipolar disorder in young people because of its early development, chronicity and its effect upon social development, and educational and occupational outcomes. Large scale surveys conducted across the Americas, Europe and Asia have found respondents reporting severe and role impairing symptoms for depression and mania, being 74% of respondents for depression and 50% of respondents for mania (Merikangas, Jin and He 2011). Bipolar disorder has been found to be comorbid with other conditions such as anxiety disorders and panic attacks, and the development of substance use disorders, such as alcohol and illicit drugs (Merikangas, Jin and He 2011). As bipolar disorder affects individuals by way of experiences of fluctuations or changes in mood, it tends to also affect the ways in which people perceive themselves, and also how other people perceive them, thus affecting personality and social identity (Inder et al. 2008, pp. 123,128).

Bipolar I and II disorders affect an aggregate world population of 1.2 per cent of people with a life-time prevalence of as much as 3.3 per cent in the United States (US) and with a further possible subthreshold bipolar cases around 4 per cent to 6 per cent (Merikangas, Jin and He 2011; cited also in DSM-V). In Australia, statistics recorded for affective (mood) disorders show bipolar disorder at 1.8 per cent (Australian Bureau of Statistics [ABS] 2008).

Mitchell (2013) states, bipolar disorder, which may be managed within the primary care setting, is one of the most treatable of all psychiatric disorders. However, bipolar disorder is not curable, it can only be managed (Parker 2007). Nevertheless, treatment within the primary care setting presents problems and challenges for the general practitioner (GP). For example, bipolar disorder has been found to be one of the most psychiatrically difficult conditions to diagnose with misdiagnosis of the condition occurring in 60% of patients who usually present for depression (Phillips & Kupfer 2013; Correa et al. 2010, pp. 12-13; Lloyd et al. 2011, p. 154). As Phillips & Kupfer (2013) have shown, Bipolar II is especially difficult to differentiate from recurrent depressive episodes, and is often mistaken for unipolar depression. This is often the case because depression has the higher prevalence, making subthreshold hypomanic or manic symptoms less likely to be detected (Phillips & Kupfer 2013). Diagnostic difficulties arise where there is no clear history of mania or hypomania, and because patients tend to present during the recurrent depressive episodes (Phillips & Kupfer 2013). Management difficulties have occurred because of the unpredictable episodic frequencies, patient lack of insight during manic episodes, and patient non-adherence to medications (Mitchell 2013; Johnson et al. 2007, pp. 549-551). And yet, as Mitchell (2013) argues, treatment is important because of its potential for substantial increases to patient functioning and life opportunities.

## **1.2. The theoretical stance – individual autonomy, care of the self and bipolar disorder**

When inquiring about their wellbeing, individuals come to the clinic, expecting diagnosis and treatment – the action of becoming a medical subject. In advanced liberal societies, where individual autonomy is encouraged and practised, becoming subjects of medicalisation

presents opportunities for negotiations to be made between the self, the clinic, and the society. For people with a mental condition such as bipolar disorder, such action, practised in the autonomous care of the self, may be difficult to do. In the first instance, detecting that there is a problem, that is, that their personhood is different from the norm, maybe hard to realise and, therefore, be a deterrent for help-seeking. After accepting a diagnosis, further problems may arise that are related to the recognition of onset of mood disorders that need to be controlled. Being in control of the self usually comprises a complex form of negotiations with the self and the social world within which there is a need to contribute. Experiencing the impaired self often means that people are unable to meet social expectations around work, family, friends and personal ideas of self-fulfilment. Since there are choices about the ways in which to take care of the self and achieve control of moods, people with bipolar disorder maybe in constant flux between being subjects of power/knowledge and using individual autonomy to engage in systems of knowledge that enable them to take care of themselves. Both Michel Foucault and Nikolas Rose have written extensively around this, and, therefore, I have used their concepts to unpack the ways in which people with bipolar disorder engage in social systems of power and individual autonomy, social attitudes towards mental illness, medicalisation in contemporary society, and the technologies of the self (Foucault 1982, 1984, 1988, 2004; Rose 1993, 2001, 2016; Rabinow & Rose 2003). These concepts have been important to understanding how social responsibilities associated with autonomy may be advantageous or disadvantageous to people with bipolar disorder. In addition, Foucauldian concepts related to 'trust' have been used, particularly with regard to interrogating internet use for people with bipolar disorder (Foucault 2001), and the concept of 'strategic freedom' in relation to how people negotiate their lives through individual autonomy and social institutions (Foucault 1984 in interview).

### **1.3. Conceptualising the study and finding the gap**

Given the above information about the characteristics of bipolar disorder, such as its chronicity, life impairment, life threatening symptoms, and the clinical difficulties with diagnosis and treatment, the benefits of the internet were considered. Under consideration was the global accessibility of the internet and its capacity to house information, and reveal social discourses. It was, therefore, considered that the internet might be a useful tool for people with bipolar disorder to gain sufficient information that would help them where clinical experiences had not been able to guarantee successful management of their condition.

There has been very little sociological inquiry into internet usage for people with bipolar disorder. A study by Depp et al. (2009) used a web-based survey tool, to conduct a survey through a large consumer organisation that was providing information about depression and bipolar disorder. Depp et al. (2009) found the US site attracted approximately 101,500 hits per month. The site was giving information about diagnosis and management of bipolar disorder, and the results showed that large numbers of people had been using the site for diagnostic and management information (Depp et al. 2009, p. 183). Other studies about more generalised health-seeking practices have found that in the new millennium there has been an increasing and ubiquitous use of internet media for seeking health information and participating in online support groups (Laing, Hogg & Winkelman 2004; Parikh & Huniewicz 2015). Recent online polls and research conducted in the US and United Kingdom (UK) on public health-seeking internet use have recorded public usages of 80% and 71% respectively (Wald, Dube & Anthony 2007; Kelly, Jenkinson & Ziebland 2013). Surveys, conducted in both the US and UK, have also found that the majority of people who use the

internet for medical information search for information about a specific condition (McMullan 2006). In Australia, the Better Evaluation and Care of Health (BEACH, 2014) study of general practice activity found that of 2,944 patients surveyed, 63.4% patients accessed the internet one month prior to the survey, 28.1% of those patients sought health information online, and 17.1% patients sought information online about a condition being managed by their general practitioner (Wong et al. 2014, p.875-6).

Considering the recent online activities for searching health information, and the paucity of sociological investigation about internet use for people with bipolar disorder, this study was conceptualised to investigate what kind of benefits people with bipolar disorder might derive from engaging with the internet. Therefore, discourse found within internet sites about the disorder was analysed to assess the type of internet use needed and engaged in by people with bipolar disorder. Exploring a life through the written online narrative provided insight for the study through peoples' intention to spread messages of help and support. In addition online chat was a way of seeing how people shared information through conversation in text.

Online chat and personal testimonies were analysed, together with lived personal experiences (through interview) to triangulate written text and spoken word. The mixture of data sets was then used to unpack the kind of interrelationships that were being formed through the internet as well as the said experience, and what affect this might have upon people with bipolar disorder being able to manage their lives.

The literature review found that much of the research into internet health information had been largely concerning physical disease, with fewer examples that have looked into mental health related internet use. For example, Salonen, Ryhanen & Leino-Kilpi (2014) and Ziebland (2004) studied the internet and cancer, Leibling (2009) neurodegenerative conditions

like Parkinson's disease, and Yen et al. (2011) and Banjanin et al. (2015) 'mild' mental illnesses such as depression. To date there has been a paucity of in-depth research into self-management that has focussed on internet use in relation to any specific, serious mental disorder, including bipolar disorder. A small amount of research on internet use and schizophrenia, for example, a study by Zaja et al. (2017) has focussed on individuals' reasons for using schizophrenia internet forums; and, Spinzy et al. (2012) has focussed on the use of blogs for schizophrenia. Most relevant to this study's focus of inquiry has been a study by Schrank et al. (2010) about the advantages and disadvantages of using the internet, based on the views of people with schizophrenia. To date, no in-depth study has been published about how people with bipolar disorder engage with the internet for self-management, including accessing information and engaging in group support.

Therefore, to begin with, I reviewed literature pertaining to self-management of health and illness, commencing with a history of social expectations around self-management and the episteme of it. An overview by Lorig & Holman (2003) has shown that much literature has pointed to the benefits experienced for patients who were instructed by their physicians in practices of self-management. In addition, I found information about fiscal benefits to health-care systems that gave greater incentive to social developments towards individual's health self-management. These, more recent trends have led to what Nikolas Rose (2014, pp. 150-51) termed the 'enterprising' individual, who 'aspire[s] to autonomy, and seeks out information in the care of the self'.

The idea of the 'enterprising' self has been derived from reforms to the health care systems in the Western world, including Australia, that have largely driven the impetus for individual

responsibility for health care practices. Evidence, in Australia, of the drive for individual autonomy in health care may be found through the Australian Government Department of Health document titled 'Promoting autonomy and self-determination' (Department of Health, 2013). This document outlines mental health policy that is aimed at, for example, (i) a person's 'right to exercise self-determination' (para. 1) that emphasises the protection of the mentally ill patient from coercion, (ii) promoting recovery, based on information sourced from lived experience, and (iii) promoting agency through the respect for individual choice (Department of Health, 2013). In addition to such ethical issues, economic interests have driven government interests in the promotion of self-determination. As Fullagar (2002) has noted, using heart disease as an example, the Australian government found the cheapest way to promote health and lessen the possibilities of individuals succumbing to heart disease was to encourage patient self-determination through campaigns promoting physical exercise. Such campaigns were designed to place the responsibility onto the individual to keep fit, with the effect of lessening government health expenditure (Fullagar 2002); also see Petersen and Lupton (1996), explaining the responsible citizen's right to be healthy and obligation to relieve others of any 'burden'.

According to Segal (1998), health policy research began around the turn of the millennium about how to create the 'informed consumer' as a part of a market-driven health services reform. Much of this policy has been driven by collaborative political processes that may have been intended as a social cost-cutting exercise, but, in fact, may not have been so beneficial to the individual due to 'vested interests' and 'entrenched social inequalities' (Segal 1998, p. 42; Greenhalgh 2009, p.8). The political processes referred to were pertaining to competition-driven cost-effective strategies that have incorporated governments, private health insurances and private practice health care that tend to favour certain individuals and

procedures over others. Such literature has been concerned with driving the idea of self-management for institutional fiscal benefits, based on a push for patient autonomy that has become a legal and moral right (see also Rice 2001; Greenhalgh 2009; Schramme 2015; Kekewich 2014).

However, as for most of the literature, these studies do not address people's cognitive abilities and how they might be able to self-manage, including locating and interpreting information found through the internet. Therefore, the question is posed: How are individuals with mental conditions like bipolar disorder able to enact social policies that reinforce individual autonomy? How might they be disadvantaged or receive benefit through engaging in taking care of themselves, including through internet help-seeking?

Considering the research already conducted into concepts around practices of self-management, I sought to investigate the use of the internet in self-management practices. Therefore, I reviewed the literature pertaining to practises of seeking health information online. Through this search, I found literature about the democratising effect of the internet and its relationship to the 'enterprising' individual where it is said to have 'empowered' individuals by providing them with information about health and illness conditions. Much of this literature discussed developments in clinical and consumer (patient) relationships due to the sharing of information that was argued to have changed the status of the medical profession as the sole owner of information (for example, Hardey 1999; Blumenthal 2002; Laing, Hogg & Winkleman 2004; Broom 2005). Largely, it has been found that the internet has become a means of sharing information through experiential knowledge, now used to extend, if not question, 'expert' knowledge. Since such studies were not directed towards

knowledge gained by people with bipolar disorder, I wanted to know what kind of interactions the internet might generate between these individuals and their medical practitioners.

Some of the literature discussed how far people were able to select safe and secure information, and also the pitfalls to online health information seeking, such as misleading information, emotive language and spurious navigation technologies (Kortum, Edwards & Richard-Kortum 2008; Thompson 2012; Mager 2009; Ziebland & Wyke 2012). Other studies explored health literacy skills, based on education levels, and how people are able to assess the quality of information as being scientific (Davis & Wolf 2004; Thomm & Broome 2011). However, none of this literature referred to people with bipolar disorder and how they may be able to access information about their condition. Nevertheless, some existing literature revealed a problem with ‘rationalities’ and how people with bipolar disorder could possibly self-manage when confronted with parts of their lives that were considered to be irrational (for example, Weiner 2011; Martin 2007). However, this particular literature was not concerned with how people with bipolar disorder might ‘rationally’ and discriminately engage with the internet.

Thus, thinking around Foucauldian concepts of the technologies of the self and power relationships, it was foreseen that enterprising individuals might use strategies that enable negotiations of power between individuals and institutions, such as the medical clinic and the internet. Therefore, this study has been designed to expand upon existing literature around self-management and individual use of the internet for health seeking information. However, the study differs quite distinctly from other research in that it focusses upon people with

bipolar disorder, their life experiences and how far the internet proved valuable to their experiences as autonomous individuals engaged in self-management.

#### **1.4. The aims of the research**

At present, the internet as a source of health information and online health communication, presents difficulties and challenges to both the consumer and the medical profession.

Nevertheless, its growing ubiquity in everyday life compels a critical examination of how it informs the illness experience and healthcare journey of people living with serious mental illness such as bipolar disorder. To date much of the literature has focussed on the internet and physical illnesses (as cited above). Less has been written about the internet and severe mental illness, in particular bipolar disorder, and several questions remain outstanding. How is information about severe mental illness, such as bipolar disorder, exchanged between individuals through the internet? How does the internet mediate how individuals with severe mental illness interrelate with their professionals? How is the internet re/shaping power dynamics between the medical professional as the ‘expert’ and the individual with bipolar disorder? How would any of these interactions matter in the self-management of bipolar disorder? In answer to these questions, this thesis aimed to:

- Investigate what type of discourse people with a diagnosed bipolar disorder are engaging in through the internet.
- Investigate in what ways the internet is ‘democratising’ and ‘empowering’ to people with bipolar disorder.
- Inquire about the ways in which engagement with the internet for people with bipolar disorder might affect their clinical experience.

This thesis begins with the literature review (Chapter 2) which explores the scholarship relating to the idea and development of health self-management, and the subsequent changes to medical and institutional thinking due to patient autonomy; the idea of the internet as a democratic way of sharing information and the consequential ‘empowerment’ of the patient; the effect of the internet empowered-patient upon the clinical experience; in addition, the downfalls of the internet and the capabilities of people in detecting problems with internet.

Chapter 3 presents an outline of the theoretical background drawing on the works of Michel Foucault and Nikolas Rose. Relevant concepts from their works include the ‘medical gaze’, which was a social construction recognised to have allowed medicine to pervade the lives of people (Conrad, 2007, p.13). The medical ‘gaze’ was used by Foucault in his work *The birth of the clinic* to explain the practise of power/knowledge within the medical profession and the relationship between the clinical setting and the patient (Foucault 2014). Recognising Foucault’s theses of the post-modern era, I then selected his concepts that were more applicable to the contemporary era, and taken up by Rose, to explain how individuals interact with institutions in a ‘set of power relationships’ (Rose 2001, p. 9). This was important because individuals are no longer ‘docile’ or submissive subjects of the medical ‘gaze’, but are constantly engaging in, through the media and other institutional resources, practices of choice for personal enhancement and wellbeing. People are, in fact, embedded in a set of power relationships or practices of ‘strategic freedom’ that entail engaging in individual autonomy while negotiating with social institutions and using technologies of the self and self-surveillance (Foucault 1988, p. 18; Rose 1996, pp. 26, 29; Foucault 1995, pp. 201-03).

As described in some detail in Chapter 4, the methodological framework used for the research, and the development of the thesis has been based on a qualitative grounded theory approach. Within a qualitative framework the focus of the inquiry is confined to a specific topic that allows the researcher to explore in some detail and depth the experiences and feelings of those under investigation (see Berg 1998, p. 7; Dworkin 2012; Charmaz 1990). In this case, using a qualitative paradigm has provided a tool through which to analyse the experiences and perceptions of people with a bipolar disorder as situated within their own particular social setting, including their interaction with the internet.

Chapter 5 is about life experiences that led to diagnosis, and was inspired, initially, by a conversation thread found at the SANE Australia chat site, with the opening question: ‘When asked, “do you hear voices?” I said, “Yes, doesn’t everybody?”’. Within this conversation thread, people were discussing their symptoms within the context of clinical consultations and how to decide what is ‘normal’. In this chapter, I used theory about biopolitics and social and medical problematising of ‘normal’ within a biomedical model of illness (Rose 1996, p. 25; Lemke 2001; Jones 2003; Jaye, Egan & Parker 2006; Foucault 1988). Within the biomedical model, there was a problem to be encountered by the participants because of their personal considerations about ‘reality’ and what was ‘truth’, sociologically recognised to be two contentious concepts (Searle 1995, pp. 1-29). This led to some discussion around what Weiner (2011) has argued, concerning the ‘paradoxical forms of agency’ where the person with a bipolar disorder is expected to be able to discern whether they are acting irrationally or rationally (see Weiner 2011, p. 465). When experiencing mania participants were unlikely to see themselves as being irrational, directing the investigative thinking for this chapter around reality, truth, and the responsibilities encumbered by practices of individual autonomy. This

chapter expands on the ideas of agency and rationality and explores how participants came to recognise that there is a problem and seek to achieve diagnosis as a response to the problem.

Chapter 6 is about the management of bipolar disorder and is based largely on the Foucauldian concept of ‘mastering the self’ and the use of pharmaceutical treatments (Foucault 1987, p. 117, in interview). The choice of concept is drawn from the idea that in the twenty-first century, people are used to using pharmaceutical treatments for self-enhancement to achieve the maximum of personal social contribution (Jenkins 2010, p. 17). As autonomous contributors to society, people exercise personal responsibilities for the care of the self by choosing certain techniques or tools of self-management that are meant to enhance feelings about ‘happiness, purity, wisdom, perfection, or immortality’ (Foucault 1988, p. 18; Rose 1996, p. 29). However, since the analysis for this study revealed that participants found the act of mastering the self to be difficult and sometimes impossible to achieve, it has been more useful to apply the additional Foucauldian concept of ‘strategic freedom’ (see Clifford 2001, p. 137; also Foucault 1984, in interview). When engaging in ‘strategic freedom’, normative social practises of self-management mean that personal freedoms need to be measured against moral and personal judgments about controlling harmful or socially-undesired behaviours. The chapter sets out the various ways in which participants used their knowledge about themselves to make choices about what personal controls are necessary and when to use them.

Chapter 7 expands on the concept of ‘strategic freedom’ in that it discusses how the participants are individuals who may choose the ways in which they should live their lives. However, the right to be free, comes with obligations to find a balance to life that also means

balancing identities associated with changing personality traits. Exercising the right of the autonomous individual for each participant, therefore, meant that some personal negotiations needed to be made. Such negotiations were required in an effort to retain or create a ‘true’ personal identity while controlling problematic behaviours, and deciding how to do so through the use of ‘natural’ therapies, as complimentary to, or without, pharmaceutical treatments.

This chapter discusses the difficulties with finding a balance to life for participants. This, in fact, needed constant self-surveillance because of the unpredictable mood swings of the condition that lie dormant, but are sure to arise causing disruption to life. Some participants claimed that accepting the biomedical approach to bipolar disorder meant transferring their ‘true’ identity to the identity of the treated condition. Loss of identity and ideas about pharmaceutical control and the need to use complementary and alternative therapies/medicines then became a part of the discussion of the chapter. The chapter is important to the thesis because it demonstrates how people may move away from the pharmaceutical approach to self-management and engage in ‘natural’ therapies. It also highlights the importance of a balanced life and its association with feelings about retaining a ‘true’ and stable identity.

Chapter 8 discusses how people with bipolar disorder use the internet. Pursuing the idea of the social obligation for the individual to perform the ‘moral duty’ to enter into the ‘culture of search’, I used the concept of *parrhesia* (fearless speech) to explore and define how successfully people with a bipolar disorder are able to engage with the internet (Hillis, Petit & Jarrett 2012, p. 1-5; Foucault 2001). Further to the Foucauldian concept of the ‘technologies

of the self', and included in these, is the practice of *parrhesia*. The practice of *parrhesia* (derived from ancient Greek philosophy) requires that the speaker tells the 'truth' about the self in order to engage in rapport with the listener who must also respectfully use the 'truth' in response. The concept uses ideas such as 'navigation' towards the truth, 'courage', 'risk' and 'reflexivity' as a pedagogical means of acquiring a beneficial 'care of the self', while engaging in the use of the 'touchstone' for measuring the truth of the object (Foucault 2001, pp. 15-16, 91-9, 111). These concepts were used to explain how participants navigated the internet and were able to make judgments about the trustworthiness of sites to be used as important resources in the practice of the technologies of the self. This chapter has been important to the thesis because it has revealed how the internet may be beneficial to both the clinic and the personal experiences of people with a bipolar disorder. It answers much of the critique found in the literature review because it argues in favour of internet use for the practises of the technologies of the self.

The penultimate Chapter 9 discusses the limitations of the research, including the scope of the work, and the intrinsic limits to using a qualitative research paradigm with a purposive sampling method. Within the limitations are demographic concerns such as confining the data collection to specific online content such as the selected testimonies, the SANE Australia chat site content, and a small sample of interview participants. This has meant that the selection of age, gender, socio-economic status, cultural diversity, and education levels could not be controlled and sorted evenly by the researcher. There are further limitations related to facets of control – one pertaining to the control of web sites over the content accessed through the internet, and the other is concerned with the researcher control over the data collected.

When selecting data from internet site content, the sampling is limited by the type of discourse found within the chosen internet sites. When interviewing, using semi-guided

questions, the data collection is narrowed to the focus of the inquiry, as initially designed by the researcher. Nevertheless, upon further reflection, there were positive results for the researcher through careful conduct during interview, resulting in the rich data collected. There was also much to be gained through the use of triangulation of data sets in that each set brought a different perspective to the data collection procedure and the analysis of the research.

Chapter 10 concludes the thesis. This chapter begins by revisiting the question of ‘what is normal?’ The chapter explains that somewhere in the participants’ lives they arrived at a point of needing to know how to make an assessment about being ‘normal’. Such assessments were driven by the consequences of mania, but, initially by depression. Working out what ‘normal’ is can also be driven by social events and clinical questions about hearing voices being linked to symptoms that indicate bipolar disorder. Further discussion is about establishing a diagnosis for bipolar disorder, and this includes the deterrents common in the delay of clinical diagnosis related to the disorder. This is followed by the reasons participants gave for going to the internet to speed up the diagnostic process. After diagnosis had been reached, participants engaged in making autonomous decisions about their treatment, using the internet to check on medications, and seek out others’ experiential knowledge. The chapter summarises the paradoxical nature of deciding to be the ‘pharmaceutical self’ through the choice to use medications as prescribed within the professional clinic or hospital. Further discussion is made about the choice to engage in using ‘natural’ treatments because of the participant preference for the self-regulation found to be beneficial for achieving a balanced life. For participants, the personal investment in work needed to bring about a balanced life was found to be due to inefficacies of pharmaceutical treatments that do not constantly control mood swings. Participants engaged in more self-determination as they tried to

manage their lives using necessary complementary treatments. Using the complementary treatments also was found to be an aid to preserving identities due to reducing side-effects caused by pharmaceutical treatments.

A final note has been made about the personal responsibilities and social obligations around being autonomous individuals within contemporary society. This is because this study found that in exercising agency as autonomous individuals, participants encountered difficulties with keeping levels of personal commitment. The difficulties of this task could be found mainly through participant expressions about practising being 'normal' through keeping a balance to life at all times. Maintaining normality or rationality for participants was found to be hard work; it required much self-reflection, and continual dedication in the management of mood swings – in other words, encapsulating this finding has revealed that living with bipolar disorder means enacting a superb performance of the Foucauldian technologies of the self.

## **Chapter 2 Literature Review**

### **2.1. Introduction: Challenges that lie within individual autonomy**

To address the research questions, academic data bases were searched to find out what kind of research was available concerning discourse pertaining to bipolar disorder and internet use. In particular, information on the ways in which people with bipolar disorder may be engaging in mental health management was searched. This information was required for the purpose of assessing the current status of the person with bipolar disorder as an autonomous individual, the internet as a means of informing patients, and any differences this might have upon the clinical experience. In fact, much of the literature has concerned physical disease with fewer examples that have looked into mental health and internet use. Therefore, the relevance of the literature to this study is in the critique around individual self-management and how the internet is used by people for gaining health information. While there have been benefits found from using the internet, such as provisions for anonymity, and instant access to knowledge, also noted were the pitfalls, especially where reliance on accurate information is mandatory for understanding and responsibly managing one's own health.

Within this context, issues arise about trust in internet sites for delivering accurate information; challenges affecting relationships between the medical profession and the patient, reliability of information, the safety of using online chat sites, and the ability of people to be able to make rational, informed choices about what kind of information to take away and how to use it. I begin with an explanation of how the concept of self-management in health has become a medical and sociological issue within the contemporary Western society. Second, I discuss how people enact empowerment to find solutions through the use of the internet. Third, I discuss some 'truths' about the internet highlighting problems

encountered due to individual educational levels and interpretative abilities as well as some of the technical problems always present within the internet. Finally, I outline the research gaps identified in the literature and give a guide to how this study, with its scope located in a specific mental health condition, aims to provide more information about how people with bipolar disorder are able to use the internet to self-manage.

Before embarking upon the discussion of the literature review, I draw attention to the fact that the existing literature has been collected in view of the scope of the research design. That is, the literature has been selected according to discussion based on the biomedically-defined criteria used to define illness, mental illness, or physical illness. Within this scope, the overview of the literature has been considered, with its critique, because of its relevance to the study of the lived experiences of people with a diagnosed bipolar disorder. In this respect, the researcher recognises, from a sociological viewpoint, that diagnoses are made as a result of sociocultural forces, including medicine, that shape the ways in which people come to be included in such definitions. As a result of this type of study, with its medicalised orientation, the research has been positioned with a critical lens on lived experiences within and without the medicalised condition, with medicine as the pivotal point.

## **2.2. A brief outline of the development of health self-management**

The term 'self-management' has become widely accepted and critically interrogated in the health social science and clinical literature (see, for example, Segal 1998; Lorig & Holman 2003; Lemire, Sicotte & Pare 2008; Lawn, McMillan & Pulvirenti 2011 and Brijnath & Antoniadis 2016). The idea of self-management is not new with the term having been used as far back as the 1960s. It was then used to describe the ways in which medical experts

instructed their patients to manage a chronic condition. Lorig & Holman (2003) found much to applaud about self-management programs that were being implemented by doctors for their patients. For example, improvements had been noted by physicians in patient behaviours towards the care of the self as a result of better clinical communications, which in turn have encouraged good self-management practices, and ultimately, a reduction in symptoms for patients (Lorig & Holman 2003).

Later, self-management became intertwined with organisational and fiscal problems escalating within health care systems, as well as the need for individuals to maximise their personal potential and contribute more efficiently to social economies. As Rose (1996) wrote, the need for the individual to take part in maximising social economies has led to a culture of individual 'enterprise'. Being 'enterprising' means that the individual must drive the self towards accomplishing practices of good self-management to maximise personal efficacy. Subsequently, such practices have been accredited to having bestowed individuals with a form of personal 'empowerment' – a term also applicable with reference to the internet (see Lemire, Sicotte & Pare 2008; Pare et al. 2009, p. 5-13). 'Empowerment' has been understood to be the 'personal involvement' and 'responsibility' taken up by individuals towards the management of their health, and has been promoted as being representative of better power relationships between patients and doctors, contributing to more efficient health management (Lemire, Sicotte & Pare 2008; Anderson 1996). Lemire, Sicotte and Pare (2008) found that 'empowerment' could be achieved through a system of logics including 'expert knowledge', being an active agent, making informed decisions through engaging with resources, and learning through social interaction (Lemire, Sicotte & Pare 2008, pp. 131-2, 134).

The idea of self-management and individual empowerment became more important as governments became aware of the escalation in health care costs and inefficiencies in the health system that created an economic burden on the public purse. The argument goes that fiscally irresponsible policies have generated inefficiencies within health systems and have failed to supply efficient quality healthcare to the consumer in the face of growing market supply and demand (Segal 1998; Anderson 1996). Academic, general societal, and political arguments, based on such lines, have mainly been about the need to foster good self-management for the purpose of easing the responsibility/burden of health systems. The outcome of these concerns has meant that the responsibility for health care should lie within the capabilities of the individual who must know when, how and where to seek health-related advice. However, such knowledges have become determined by the status of each consumer within what has become a competition-driven health market that is subject to often inadequate and inequitable health supply systems (Segal 1998; Brijnath & Antoniadis 2016). For example, in Australia, Brijnath & Antoniadis (2016) found that the health system tended to rely upon the patient's ability to find their own mental health care as there was no satisfactory provision for helping the patient to find the right kind of clinician for their needs, leaving patients to spend much of their time trying to find suitable specialists. In addition, people on middle to low income levels found the cost of specialists (psychologists and psychiatrists) too great, and where individuals sought fully rebated costs there would be a longer waiting period (Brijnath & Antoniadis 2016). As Segal (1998) argued, it is apparent that the health care market has not been able to comply with economics designed to be competitive by delivering responsive supply, as there is inefficiency between supply and demand (Segal 1998). Furthermore, as Greenhalgh (2009) argued, changing policies in health care in some Western societies, apart from contributing to patient efficacy, has led to no significant improvement in health outcomes.

Most social research concerning e-health and illness has been about the use of the internet for generalised health problems. Attempts at estimating the prevalence of internet health-seeking information have been validated by Eysenbach & Kohler (2003) who used algorithms to 'harvest', identify and validate health-related searches via a single search engine. This small-scale study served to qualify claims about the ubiquitous use of the internet generally for individual inquiry about health and illness. Kirmayer, Raikhel and Rahimi (2013) compiled a concise history of the development of the internet and provided some ontology related to identities revealed through 'virtual places', 'imagined global communities', internet addiction and the attraction of the internet to groups of people with 'stigmatised' conditions such as mental illness. According to Thompson (2012) the more recent interest in the development of the internet for use in engaging in mental health communication activities follows Western political concerns about health parity with health insurances and the need to improve social discourse about mental health. Public awareness about mental health was thought to be necessary for improving government policy that should include mental health on an equal basis with physical health. For example, in the United States, the Obama administration moved to narrow the disparity between mental health insurance and that for general medical treatments in a bid to uplift and maintain the mental health status within the population. Closing the disparity gap was a measure to avoid economic losses due to individuals being unable to contribute to society through mental illness (Thompson 2012; see also Churchill 2010). Such political discourse about the need to treat mental health problems as less 'insignificant' than they have been treated so far has filtered into the larger society. The discourse created has featured the concerns about lost productivity and the need to attend to mental illness, and has been reproduced through narrative in the public arena, observed most recently on the internet (Thompson 2012).

The position of the internet as servant to government policy, pharmaceutical and psychiatric interests has been explored in a study by Gardner (2007). Health-seeking related internet sites have been created through pharmaceutical interests, health policy and consumer advocacy organisations. Such sites function as web campaigns that have been presented as 'objective' consumer information linked to risk, associated with chemical imbalances within individuals. Consumers are encouraged by the sites to use tests or gauges to assess their risk and to view bio-psychiatric script that creates people as subjects in need of recovery through the imperative to self-manage. These sites use conventions of the narrative around disease, through the voice and images to normalise cultural ideas about risk, responsibility and biotechnical treatment (Gardner 2007).

The internet affords a relatively democratic public sphere compared to other forms of media, and according to Anderson, Rainey and Eysenbach (2003, p.68), the internet may be viewed as a 'democracy' that is, in fact, a 'consumer centric' entity where consumers can be 'publishers' and may receive 'feedback' on their ideas. The 'democratisation' effects being produced by the internet have attracted a significant amount of academic interest concerning the debate about the use of the internet in the self-management of health, lay diagnosis and challenges to the traditional authority of the medical profession (for example, Hardey 1999; Giles & Newbold 2011; Blumenthal 2002; Ziebland 2004; Kirmayer, Raikhel & Rahimi 2013; Wald, Dube & Anthony 2007; Foster 2016; Broom 2005). As Foster (2016) found 'expert knowledge' has transgressed from medical journals and professional consultations to online information resources, and through virtual peer groups that facilitate lay knowledge and experiential expertise. The following section explains more fully how the internet has challenged and changed attitudes and practices of self-management between the clinic and the patient.

### **2.3 Changes to medical thinking and patient attitudes and practises**

In the past, when the experience of the internet was beginning, there was an interesting discrepancy between patient opinions and professional opinions about internet use. From a professional viewpoint, the results from some surveys carried out just before the turn of the millennium in the US concurred that fewer than 40 per cent of doctors thought that the internet was a reliable source of health information, with an American Medical Association survey, at that time, finding only 11 per cent of doctors believing that the internet was useful to patient education (Anderson, Rainey & Eysenbach 2003). The reasons given for the professional dissent was that doctors viewed the internet to be ‘problematic’, remonstrating concerns about patients with a serious condition who should be seeking professional advice (Anderson, Rainey & Eysenbach 2003). Doctors have generally argued that the internet is not always accurate, often information overloaded, and does not provide the patient with the kind of expertise in medicine required to make their own medication adjustments (see Blumenthal 2002; Broom 2005). At the same time, in an interesting contrast to professional opinions, 70 per cent of consumers using the internet for health information agreed that the ‘empowerment’ that the internet gave them enabled them to make ‘better life choices’ (Anderson, Rainey & Eysenbach 2003, p.78).

As Laing, Hogg and Winkleman (2004) found, the initial advent of internet information brought to the clinic by a patient was often met with professional resentment and contention. Broom (2005, p. 325) and Blumenthal (2002, p. 528) noted there has been much written about patient engagement with the internet and the ways in which information has been used to ‘disrupt the status and power of the medical professional’. Such concerns have contributed to the debate about the ‘proletarianisation’ of the internet and the ‘deprofessionalisation’ of

the medical profession (Broom 2005, pp. 325, 320; Blumenthal 2002, p. 528). Foster (2016) found that the 'embodied' experience of illness forms the experiential knowledge that is shared by people of similar experience and serves to 'enhance a patient's ability to challenge medical expertise' (Foster 2016, p.27). Such arguments have highlighted the ways in which patient engagement with the internet has been attributed to creating new challenges to the medical profession and medical expertise.

Nevertheless, professional support for the well-informed patient has grown. For example, in Australia, Broom (2005) recruited cancer specialists for interview, and found that, contrary to previous opinion supporting the disruptive potential of the internet on the power and status of the medical profession, there was much professional support for the idea of the well-informed patient (Broom 2005). Referring to the internet as the 'information revolution' Blumenthal (2002, pp. 525, 526, 530) used a 'conceptual framework' to assess the effects of information from the internet on the profession of medicine. Blumenthal (2002) found that, contrary to facing the threat of extinction, the medical profession was thought to possess the physical and procedural competence that patients believed they needed to access for good quality health care. Even though the internet was regarded by patients to be an alternative way of accessing medical knowledge, they also viewed it as a way of 'enhancing' their relationships with their medical professionals (Blumenthal 2005, p. 536). In a later study, using semi-structured interview within Switzerland, Caiata-Zufferey et al. (2010, pp. 1051-1054) found that participants placed the 'legitimacy' of the doctors before the internet, using the internet to 'complement the consultation'.

For people with bipolar disorder, challenging the clinical professional may be a part of coming to terms with diagnosis, diagnostic achievement (which is often slow), treatment options associated with depression and mania, and the need to negotiate or retain personal identities. For a condition that is difficult to diagnose and treat, often with physically and mentally impairing side-effects, and fluctuating personality traits, the temptation for the individual to seek information, keeping up with the latest scientific developments, may be gratified through quick internet access. Furthermore, patient experiential knowledge, shared through the internet, may give considerable impetus to the ways in which clinical consultations are viewed by patients, and the trust an individual decides to place in the doctor.

In fact, the responsibility usually given to the doctor for decision-making in treatments may have been somewhat diminished since patient engagement with the internet. Patient trust in doctor decisions may now be tested by what information is brought to the clinic from the internet. Internet information has been thought to be responsible for inspiring the patient to ask questions of the doctor, a practice that has been interpreted by doctors to be 'combative' or a way of challenging the doctor's competency and expertise (Broom 2005, p. 330).

Therefore, new patient practices and expectations have been seen to have had a transforming effect upon the medical power/knowledge status, even to the extent that there is a chance that the doctor may not be needed at all (Hardey 1999; Blumenthal 2002; Broom 2005; see also Kirmayer, Raikhel & Rahimi 2013).

For example, Hardey (1999) found, through qualitative interview, that participants were able to explore the internet and enjoy its 'unregulated' space, a different experience from what the

clinic offered. Space outside of the control of a clinic meant that people could search for alternative treatments and ways of obtaining treatments to health problems where, for example, doctors had not provided them with sufficient information. Online information offered an informed choice to alternative treatment practices for patients, where, for example, osteopaths and homeopaths had not advised the patient about the treatment of pain, or where side-effects had not been talked about (Hardey 1999). Caiata-Zufferey et al. (2010) also found that patients searched the internet where insufficient information had been provided by their doctor. These are examples of the changing doctor/patient hierarchy, where new platforms, consisting of professionals, the internet, and individuals are forming to disrupt the traditional medical professional/patient dynamic. This is similar to what McLean (1995, p. 1056) has referred to as a 'struggle' in power relationships between the medical supplier and the consumer, in this case where the control of options for production and who determines the need for production is no longer solely in the hands of the clinic.

It may be seen, therefore, that the internet offers an opportunity for individuals to be 'empowered', keeping abreast of rapidly changing attitudes towards what clinical knowledge, and experiential knowledge obtained through engaging in world-wide knowledge-flows. In a recent compilation of academic study on the empowerment of the patient, Palumbo (2017) reviewed the significant literature supporting the 'co-production' of health through the doctor/patient relationship, while acknowledging the role of the internet. Furthering the argument of the co-production of health, Blumenthal (2002) argues, doctors who join their patient's internet activities, updating their own information through the internet, will most likely earn patient respect. According to Blumenthal (2002), patients' trust in doctors' advice is based on their beliefs about the cognitive ability of the doctor and their sense of moral duty practised in reaching diagnosis, treating and comforting the patient. If doctors fall short of

these obligations, then patients' beliefs about their value change. Therefore, doctors may also find that gaining respect means using the internet to keep abreast with scientific knowledge (Blumenthal 2002).

#### **2.4. Individual health management and the internet**

Patient autonomy and the availability of the internet has altered the ways in which health information may be accessed, impacting upon medical practice, and has affected the ways in which individuals now manage their health. One of the most important focusses of discussion in the literature was about gaining knowledge for the purposes of health self-management practises (for example, Lemire, Sicotte & Pare 2008; Lawn, McMillan & Pulvirenti 2011; Weiner 2011; Depp et al. 2009, p. 183, and Anderson, Rainey & Eysenbach 2003).

Considering that people, in particular, with a chronic mental condition like bipolar disorder, exercise agency as individuals to search the internet for information, there is considerable concern about the ways in which the information is viewed and selected. Sundar et al. (2011) have identified the link between autonomy and agency required in the selection and customisation of particular information through the internet, at the same time noting the challenges to retrieving specific information, credibility and accuracy (see also Cline & Haynes 2001; Naghieh & Parvizi 2016). Augmenting such challenges, there have been concerns about the ways in which the impact of patient use of the internet may change the strategic practices of health care systems and strategies for the management of the individual within the clinical setting, considered to be important to patient outcomes and institutional efficiencies (Laing, Hogg & Winkleman 2004; Naghieh & Parvizi 2016).

For the purpose of analysing changing practices around health care systems and individuals, particularly as used in Chapters 6 and 7, I have used the concept of ‘strategic freedom’. This concept was found to be important regarding the ways in which people with bipolar disorder, as autonomous individuals, learn to manage their condition. I use the concept of ‘strategic freedom’, as derived from the Foucauldian concept of ‘strategic’ power relationships, in order to explain some of the complexities within systems of self-management practises for people with bipolar disorder. Therefore, a background for understanding the ways in which knowledge is used by individuals, from the clinic and through the internet, has been necessary. Accordingly, the following sections outline how concepts of empowerment, self-management and trust have been used to make strategic choices towards solutions for self-management and better health outcomes:

#### **2.4.1. The internet – at the clinic**

As aforementioned, the tendency has been for health policy to be geared towards health efficiencies within institutions and clinical settings through promoting ‘empowerment’ of the patient. At first, ‘empowerment’ may have been seen to be encouraged through specialist teaching of self-management practices, and the presence of written information distributed within the clinical setting (Lorig & Holman 2003; Davis & Wolf 2004). More recently, patient ‘empowerment’ has been extended and made transparent by the amounts of internet-downloaded literature brought to the clinic (Davis & Wolf 2004). Resources, found through use of the internet, have provided online self-management programs where users have come to perceive themselves as being ‘more competent and in control’ thus fulfilling a sense of personal empowerment (Lemire, Sicotte & Pare 2008, p. 136; Lorig & Holman 2003). However, according to Lemire, Sicotte and Pare (2008) and Adams & de Bont (2007), there

are ambiguities within the term because it cannot be solely attributed to belonging to the individual, and depends upon 'right' choices being made. In other words, there is growing thought that the individual is an integral part of 'strategic' power relations (see Foucault 1987) that involve pharmaceutical enterprises (see Jenkins 2010, p. 6), clinical systems, information resources such as from the clinic and the World Wide Web, and social practices of autonomy and choice.

Studies that have investigated such practises have found some positive effects from patient internet use because of the amount of extra 'expert' knowledge that may be attained. Knowledge brought to the clinic, from the internet, has been found to be responsible for the implementation of strategies being practised between the doctor and patient that, in effect, have resulted in forming doctor/patient partnerships, for example, Hardy (1999); Blumenthal (2002); Laing, Hogg & Winkleman (2004); Broom (2005).

When considering the clinical encounter, it is important to note that most patients seek information through the internet about a specific medical treatment or preventative treatments. As Smith et al. (2015) found, through large scale survey conducted in the US, half their respondents used the internet for information about a specific medical treatment, or to learn about preventative practises. The ability to be able to select and download information from the internet relating to a specific condition has been referred to as a procedure called 'tailoring' (Sundar et al. 2011, p. 188). When 'tailoring', individuals actively seek to glean information about issues that are directly related to their particular interests, needs, and within their own sphere of expertise or understanding (Ziebland 2004; Sundar et al. 2011, pp. 188-9; Cline & Haynes 2001). In fact, 'tailoring' has been found to be

one way in which the doctor/patient relationship has changed, and doctors have recognised the benefits. For example, Broom (2005) found that some specialists encouraged their patients to ‘tailor’ information, providing them with appropriate search engines that would ensure that helpful information was accessed and brought to the clinic. Such ‘empowerment’, bestowed upon the patient, has been claimed to have had a positive effect in changing relationships within the clinical practice (Broom 2005). Nevertheless, it should be noted that ‘tailoring’ information ensures patients download the information that the specialist thinks they should know. In this sense, ‘tailoring’ information does not allow for a broader management experience for the patient, due to limiting the information accessed.

Nevertheless, whether ‘tailoring’ information or seeking health information more broadly, patient knowledge has been acclaimed by some professionals to be beneficial in creating a more efficient clinical encounter. Increased communications between doctor and patient have been noted to contribute to more clinical efficiencies due to better explanations provided by the well-informed patient and enhancing doctor understanding of the patient’s perspective (Sundar et al. 2011, p. 189; Broom 2005; Wald, Dube & Anthony 2007). In addition, better understandings of symptoms and treatments, gained through shared knowledge, have been acknowledged to be more advantageous for the clinic because the responsibility is shared (Broom 2005). Shared responsibility, involving the ‘active’ and ‘well informed’ patient, has been found to have had an effect on an increase in safety during the management of serious disease (Broom 2005, p. 326). In addition, Wald, Dube and Anthony (2007) found that when additional knowledge is gained, quicker, more informed decisions can be made between the professional and patient, leading to more efficient use of clinical time. Time savings to the clinic have been noted to have had a flow-on effect to health institutions as well. For example, McMullan (2006) found that individual trends in online health information-seeking

had also led to a reduction in the number of visits made to the clinic. This savings has resulted in lessening the financial ‘burden’ on national health services (McMullan 2006). It has been argued, therefore, that personal responsibility, through empowerment, ensures the patient greater prospects for a healthy life, at the same time alleviating the over-burdened health system.

#### **2.4.2. Online forums and chatting**

Some studies were about using online forums to gain health knowledge, and support through community interaction. For example, Naslund et al. (2014) and Leimeister, Schweizer and Krcmar (2012) studied the forming of virtual relationships by cancer patients; Stokken & Eikli (2012) studied online self-help groups where like experiences were shared and understood through familiarity; Stokken & Eikli (2012) examined the blend of professional knowledge as accredited to a specialised occupation, and experiential knowledge as gained from living through a problem first hand and exchanged within online self-help groups; Leibing (2009) studied online communities with Parkinson’s disease to make critical evaluation of peoples’ tendency to make judgments about advice regarding pharmaceuticals based on a ‘politics of hope’; Gibson, Sloan & Moncur (2012) studied e-health systems design for enhancing quality of life and reducing social exclusion through online support groups; and Giles & Newbold (2011) used online mental health communities to find how clinical diagnosis and lay diagnosis formed identities.

Only one paper, found at the time of this study - Vayreda & Antaki (2009) - was specifically about people with bipolar disorder and how they engaged within an online forum. The study was based on a public web site for bipolar disorder that was conducted in the Spanish

language (and translated into English by the researchers). This article outlined faults found within online chat sequencing due to ‘mismatching’ of answers to opening questions that led to dubious social support through ‘unsolicited’ advice. The study selected first time entrants to the chat so that they could see what type of replies they received. Conversation analysis revealed the differences between long term bipolar users’ identity and newcomer identity, and, although not made significant within the findings, revealed a hierarchical difference between first time users and established users. This study was very limited to critique about comparisons between rules of conversation between people face-to-face and online, and did not venture to make any other analysis about social interactions within chat forums.

### **2.4.3. Online social (‘tribal’) support**

A characteristic of the internet that cannot be found with a face-to-face encounter, either with a friend, family member, or the clinic, is the anonymity of online communication. The anonymity of the internet may be appealing to people where pseudonyms may be used and no identifying information given. Face-to-face encounters may be difficult where people feel they may not be understood or accepted. Public beliefs about the attachment of personality traits with conditions such as bipolar disorder have been found to have produced emotional responses that are likely to provoke distancing (Ellison, Mason & Scior 2015). For people with bipolar disorder discussing personality traits may be difficult even when they are aware of them. People have found internet community groups useful for finding out how other people have been able to be open about their condition with family and friends, an area often left unattended by professionals (Ziebland 2004).

Working within a proposal to improve internet social networks, Gibson, Sloan and Moncur (2012) outline the importance of internet social support through e-health networks. The authors argued that the internet has the ability to replace the 'natural social network' that is apt to become reduced, through social separation, or made inaccessible through difference such as a 'rare' illness (Gibson, Sloan & Moncur 2012, p. 200). In addition, Ziebland (2004) found that online community is particularly important where a condition is rare because of the reach of the internet, a feature not possible within local face-to-face support groups where people may not be so diverse.

Filling in the needs of marginalised people, internet social networking forms a 'mega-band' of 'support cliques' where social support is received and given (Gibson, Sloan & Moncur 2012). In Australia, information internet sites such as *beyondblue*, SANE Australia and the Black Dog Institute offer people with mental problems a chance to chat about it. As Ziebland & Wyke (2012) found, discussion sites within the internet offer far more than just health information about coping and clinical decision-making. Discussion sites offer a sense of belonging to the 'tribe', offering sympathy through understanding and 'stress buffering' (Gibson, Sloan & Moncur 2012, pp. 200-01).

Internet communications between individuals have been found to be beneficial because of the emotional support that may be offered by contributors. The internet offers a space for sharing information with others that helps with self-management and coping strategies, thus having a two-way effect of benefit. That is, on the one hand benefit may be gained by the person who is needing support for self-management, and on the other hand, benefit has been attributable to a sense of morality derived from individual contributors through being able to help others

online (Ziebland 2004). For example, in a study with cancer patients, Leimeister, Schweizer and Krcmar (2012) showed that emotional support could be beneficial in influencing well-being for patients. Emotional support came from sharing what others have experienced and being able to express empathy (Leimeister, Schweizer & Krcmar 2012; Kelly, Jenkinson & Ziebland 2013). Furthermore, as with the treatment of a cancer patient (see Ziebland 2004), clinical practice, often focussed upon the scientific approach, tends to disregard the emotional experiences a patient may need to deal with, sometimes due to apprehensions resulting from the clinical experience. Clinical practise, where the patient assumes the passive role, and where the doctor takes the responsibility associated with 'expertise', may leave out the emotional needs of the patient. Online communities have been found to have filled this need through sharing information with people who understand through like experiences, and in alleviating personal apprehensions about the condition and how to manage it (Ziebland 2004; Leimeister, Schweizer & Krcmar 2012).

Online communications between individuals may also be beneficial to establishing identity and achieving early diagnosis. In a clinical setting, people may be inhibited about discussing symptoms, preferring to find 'tailored' information anonymously accessed from the internet (Ziebland 2004; see also Hardey 1999). Inhibitions about disclosing symptoms during face-to-face encounters may be driven by patient reluctance to accept a diagnosis or fears about symptoms being disbelieved or not taken seriously by doctors (Giles & Newbold 2011).

Online support is used then to help establish identity as a person with bipolar disorder, and to receive/offer advice about where the individual should be accepted for treatment (Giles & Newbold 2011).

Even when a patient seeks clinical help for something that is worrying to them, internet social networking has been recognised to be useful in providing a discourse that might lead to the early recognition of symptoms and diagnosis (Ziebland 2004). Especially in cases of rare disease where doctors may be unwilling to investigate the case due to the unlikelihood of the condition being present, internet information may be found to be even life-saving. For example, Ziebland (2004, p. 1788) describes how a patient with a rare form of breast cancer joined a chat group to warn others of the impartial attitudes expressed by her professionals when trying to gain a clinical diagnosis, and the need to avoid 'dangerous delays' in diagnosis. Liang et al. (2015, pp. 465-70) set up an online screening test for identifying inflammatory polyarthritis (rheumatoid arthritis) consisting of a questionnaire – which could be taken to be similar to many online self-test questions downloaded through condition-specific sites. The study was able to prove that online question-style tests could detect onset polyarthritis for users, which was then confirmed in consultation with a rheumatologist (Liang et al. 2015, p. 468). However, the small population sample, which when combined with the small prevalence of 1 – 2 per cent, makes it difficult to know how self-testing may prove to be beneficial in early detection (Liang et al. 2014, pp. 468-9). Nevertheless, the idea has helped contribute to the line of investigation for this study because people with bipolar disorder may find online self-testing and shared experiential knowledge helpful since the condition is often diagnosed as depression, leaving manic symptoms unattended. I found no other literature based on studies specifically about chat sites where early recognition and diagnosis of mental illness was claimed to be the consequence of shared knowledge, but Gibson, Sloan and Moncur (2012) and Ziebland (2004) have both acknowledged the benefit of online social networks and social support to those experiencing a rare condition.

Therefore, the internet has provided a space for social inclusion, important for people with rare conditions. The internet may offer support through connecting to the right 'tribe' where family or face-to-face community communication, even within the clinic, may not impart understanding or emotional support due to lack of empathy and lived experience.

Establishing identity and seeking diagnosis may be assisted through online communication with people of like experiences.

## **2.5. Knowledge, trust and problems encountered**

However, while there are many benefits to be gained from online communication and information resources, there are also negative effects to be experienced by individuals. For people with bipolar disorder, having quick access to information may be useful provided it is safe to use. Being able to assess the quality of online information may be imperative to their well-being. So, how far should internet resources be trusted?

### **2.5.1. Truth and visibility of internet sites**

Some studies have been devoted to examining the accuracy of internet sites and also the ways in which people have been accessing them (Kortum, Edwards & Richards-Kortum 2008; Thompson 2012; Mager 2009). These studies have included examining internet websites in relation to the ways in which online information is directed through site links; and the ways in which information is presented to attract consumers, in sometimes misleading and self-interested ways (see Thompson 2012 and Mager 2009). Commercial interests, for example, have been concerned about protecting their sites by employing internet technical abilities that produce prioritised site access, creating visual and contextual messages and linkages that are designed to attract and keep the customer, arguably disabling consumer contact with other

sites (Thompson 2012; Mager 2009). This has been in contrast to not-for-profit web owners, who commonly redirect consumers to recommended information sources, and are often not willing or financially able to ‘gain visibility’ through ‘manipulating’ Google algorithms (Mager 2009, pp. 1131; 1133). Often searchers of the internet will find themselves with a monopoly of well-connected sites indicating the connection between commercialisation of information, the democracy of the internet, and who really gains ‘empowerment’ (Mager 2009; Hillis, Petit & Jarrett 2012). In addition, Thompson (2012) argued that accuracy of information was strongly connected to agency and ownership of the sites. For example, although a medical expert maybe employed to review writing content of a website, the type of contributors to the site design and content are likely to be journalists and other non-medical people (Thompson 2012). In support of this argument, Thompson (2012) found that a major privately owned company based in the US employed business personnel, journalists, psychiatrists and web-designers (Thompson 2012). Although a medical director oversaw the content, the actual writers of the site content were non-medical people. Therefore, in the first instance, being able to assess the quality and quantity of information returned to the mental health consumer may present some problems due to the various interests of site-owners and the ways in which the information is to be found.

### **2.5.2. Making sense of the information**

For the lay person, difficulties may also arise from engagement with internet use due to individual abilities to interpret and use the information. In a qualitative study about individual internet use for seeking facts and experiential health information, Kelly, Jenkinson & Ziebland (2013) found that, although participants felt they had access to much instant information, they sometimes experienced difficulties ‘making sense’ of information.

Sometimes information downloaded from the internet was thought to be ‘overwhelming, conflicting and confusing’ (McMullan 2006, p. 26). In addition, while individuals found the internet valuable for instant access to information they reported having difficulties assessing the credibility of the information (Kelly, Jenkinson & Ziebland 2013).

### **2.5.3. Lay assessments of online content**

Results of a study with secondary school children who were studying science subjects (see Kortum, Edwards and Richards-Kortum 2008) found that they had difficulties with assessing the credibility of online health information: Most of the information was, in fact, found to be inaccurate (Kortum, Edwards & Richards-Kortum 2008). Addressing Australian government findings that Australian health consumers face concerning access to relevant material and quality control, Fisher et al. (2008) examined three Australian non-commercial web sites. The results found 24 per cent of users unable to find information relevant to the searched topic and 33 per cent were dissatisfied with the amount of information retrieved; and found information about quality control hard to find (Fisher et al 2008, pp. 482-3).

However, a study by Thomm and Bromme (2011), whose participants were university students in a scientifically-based stream, used visual text examples to test the students’ judgments of scientific-style information. So that their study could be related to the lay person, Thomm and Broome (2011) argue that the design of their study was set up to mirror the same type of material lay people would be seeking; that is, the content was intended to represent scientifically-mirrored texts (Thomm & Broome 2011). The study found that the students were able to make credibility judgments through recognising scientific text,

regardless of the type of text used and the way in which it was presented; however, they were not readily accepting of an 'assumed expert' opinion (Thomm & Bromme 2011, p. 206).

Their finding is particularly pertinent for this study as it points to the fact that people, when accessing information, for example, from a bipolar disorder internet site, may not make their judgments based on scientific-looking text. It also points to the fact that they may be discerning about what constitutes 'expert' opinion. In fact, the study revealed that people use their experiential, or past knowledge, to make new judgments about information, and not necessarily based on a scientifically-oriented education or scientific-looking text. As Thomm and Bromme (2011) found, the students were apt to make their assessments based on their prior beliefs, formed from previously accredited 'expert' sources, for example, regarding topics such as global warming (Thomm & Broome 2011). If the 'expert' opinion matched up to the one they already knew, then it could be taken to be accurate information. Thus, experiential knowledge may be the way in which people with bipolar disorder, as lay people, are able to make judgments about the validity of information found through the internet.

In addition, an Australian study with third-year undergraduate tertiary students who were selected from human computer interaction courses, found that the students associated government-approved sites with 'good' content. However, the students were unable to make judgments about reliability and quality of information within any of the given sites, and had difficulties with spelling medical terminology to access the required set topic (Fisher et al. 2008, pp. 487-488). These points are particularly significant when visualising how lay people are able to assess which internet sites to use, and seek out the required content for current information and scientific accuracy for diagnosis or medication.

#### **2.5.4. Worrying emotional content**

Even when finding an appropriate web site people have been found to have experienced unwanted emotional responses triggered by site content. In some cases people have reported avoiding online resources which they thought might invoke adverse emotional responses (Kelly, Jenkinson & Ziebland 2013). Some emotional responses have been noted to have been invoked by viewing emotive health cases, coming across deliberately false and exploitive messages, or reading about cases that are unnecessarily worrying because they are not exemplary of the general experiences of illnesses (Ziebland & Wyke 2012). As Ziebland (2004) found, in the case of a women's online support group for breast cancer, there was content of worrying symptom descriptions and conversations about death (Ziebland 2004).

Studying online chat forums, an article by Vayreda and Antaki (2009) was concerned with the type of discourse within a bipolar disorder chat site and its possible effect upon the emotional well-being of some of its participants. In this case, Vayreda and Antaki (2009) found that, first, the identity of a new contributor was likely to be recognised by personal description that was not necessarily evidenced by any supported clinical diagnosis. After identity recognition, responding members were apt to offer 'unsolicited' advice to the entrant, instead of simply answering the question asked which was about, for example, obtaining help (Vayreda & Antaki 2009, p. 935). In agreement with Vayreda and Antaki (2009), Giles and Newbold (2011) found conversation that indulged in responses that were based on a 'personal declaration' and contained advice (based on identity recognition) rather than the support solicited (Giles & Newbold 2011, p. 422).

These studies offer two different aspects of how chat site content may invoke emotional or worrying responses. The first point is related to identity and the assumption of like identity that other contributors make when a person describes their moods or feelings. As Giles and Newbold (2011) suggest, online communities may be places where identities are explored and achieved and may contribute to the medicalisation of madness. Thus, inappropriate lay diagnosis that has been achieved online, may result in unnecessary emotional discomfort, particularly if the diagnosis proves to be incorrect when clinically tested. Second, advice, not even asked for, may be interpreted in such a way as to cause undue stress, especially when the actual inquiry was not answered. Thus, the two papers outline in some ways the negative effects of experiential knowledge imparted through online chat sites. Certainly, the studies show that lay discourse online resembles chat rather than any content of a serious nature. As Giles and Newbold (2011) stated, the analysis of their conversation content revealed a certain ‘playfulness’ within the context of conversations that might indicate that any advice offered should not be taken seriously. In that case, any analysis of such conversations could not be conclusive with regard to emotional responses invoked as such content could only be judged upon the ways in which things are being said, and not what is actually said. As Giles and Newbold (2011) have concluded, chat sites are a part of a ‘consumer autonomy and the internet [that] are now powerful forces of the manufacture of madness’, where people are seeking identities and in need of related explanations and support (Giles & Newbold 2011, p. 427; also cited in Charland 2004, p. 335).

## **2.6. Understanding health**

Individual health literacy skills are also important to consider when designing an investigation that seeks to understand how people with bipolar disorder use the internet to

seek health information. To quote from Davis and Wolf (2004, p. 595) the definition of health literacy is ‘...the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions...’ (also cited in US Department of Health and Human Services, 2000, para. 1; Australian Bureau of Statistics, 2009, para. 9). Health literacy skills have been necessary before the existence of the internet, and have been the target of information handed out in the clinic. However, as Davis and Wolf (2004) found, albeit in 1993 in the US, health literacy skills have been inadequate. It has been proposed that information gained from internet web sites could enhance patient understanding of a condition by increasing health literacy skills (Davis & Wolf 2004; see also Wald, Dube & Anthony 2007).

In Australia, in 2006, 41 per cent of adults were assessed as having adequate or better health literacy skills, there being no measured difference between males and females. Health literacy, as measured by scores that were then placed into levels of competency – 1 being the lowest competency and 5 being the highest – improved within the younger age groups.



Fig. 1. Health literacy skill levels: Levels 3, 4 and 5 represent adequate or better health literacy (Australian Bureau of Statistics, Health Literacy Australia 2006).

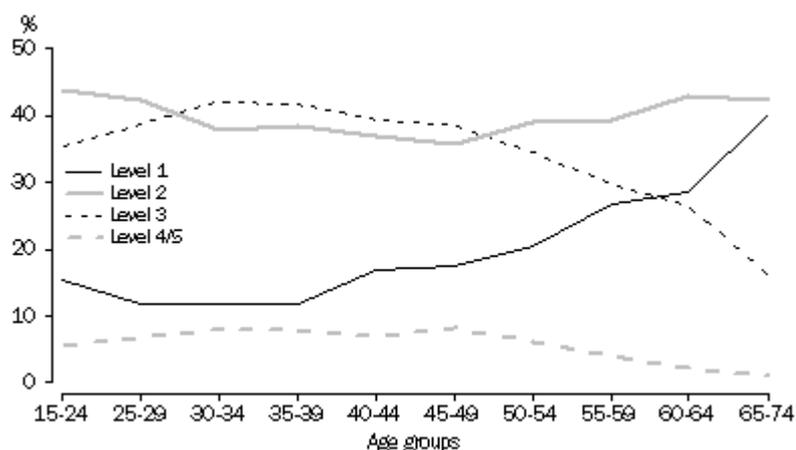


Fig. 2. Health literacy skill levels by age group (Australian Bureau of Statistics, Health Literacy Australia 2006).

Younger groups of people may be more equipped with literacy skills that would enhance their ability to interpret and assess information downloaded from the internet. For people of older age groups assessing the quality of online information may be found to be more difficult. Accessing the required information may also be difficult if knowledge of key words and medical terminology is also poor. In addition, for people with mental illness, such as bipolar disorder, using personal literacy skills may be made more problematic or even useless where mental rationality is also a part of individual abilities to assess and process information.

## 2.7. ‘Empowerment’: Rational assessments and self-management

Much sociological literature has been devoted to analysing concepts about emotional behaviours and/or rationalities/irrationalities and how these have been placed within Western societies as social and biological constructs that have drawn individuals into being subjects of power and power relationships (for example, Foucault 1984; Rose 1996, pp. 98-9; Williams

2000; McLean 1995; Jenkins & Karno 1992; Weiner 2011). Within the conceptualisation required for this study, it has been necessary to think about the more recent developments in power-relationships and rationalities that affect self-management. When studying how people with bipolar disorder are able to take on an approach of personal 'empowerment' towards their self-management, the relationship between personal 'empowerment' and rationality should be understood. How can a person, who by definition of their 'condition', being deemed to be irrational, be required to seek and download appropriate information from a web site? Weiner (2011) argues that knowledge gained about the biomedical model of bipolar disorder is difficult to use for the person with a bipolar disorder because of the inability of such individual to be able to make rational choices for self-management. Thus, it would make more sense for people with bipolar disorder to have their condition managed by a professional person (Weiner 2011). The following literature offers some answers to the ways in which societies and individuals may understand rationalities: Such understandings are around the social construction of mental illness as a form of judgment; rational choice and its connection to emotion; social/individual tolerances to behaviours; and, the mastery of the self in accordance with emotional awareness.

First, how do we construct mental illness so that we know whether or not we are rational? Williams (2000) argues that the biological notions of mental disorder/mental illness including the diagnostic 'label' have been derived from the way societies are constructed and the ways in which individuals are subjected, throughout their lives, within the context of their social worlds (Williams 2000; see also Pilgrim & Tomasini 2012). In addition, Pilgrim and Tomasini (2012) argue that with physical disorder there is a probability of failure to meet social expectations around role performing: For a mental disorder, however, there are strong social implications regarding failure to obey rules (Pilgrim & Tomasini 2012). However, as

Pols (1989) argues, if one is to take the social constructionist view, to make a judgment about anyone's rationality/irrationality requires a comparative judgment. A comparative judgment may be based on certain socio-cultural moral values in historical context. Making comparative judgments, therefore, means that there would have to be a clear indication of who is performing more rationally/irrationally within understandings of a given socio/cultural context – and separating out human beings in this way may be considered virtually impossible (Pols 1989). In any case, there is a risk with assessing people in this way. In arguing who decides what rules are broken and who is not able to dutifully fulfil their social roles, there is a risk of misappropriating personal identities through casting labels given upon making comparative judgments. Furthermore, Jenkins (2010, p. 4) argues, that one has to be careful how much emphasis is placed upon labels, acquired by making assessments or judgments, because doing so ensures that people become products of pharmaceutical companies – expressed as 'pharmaceuticals selves [who are] transformed by regular ingestion of drugs...'). But, how does one discern when transformation is necessary, when a personal identity, or daily living cannot be tolerated anymore, and how should one go about doing something about it? That is, assuming that the individual wants to keep taking part in the same society that constructs the values one already knows.

I cite the conventional Western notion that 'reason' is firmly connected to 'emotion' as Williams (2000, p. 562) describes, and suggest that this is the most expedient way to explain social/individual action within the context of 'rational' choice. Williams describes the famous case of Phineas Gage's brain damage which revealed that the damaged part of the brain responsible for controlling emotions caused the ability to plan daily routines reasonably to be severely affected (Williams 2000). Rational choice, therefore, can be considered to be what people need to do by employing their own, or managing others', emotional responses to daily

routines as well as unexpected situations within their social context. In this context, rational behaviour is maintained through becoming, as Foucault expounded, a way of exercising ‘mastery over oneself’ (Foucault 1988, p. 35).

Jan Pols (1989) offers one description of the concept of mental illness as being a deviation from the norm that excludes a person’s ability to use their rational capacities or act in a rational way. A further explanation can be offered in that rationality can be defined as a way of being able to assess what is risky behaviour and what risks should be taken. Being rational, therefore, is linked to the way in which societies define and control risky behaviour (Pilgrim & Tomasini 2012). Within this definition, however, there are many behavioural nuances pertaining to personal performances that, arguably, are left unchecked within societies and many that may be unreasonably checked.

As Pilgrim and Tomasini (2012) argue, ‘draconian’ preventative measures, such as government-imposed curfews for controlling behaviours that are usually a part of social activities, such as road traffic accidents and alcohol consumption, do not usually meet the consensus of democratic societies. However, as Pilgrim and Tomasini (2012) neglect to point out, individuals and societies learn to foresee the consequences of being unruly and determine to avoid such risk. Nevertheless, it may be rightly argued that many socially-accepted behaviours may well be defined as personality disorders that are risky and harmful but are not subject to social control (Pilgrim & Tomasini 2012). Therefore, making decisions about what is rational/irrational may depend upon how far societies and individuals can afford to tolerate certain behaviours (Pilgrim & Tomasini 2012).

Individual feelings about being rational/irrational are usually defined and experienced within the context of specific cultural and social constructions pertaining to appropriate and inappropriate emotions. However, making decisions about what constitutes an appropriate emotion, deciding when to take action to control an inappropriate emotion has been made more difficult in contemporary Western societies. It would appear that tolerance levels towards emotional experiences have been declining, even to the extent that personal temperaments need enhancing (Jenkins 2010, p. 4). However, as Williams (2000, p. 572) points out, being healthy is also experiencing being ‘dissatisfied, disillusioned or even downright depressed’, not because we are trying to fulfil current social ideologies about personal fulfilment and contributions to society, but just because human existence brings with it some ‘predicaments’. While these kinds of emotions may be quite normal, societies have been more recently constructing them in such a way that emotional experiences have become, arguably, the cause of over-used pharmaceutical treatments (Jenkins 2010, p. 4; see also Conrad 2007, p. 70). The question remains, therefore, as to what extent people with bipolar disorder are able to make judgments about the extent of their moods, and how far should they rely upon pharmaceutical treatments to manage their moods?

Both Williams (2000, p. 563) and Foucault (1988, p. 35) have interpreted the writings of Plato and have agreed that the concept of ‘mastery of the self’ means being consciously concerned with the self and in a state of ‘self-possession’. However, as Williams’ (2000, pp. 566-67) studies of Merleau-Ponty (1962, p. 387) point out, there are many emotional states that are not as a result of being ‘consciously aware’ of the self. Therefore, ‘normal’ behaviours may be the result of habitual or customary performances according to a widely-performed and accepted social interaction between individuals. For people with bipolar disorder, being consciously concerned with the self may, in fact, mean relying upon knowing

the diagnostic label. In fact, for people with bipolar disorder, taking on a medical label may produce the unconscious effect of performing unacceptable behaviour due to its legitimacy. However, as Martin (2007, p. 57) explains, there is often a ‘double bookkeeping’ being enacted by people who portray themselves as being mentally ill, who at the same time are quite capable of revealing great insight about what is actually being said and done within a social setting. Therefore, the question remains as to what kind of self-management obligations people with bipolar disorder are able to perform?

## **2.8. Gaps in the literature**

Incentives for the promotion of self-management have grown from early practises of management by doctors with their patients where health benefits for patients have been acknowledged (Lorig & Holman 2003). Due to problems within health systems in Western societies, practises of self-management have been reinforced due to the need for better patient care and more efficient economic practices (Segal 1998; Anderson 1996). With the development of the World Wide Web, and the availability of the internet to households, individuals have been statistically represented as increasingly prolific users of internet health websites (Laing, Hogg & Winkleman 2004; Wald, Dube & Anthony 2007; McMullan 2006; Wong et al. 2014). Arising from practices of self-management, the term ‘empowerment’ has become widely-used with regard to health self-management, moreover since the advent of the internet, and has been used to promote individual autonomy, personal involvement and responsibility (Lemire, Sicotte & Pare 2008; Anderson 1996). As a consequence of individual ‘empowerment’, much of the academic literature has been concerned with the resultant changes in power relationships between patients and doctors. In fact, there has been much written around concepts of lay and expert knowledges. These concepts have included

challenges to the medical profession, and the benefits of both lay and scientific knowledges when used in strategies between the patient and the clinician.

Both professionals and patients have had mixed opinions about internet use for acquiring patient knowledge and self-management. Considerable academic articles have examined the internet for its reliability, whilst critiquing the role of the patient in self-management (for example, Blumenthal 2002; Kortum, Edwards & Richards-Kortum 2008). Concerns arising from the professionals have been about the changing relationships with their patients, the scientific accuracy of the internet information, and the ability of their patients to understand it (Broom 2005; Blumenthal 2002; Anderson, Rainey & Eysenbach 2003). While individuals were found to regard the internet as ‘overwhelming, conflicting and confusing’ (McMullan 2006, p. 26), they have been more concerned about avoiding unwanted emotional reactions to internet content that conveyed adverse illness-related text (Kelly 2013; Ziebland & Wyke 2012). While individuals felt they could make better life choices through using the internet (Anderson, Rainey & Eysenbach 2003), much of the critique pointed towards individual ‘empowerment’ and the potential for increasing the doctor/patient partnership through health information gained online (McMullan 2006; Anderson, Rainey & Eysenbach 2003; Broom 2005 and Wald, Dube & Anthony 2007).

While the abundance of academic literature about health self-management and online self-help is an indication of the escalating public use of the internet for health information, there has been a paucity of study about health self-management and the internet for specific conditions. Furthermore, most academic literature about self-management and the internet has been with regard to physical health, with much less about mental health. Examples of

studies that focussed on mental health and illness and the internet were: Thompson (2012) on studying internet site presentations of mental health and illness, Parikh & Huniewicz (2015) presenting an overview analysis of mood disorder internet sites, Giles & Newbold (2011) on mental health online communities, and Naslund et al. (2014, pp. 1-7) on studying severe mental illness and using YouTube. Usually, studies that included any specific mental condition did so within a broader investigation about internet use and mental health/illness. A few studies Zaja et al. (2017, S149), Schrank et al. (2012) and Spinzy et al. (2012) have examined schizophrenia self-management focussing on some particular form of internet use, such as blogs. Therefore, there has been a paucity of study concerning self-management, the internet and severe mental illness. Some of the research found that ‘tailoring’ information from the internet for and by patients had resulted in more satisfactory outcomes for both the doctor and the patient (Ziebland 2004; Sundar et al. 2011; Cline & Haynes 2001). Therefore, it would seem timely to include some study about how people with a specific mental condition, like bipolar disorder, engage with the internet for information and support. I found only one study by Vayreda & Antaki (2009) about bipolar disorder and social support from an online forum.

In this study I collect samples of data from within an Australian cultural setting, with which to uncover the ways in which my participants were able to engage with the internet and learn to self-manage their condition. It is anticipated that this research will mark the difference between the general overview about the internet and mental health literacy already embarked upon, and open up an area of thinking around problems associated with a severe mental condition.

## **Chapter 3    Theoretical Background: Power and individual autonomy**

### **3.1.    Introduction: Choosing the overarching concepts**

Two main theorists have been chosen for this thesis: Michel Foucault and Nicolas Rose.

Michel Foucault is important to this thesis because of his insights into the analyses of power relationships, subjectivity, social economies, and concepts about ‘technologies of the self’; and Nicolas Rose because of his work which explains the concept of the autonomous individual and the interdependency of the individual and the social networks that lie within the twentieth and twenty-first-century social and political economies (for example, Foucault 1982, 1984, 1988, 2004; Rose 1993, 2001, 2016; Rabinow & Rose 2003). The concepts that have formed the thesis have been chosen because of the need to explain the problems associated with being in control of bipolar disorder and exercising individual autonomy. To control the symptoms of bipolar disorder individuals would need to engage in technologies of the self that require being subjects of medicalisation (see Conrad 2007, p. 13). Such technologies of the self often mean that individuals need to use ‘apparatuses’ that are transforming and thus tend to be identity altering.

While needing to conform to social practises that entail forms of medicalisation, people with bipolar disorder, as autonomous individuals, have choices that are apt to complicate decisions around using transforming ‘apparatuses’. For people with bipolar disorder, it is important to know the self, be in control of the self, maintain respect from others, and yet retain personal identity, associated with the very nature of ‘being bipolar’. All of this requires knowledge, acquired by a set of, what Foucault has termed, relationships of power that enable certain negotiations between institutions (such as the medical clinic), their apparatuses (such as

pharmaceutical treatments), and the self. For people with bipolar disorder, such negotiations may be difficult due to the condition, and due to social norms that require people to engage in self-management practices that are a part of individual autonomy as practised within Western culture, including Australia. Achieving the desired effect from self-management, in advanced liberal societies means the establishment of a set of power relationships between social and medical institutions, individuals and the internet that enable choices that need to be rationally calculated by the individual. In the next section, I will explain why Michel Foucault and Nikolas Rose have been important to this thesis by giving an outline of the history of behavioural controls, first as conceptualised by Foucault and then as later expanded upon by Rose.

### **3.2. A brief history of the self and the disciplines of ‘normalisation’**

In his *Discipline and Punish*, (1979, pp. 3-21), Foucault described how individuals have been subjected to disciplines upon the body and soul to bring about the ‘normalisation’ of the individual. Furthermore, Foucault uses the concept of the ‘technologies of the self’ to describe the self-disciplines engaged in by individuals to meet behavioural obligations that societies have enforced, and reinforced over the centuries. In contemporary societies, the concept of disciplining to bring about a state of being ‘normal’ is still being enforced, albeit by some different ways and means than in previous centuries.

Constructing a short synthesis of some of the works of Foucault and Rose, there are three main periods in history that combine to comprise the notion of practices of technologies of the self. For Foucault, social understandings about taking care of the self were evident within ancient Greek stoicism where being mindful of one’s own thoughts and actions meant being

the responsible citizen. This thought was also carried throughout Christian philosophy; however, with an emphasis on the practise of the 'confession' and a 'renunciation' of the self (Foucault 1988, pp. 16-21).

The concept of the care of the self has since been extended and re-evaluated around the 17<sup>th</sup> and 18<sup>th</sup> centuries, noted through a shift from sovereign power over land, birth and death, to state control over individual health and quality of life of individuals for the benefit of the whole community (Braun 2007; Rose 2001; Foucault 1991, pp. 10-12). Building upon Rousseau's writing, Foucault uses two main concepts to describe the ways in which individual behaviours and health were controlled in the 16<sup>th</sup> to 18<sup>th</sup> centuries (Foucault 1982; 1991, p. 10). These concepts are (i) the 'political economies' which Foucault interprets to be integral to a welfare state that took as its responsibility (ii) the surveillance of its citizens in order to ensure 'the common welfare of all'. Surveillance was enacted through a kind of 'pastoral power' carried out through such institutions (referred to as 'state apparatuses') as the police force, which was responsible for the maintenance of 'urban supplies, hygiene, [and] health standards necessary for handicrafts and commerce' (Foucault 1982; 1991, pp. 10, 14). The 'political economies' performed through 'pastoral power', therefore, were not focused so much upon the individual as an autonomous being, but more upon the welfare of individuals within the population so as to ensure the functioning of the society as a whole. The concept of 'pastoral power', once the dominion of state and church as promulgators of the promise of 'salvation' in the after-life, changed in contemporary society with new connotations of 'salvation' in the here and now world (Foucault 1982; Rose 1996, p. 151). As Rose (1996, p. 151) has put it, this now means that people are subject to aspirations of autonomy, and are required to aim for personal fulfilment, and do this through acts of choice

that entail employing ‘experts of subjectivity’, gaining their ‘salvation’ through being socially judged, self-judged and re-inventing or modifying themselves.

In Foucault’s work *The Birth of the Clinic* he wrote about the ‘medical gaze’, which broadly speaking concerned the relationship between the clinical setting and the patient (Foucault 1989, pp. 107-09). In Foucauldian terms power/knowledge, which was performed through the ‘medical gaze’, was a social construction that allowed medicine to pervade the lives of people (Conrad, 2007, p. 13). In a similar manner, the idea of surveillance techniques applied to prisons and the ways in which inmates were watched and disciplined, the medical ‘gaze’ may be thought of as a kind of surveillance that controls the behaviour of the body and mind of the patient. The effect of this institutionalised ‘gaze’ is that it trains the individual to know and practice self-surveillance methods in order to exercise certain self-disciplines for the purpose of ‘normalisation’ (Foucault 1995, pp. 200-204). Even in contemporary society, this practice of self-surveillance is present and is what drives the individual to exercise choice over how they determine how sick they are and in what ways they should take action to manage their sickness. However, decisions about taking care of the self are not made easy by changing ideas about health care and what factors determine ‘abnormal’.

While it is still recognised that the medical profession has the knowledge and control over what Conrad calls the ‘legitimization’ of medical categories of disease, the boundaries of medicine, due to changing social constructions of individual problems, are being challenged (Conrad 2007, pp. 10-11; 155-6; Williams 2001). These changes are occurring because of continually changing concepts of what is deviant, a disease, or just another social difference, thereby making the concept of illness more complex for individuals to understand, and

labelling difficult to negotiate and accept. For example, newer categories of illness are being discovered, like chronic fatigue syndrome, by putting together certain symptoms previously medically and socially disregarded, into a legitimized medical category (Conrad 2007, p. 11). Conversely, demedicalisation may occur whereby, for example, homosexuality, once criminalised, and later medicalised, no longer belongs to either category (Conrad 2007, pp. 97-8).

In addition to such changing concepts about illnesses, there have been social changes to risk management, since the latter half of the 20<sup>th</sup> century, with less emphasis on the state, which have meant that insurances have become more an individual responsibility (Beck, 1999, pp. 76-77). Within the idea of risk management, individuals are now subjected to 'profiling' for all sorts of reasons: For example, for health risks they are profiled according to family history of illness, whether they may pass on the illness to future generations, whether they drink alcohol or smoke tobacco or live in a polluted area (Rose 2001). Such movements have been responsible for the ways in which surveillance has shifted from church and state to individual surveillances. Individual self-surveillances are now more based on individuals being able to engage with institutions that will provide them with information for the purpose of self-improvement practises. In a 'set of power relations' that Rose (2001, p. 9) argues may be termed 'pastoral', potential risks to health are profiled and supervised by the clinic, and individuals are encouraged to make responsible decisions about such risks, for example, taking genetic tests, giving up smoking or moving to unpolluted suburbs.

Since the later twentieth century, health responsibilities have been pushed further onto the individual who is now supposedly more equipped to manage their own affairs, because of

higher education levels, which also permit engagement with new technologies such as the internet (Anderson, Rainey & Eysenbach 2003). In contemporary society, individuals are now playing a greater role in the care of their health through knowledge made available through resources such as the internet. Nevertheless, there are cautions to be made in view of individual autonomy, health choice and easily-gained health information.

As Rose (2013) points out, as economic interests dictate, it is the duty of those engaged in scientific discovery and technology to comply with the demands of commerce to provide ongoing claims to discovery and its associated promises. Bound up in those interests, are the consumers who, according to Rose (2001), are ‘coerced’, ‘restricted’ and ‘eliminated’ in order to comply to the perceived social benefits to be gained through individual engagement with the technologies. Therefore, these are some of the political/social economies that form the institutional ‘apparatuses’ that permit inter-subjectivity between individuals and technologies.

In the following section, I will discuss the concept of being a subject with bipolar disorder in relation to the ‘problematization’ of the condition, as a way of gaining insight into how people might come to know about their condition. I will then discuss concepts used to explain how people with bipolar disorder may feel the need to find ways to perform as individuals in social conditions where individuals are expected to contribute to social economies. I then move on to the use of concepts that help describe and explain systems of knowledge that individuals with bipolar disorder would need to engage in to define and understand their problem. Finally, I elaborate on the type of ‘technologies’ as explained by Foucault, that

people with bipolar disorder would be likely to learn and engage in to learn about themselves and control their condition.

### **3.3. Subjectivity, Inter-subjectivity and bipolar disorder**

Before I begin the discussion about my choice of a more pragmatic approach to explaining bipolar disorder and the ways in which it has been conceptualised as a biomedical condition within social understandings of normal, I outline some concepts of Judith Butler (2014).

When analysing the discursive formation of social constructions of, say, normal, there exist linguistic forms that are exchanged over time that come to construct the meaning. For example, when considering social identities, the understanding of a person as the 'I' is formed by the authoritative knowledges available at a given time to explain the person as object (for example sex, gender, normal/abnormal). This construction of the 'I' then is reiterated and reinforced by the use of the 'we' which serves to socially define the 'I' as it comes to be understood as the subject. Therefore, the construction of identity, and its subjectification, is only made possible by the relationships between individuals (Butler 2014). When using the linguistic meaning of the subject of concern in the context of nature or what is 'natural' or to define 'normal' from the abnormal, social values are applied.

The production of normal in mental health is made through various psy knowledges/authorities and reiterated through discourses of power that decide about what qualifies 'normal' (Butler 2014). Butler (2014) explains that Foucault's idea of power/subjectivity was not a personification of power that constructs social activity, but should be understood in terms of linguistic forms that reinvent social actions. In linguistic terms, power should be understood as being invented by humans, and thus, power should be

understood as a subject of social construction formed socially by reiteration of acts (Butler 2014).

As for anyone, living within a society, people with bipolar disorder will find themselves the subjects of the rules and conditions of their social world. At the same time everyone is the subject of themselves, as they are interested in shaping the ways in which they come to think about themselves (see Rose 2016). Furthermore, the ways in which people think about themselves are linked to current ideologies about what a human should be (Rose 1996, pp. 151, 23; Rose 2016). The association of the individual with the society is what may be referred to as its inter-subjectivity, and this is crucial to understanding how, for example, people with bipolar disorder experience their life. Rose (1993) explains Foucault's idea of subjectivity in government in a way in which I believe clarifies the ways in which people with bipolar disorder, similarly to any other condition, are situated within their life context. As Rose (1993) explains, today there is no 'polarisation of public and private': rather, there is a 'multiplicity of interlocking apparatuses' that basically are there to be engaged in, and are responsible for shaping life (also Rabinow & Rose 2003, p. 12). This is important to this thesis because it explains that people are not so much governed by any overlord and single rule, but that they are a part of many social interactions within which they need to find their way, and learn to choose what type of action they may want to use upon themselves.

The next point to be considered is concerned with thinking about being a subject and having a relationship with society in an inter-subjective way. This concept is important in the analyses of the ways in which people with bipolar disorder come to think about themselves and their functioning within their society. Here, as a starting point, Foucault is useful for his thought

around government and making life a problem – everything is in existence and seemingly unproblematic until it is made problematic. However, not quite; for Foucault, ‘problematizing’ is the result of thought processes that determine what is ‘true’ or ‘false’ and may, for example, concern personal reflections and scientific discoveries (Rabinow & Rose 2003, pp. 12-13). Such objects become ‘problematized’ and are present through social action of inter-subjectivity (Rose 1993, p. 288). This concept should be remembered, therefore, when analysing how it is that the participants for this study learn to recognise they have a ‘problem’, and know when they should do something about it.

Understanding how people with bipolar disorder may come to reflect upon their lives and decide when they have a problem is an important beginning to this study. When analysing problematic conditions and lives, Foucault’s work on ethics, subjectivity, truth and freedom provides a background to understanding how people might make their personal judgments about themselves in relation to their social settings. Therefore, through ‘problematizing’ the condition people need to be able to care for themselves. Rather than aspiring to the Christian doctrine of the care of the self as an inhibiting, selfish concern, Foucault (2000) prefers to use the Greek doctrine of the care of the self to explain post-modern thinking around mental illness. As Foucault (1987) argues, this doctrine of the care of the self fits well into later and more recent social practises including, for example, psychiatry and medicine. As my intention has been to find a way to explain how people with bipolar disorder may be concerned with themselves in today’s society, the ancient Greek ethical practice sits well with the idea that people with bipolar disorder learn about themselves through self-examination and use self-control for aspiring to and achieving social principles and rules of conduct. Foucault (2000) sees these practises as a form of ‘concrete’ freedom that are visible within society through images of individuals who choose to conduct themselves as exemplary

citizens. Therefore, this thinking, which Foucault (2000, pp. 286-288) also relates to the practise of being able to recognise the ‘truth’, would help to explain how participants for this study may come to see themselves and how they are seen within their own society, and, therefore, how they may be subjects of personal and inter-personal judgments (see also Foucault 1987 in interview).

### **3.4. People with bipolar disorder as subjects of enterprise culture**

As people with bipolar disorder are autonomous subjects living within contemporary society, I felt it necessary to understand what purposes there were for engaging in certain practises of the care of the self. I needed to understand the forms of power that might influence my participants to try to know the ‘truth’ about themselves and begin to engage in taking care of themselves. In this regard, I have used concepts, as considered by Rose (1996, p. 151) and Foucault (1982), concerning political economies that are forms of power relations that shape people as subjects; and are responsible for how people have learned to become subjects of themselves.

Practises of the care of the self, in contemporary society, which requires individual autonomy, are due to social changes in political economies that have changed the ways in which people think of themselves and conduct themselves. I have aforementioned political and social economies broadly speaking and now I elaborate: Political and social economies with regard to health practises are no longer the responsibility of the state as they are not tied up with the national strength and wellbeing, as previously practised when protection was needed against, for example, external threats (Rose 2001). The focus is now upon the individual and family health, with emphasis on the individual being the subject of their own

health status. Protecting the individual health status (through, for example, medicine, health programs and insurances), therefore, is calculated according to individual contributions to the work-force. Continuing contributions to the work-force are important to controlling loss of profit/income due to days off work, rising insurance costs due to sick pay-outs, and efforts to reduce inequalities in health care (Rose 2001). Therefore, when studying people with bipolar disorder, it should be remembered that they are a part of such political/social economies that depend upon ensuring that individuals are able to contribute to the work-force.

As Rose (2016, p. 800) explains, the rise of the 'enterprise' culture was an invention of the kind of subjectivity that meant that people needed to be 'enterprising', 'calculating' and 'thinking' in order to maximise their potential. This in fact, may be related to an inter-subjectivity where people have been expected to engage in social patterns of thinking about practises of material consumption, work insurance and risk. Within such subjectivities there are social ideals about maximising ones' health status, assessed by what people have come to regard as social 'norms'. When someone does not 'match up' to such social 'norms' then they become the subject of 'interventions', or 'disciplines' to make sure that they are able to 'maximise' their own health status (Rose 2016, p. 800).

Ways in which social actions that hold individuals responsible for their own health and wellbeing may be noted through the many health and wellbeing internet sites. People who are used to engaging with the internet, are invited to engage in a practice of 'somatic ethics', encouraging individuals to be responsible for knowing and avoiding their own health risks (Rose 2007). In a set of power/knowledge relationships between science, pharmaceutical interests and the community, websites have been set up to position people as

consumer/subjects, flagged as the responsible, enterprising individual (Fullagar 2008b). Through psychiatric discourses within the internet the individual is encouraged to 'self-gaze', recognising themselves within the medical discourses, and taking their answers from the onsite self tests back to the clinic. Such discourses are meant to encourage individuals to feel normal about conceding to the problematisation of mental illnesses (Fullagar 2008b). The end result is that individuals, in the act of being responsible for the self, have the effect of negating any social obligations concerning social causes of, for example, depression (Fullagar 2008b). In the light of negating any social responsibility for the large numbers of people with depression that have been occurring, the discourse remains firmly in the need to medicalise the biochemical individual (Fullagar 2008b).

Rose (2007) explains 'ethics' as the 'ethical considerations that shape the conduct of conduct' that, in advanced liberal societies, concerns personal outcomes from knowledge through enacting within that knowledge and creating hope; and, 'somatic' because of individual understandings about the somatic function, gained through involvement with medical science, health promoters, genetic councillors, advice and support groups and bioethics that become embedded within lay discourses pertaining to everyday life (Rose 2007). In fact, Rose (2007) argues that, within advanced liberal societies, health has become a key ethical value. Social discourse now comprises values that place an emphasis on being 'active' about one's own health, being 'active' concerning one's citizenship, and making 'active' decisions based on knowledgeable choices to use medicine/alternative medicine (Rose 2007). Thus, within advanced liberal societies, there has become a new kind of subjectification related to autonomy, and a new kind of ethics.

Since individuals living within a contemporary society need to be ‘enterprising’, these are important concepts to remember when trying to uncover the ways in which people with bipolar disorder may be able to exercise such rights and duties. For a study such as this, ideas about whether people with bipolar disorder may be calculating and enterprising subjects, that are able to take advantage of their existing social subjectivities, form a necessary part of the investigation. In addition, it is also necessary to use concepts that lead to an understanding of how people with bipolar disorder may be able to seek out and use ‘interventions’ or ‘disciplines’ that will ensure their contribution to the social economies and their personal lives.

### **3.5. Gaining knowledge through systems of power/knowledge**

Further thinking around the subjectivity of people with bipolar disorder spurred the notion that I might need a concept that would help me to analyse in what ways individuals might acquire knowledge about themselves and their condition. Therefore, I needed to understand, through my participants, how knowledge might be accessed and what the systems of knowledge are in contemporary society. In addition, I needed to understand how forms of knowledge may be used by people with bipolar disorder to help them to fulfil their social contributions and their life expectations. Some concepts from Foucault were instrumental for understanding how autonomous individuals might use their ‘enterprising’ nature to access knowledge required in the detection and treatment of bipolar disorder.

I, therefore, chose to use Foucault’s concepts about power/knowledge to explain how knowledge might be exchanged through, for example, the internet, or the clinic. There are probably, although not decisively, two main ways in which people with bipolar disorder may

be considered to be subjects who engage inter-subjectively in forms of power/knowledge. First, if I were to consider any dominant form of power that was to be used to control an individual with bipolar disorder, such as law enforcement or hospitalisation, I might think of a form of power that was totally controlling. Such form of power may be, as Foucault conceptualises, an imperial power that does not allow any kind of resistance. However, Foucault did not believe that this kind of power, in modern societies, could be enduring because there would be no constant dominant force to keep it stable and enforceable (Foucault 1984). Another form of power, as Foucault (1984) argues, consists of a set of power relationships, within which individuals and institutions exchange knowledge, and wherein power dominance is always changing. At any given time, power dominance may be achieved by acquiring a set of knowledges that form an expertise, whether a clinical (scientific) expertise or lay (experiential) expertise. Foucault (1980, pp. 51-2) argues that power and knowledge are intertwined, a concept that would be useful in understanding how people with bipolar disorder were able to interact between their clinic, and the internet. It is the desire to know that is the force, or 'power', that seeks knowledge; at the same time, knowledge engenders power; thus it is an ongoing cycle, often written within Foucault's philosophising, as 'power/knowledge'. This concept maybe used in a somewhat transforming way when applied to the autonomous inter-subjectivities as for the experiences of people with bipolar disorder: For example, it helps explain experiences such people have when being autonomous and needing to acquire much knowledge.

### **3.6. Medicalisation: The 'psy' disciplines and bipolar disorder**

Foucault asked: 'How was the mad subject placed in this game of truth defined by a medical model or a knowledge?' (Foucault 2000, p. 290). To begin with, medicine has been used,

over a long period of time, to protect the organism from hostile agents (Foucault 2004). However, there have always been positive and negative effects from the use of medicine; in fact, medicine can cure and it can equally kill (Foucault 2004). Therefore, there has always existed a balance between the positive and negative effects of medicine and this has been accepted at an individual and social level (Foucault 2004).

When anybody enters systems of knowledge that pertain to medicine or medical intervention, they are subjected to the act of seeking or accepting 'medicalisation'. To quote from Conrad (2007, p. 4), 'Medicalisation' describes a process by which nonmedical problems become defined and treated as medical problems, usually in terms of illness and disorders'.

Medicalisation may be seen to comprise dominant forms of power, thus compromising individual autonomy, because it holds a power related to the expertise that has the knowledge. This concept is necessary to understand at what times people with bipolar disorder may need to accept the label given to them through medicalisation along with the accompanying medical control over treatments provided. The concept is also useful to uncover the reasons why people with bipolar disorder may not accept a diagnostic label and/or the usual treatments that accompany such scientifically-produced categories pertaining to personality.

When entering a clinic for treatment, people become a part of what Rose (2016, p. 799) has argued is a system of 'authoritative knowledge' that is applied to the individual. In fact, as Rose (2016) argues, this authoritative kind of knowledge forms scientific disciplines, including the 'psy' disciplines; that is, psychology and psychiatry. It is these disciplines that educate people to shape a certain way of thinking about themselves (Rose 2016). For people

with bipolar disorder, gaining medical knowledge about their condition, therefore, may have certain transforming effects upon the ways in which they have previously understood themselves to be. The concept of 'psy' disciplines that intend to reshape people, therefore, arises whenever one wishes to investigate the ways in which individuals seek diagnosis and treatment. For bipolar disorder, like other mental illnesses where personality traits are affected, being medicalised, therefore, means that there are likely to be changes made to personal identities because of the ways in which clinical knowledge may alter the individual's perception of them self.

Furthermore, concepts pertaining to the 'psy' disciplines are useful for analysing how people with bipolar disorder may perceive themselves through transformations made to their existing characteristics. As Rose (1996, p. 88) points out, the power of psychology is such that it is meant to enhance the personality, rather than suppress it. However, in trying to achieve such aim, the methods of the 'psy' sciences are such that they are more committed to achieving the reduction or conformity of people to certain standards of morality and normality (Rose 1996, p. 88). Because of the characteristics of bipolar disorder in relation to the person who carries the condition, this is a complex concept, especially when considering how people with bipolar disorder may wish to retain certain personal characteristics while managing to conform to social constraints that enable them to contribute to their society.

As Rose (1996, p. 88) argues, science has dominated nature in such a way as to define individuals as beings who are 'calculable'. This definition ensures that individuals meet a conformity according to scientific definition of what is healthy, and that they do so by using certain types of medical treatment. Calculability is a concept used to describe the ways in

which science uses evidences and statistics to produce norms, for which individuals are measured against and brought within by technologies (Rose 2001). However, people with bipolar disorder may neither wish to be calculated in scientific ways, nor according to the social conventions pertaining to how people should conform. Therefore, the concept of conforming to scientific criteria is useful when analysing how people decide what measures that are made for them should be accepted, and how far they should be accepting their condition as a 'problematised', 'medicalised' way of being.

Nevertheless, there is always risk with any kind of health problem. There are also many ways in which individuals are able to gain information about their condition. Gaining information may mean that vulnerabilities are better understood and people may be able to decide what risks they are prepared to take and what kinds of help and management regimens they are prepared to use. Therefore, concepts about how individuals become the subject of their own disciplines are important where medical and personal interventions may be a necessary part of life. In this regard, I use Foucault's concepts about the 'technologies of the self', including the concept of the 'care of the self'.

### **3.7. Bipolar disorder and the use of the technologies of the self**

Foucault's writings about the technologies of the self are fundamental to studying any form of self-discipline. That is, where individuals find that they are in need of education, correction, or health care, knowing how to use appropriate techniques to increase their knowledge and maintain wellbeing has become an integral part of human life. In contemporary life, the technologies of the self have become important to risk management, social conduct and employment (Rose 2013; Rose 2001). Therefore, understanding how

people with bipolar disorder might engage in the use of the technologies of the self to ensure that they are able to maintain their health and contribute to society is integral to finding out how they experience their lives.

In fact, Foucault (1987) believes that the phenomenon of what might be called the 'practice of the self' has been important in societies since Greek and Roman times. Left to their own autonomous devices, the technologies of the self, according to Foucault (1987) have had great effect within societies, as in ancient Greece, and, it may be argued, as they return with individual autonomy in contemporary society. When linked to individual autonomies, therefore, technologies of the self are most important to understanding the ways in which people with bipolar disorder go about self-management. Especially considering the availability of the internet and its resources pertaining to, for example, conventional medical advice as well as alternative health practises, the concept of the technologies of the self helps to unravel how much of the self is, in fact, in control. That is, as Foucault (1987) outlines, technologies of the self maybe regarded to be more autonomous acts when they are practised without the assistance of institutions such as religion, pedagogical, medical and psychiatric institutions. Therefore, this concept would contribute to understandings about the inter-subjectivity of people with bipolar disorder concerning their position between clinical control and individual autonomy.

The technologies of the self are described by Foucault (1988, p. 18) as ways and means individuals are able to perform 'operations' on themselves, including their 'bodies, souls, thoughts, conduct and way of being' so that they may achieve the highest state of living. The technique is interesting to this study because it moulds into ideas about social relations as

experienced by people with bipolar disorder, being, as Foucault (1988, p. 18) has stated, not separable from other forms of social technologies that are practised. For example, such technologies as associated with the production from work, technologies of sign systems that people with bipolar disorder need to learn to know and use to detect symptoms, and technologies of power that, for people with bipolar disorder are usually encountered, but for autonomous individuals, are usually negotiable (Foucault 1988, p. 18; Rose 2016).

Pertinent to this study is the idea that technologies of the self are not separable from other forms of technologies (Foucault 1988, p. 18). Furthermore, as Foucault (1988, p. 19) states, the technologies of the self are applicable both inside of the asylum and outside because they form types of ‘governmentality’ upon the individual. With a condition like bipolar disorder, if there is no form of control or ‘government’ over the individual, then the individual must be able to find a type of control that they are able to administer for themselves. This idea sits well with a study whose analytical framework has been designed to understand how people with bipolar disorder, as enterprising individuals, retain their autonomy while engaging with medical institutions.

The technologies of the self also explain how the idea of being concerned with the self has become a function of morality. Being concerned with the self is a concept that is in relation to a type of personal introspection; in other words, a self-surveillance that ensures people, by self-examination, check their conduct according to certain social rules (Foucault 1979). In a contemporary society the function of morality may be considered to be what people feel they are able to contribute to society, and how they feel they are able to maintain successful personal relationships. The idea of being concerned with the self, therefore, is useful to

consider when trying to understand how people with bipolar disorder maybe involved in making certain life altering choices.

Foucault (1988, p. 17) explains that being concerned with oneself in Greek antiquity was related to how people conducted themselves within a city, but the concept is understood today more as the Delphic principle of ‘know yourself’’. Knowing the self is associated with thinking before you come to the oracle for advice; it, therefore, means that one must make sure of what they have been interpreting within themselves before they speak (Foucault 1988, p. 20). To present the concept further and to relate to how it might apply to understanding the lives of people with bipolar disorder, there are two principles of the concept that are most pertinent. The first is that taking care of the self is therapeutic, as extended from the Hellenistic and Hebraic cultures, meaning ‘Therapeutae’ (Foucault 1988, p. 21). This understanding of the concept also integrates community and the individual through various therapeutic practises (Foucault 1988, p. 21). It also relates to finding the ‘truth’ about the self through a counselling service or a friend (Foucault 1987). The concept, therefore, relates to the ways in which people with bipolar disorder may wish to understand themselves in relation to their social settings, and how they might choose to use certain therapeutic practises offered today. The second most relevant point from Foucault’s discussions about the care of the self, is concerning the reflexive task that asks the individual ‘What is the plateau on which I shall find my identity?’ (Foucault 1988, p. 25). Given that bipolar disorder has two poles that may be experienced as completely opposite emotional states, understanding the dilemmas and uncertainties regarding establishing personal identities has been a point under consideration. How people reflect and choose what type of treatments they may engage in may depend on a set of community and personal values they aspire to in relation to what they know about themselves.

In the various core chapters of analysis for the thesis, I also briefly outline particular concepts pertaining to ‘truth’ and the discovery of the self by measuring ‘norms’; making decisions through choices, conceptualised as practises of ‘strategic freedom’, and the individual practise of discerning ‘truths’ within the internet through abilities related to concepts of *parrhesia*. These concepts have been treated within this thesis as sub-concepts to the overarching concept of power and individual autonomy. The sub-concepts are Foucauldian concepts often used, and expanded upon by Rose, to explain governmentalities, control, self-control, power strategies, and the ways in which individuals gain power/knowledge due to ‘truth-seeking’ practises (for example, Rose 1993, Rose 2016, Foucault 1984, 1987, 2001).

### **3.8. Conclusion**

Michel Foucault and Nikolas Rose have been important theorists for this study because of their sociological thinking in relation to the ‘psy’ sciences. As I have demonstrated, to begin with, a most important concept for this study has been around the ‘problematization’ of bipolar disorder and how the discovery of the condition as a ‘problem’ is associated with understandings about ‘normalisation’ within the contemporary society. In addition, placing bipolar disorder as a problem has been due to contemporary understandings and classifications of the condition as a medicalised mental illness. This has been possible due to scientific knowledge pertaining to medical understandings of personality.

Further concepts that are necessary when studying people with bipolar disorder, are those that concern political and social economies because of the ways in which they involve people’s abilities to conform to social requirements, and continue making personal contributions.

Personal contributions are associated with individual autonomy and the need to be able to

work and contribute to private and public economies. Such social actions require the autonomous individual to be able to interact with social institutions such as providers of knowledge. According to such concepts, there are individual responsibilities, where people with bipolar disorder become the subjects of their condition and enact inter-subjectivity with the social institutions. In other words, people with bipolar disorder, like anyone else, need to be what Rose (2016) has conceptualised as ‘enterprising’ individuals.

The concepts of self-surveillance and the technologies of the self have been useful to understand how people with bipolar disorder are able to learn how to detect when they have a problem and how to manage their condition. The technologies of the self and self-surveillance techniques are learned through systems of power/knowledge that have been reconstructed, within contemporary society, to be forms of knowledge exchanges. While the autonomous individual may still need to rely upon power/knowledge in the form of the medical ‘gaze’, there are many opportunities for regaining personal power through actions of acquiring self-knowledge. Therefore, the concept of the technologies of the self combined with power/knowledge both provide the insight to the sort of opportunities that are open to individuals with bipolar disorder to take control of their lives.

## **Chapter 4    Methods**

### **4.1.    Introduction: A Personal and social progression**

Considering the ubiquitous use of the internet for health-related discourse, I reasoned that the internet may play an important role in this investigation. While topics of health have always been a part of social discourse, and reflected in the media, by the twenty-first century the internet has become central to health-related social interaction. However, specific health-related problems are generally best understood by those whose lives have been personally touched by them. For example, while most people may understand a cancer by means of social discourse, to speak more fluently about it is best done by those who have intimately had to live with it or deal with it within their own personal lives (see Plummer 2001, Frank 1995, Kleinman 1988).

Rather than attempting to undertake a large-scale questionnaire survey that would provide data about a wider social understanding of mental illness, I decided to confine the area of investigation to one specific group of people. This consideration was initially generated by my own interest in people with bipolar disorder. The idea was then taken up for this research project because of the paucity of social research on the disorder. The decision to focus this study on a particular group meant that a qualitative paradigm should be employed allowing the narrowing of the inquiry in order to understand more specifically the type of problems people with a bipolar disorder face and by what means they are able to communicate their concerns.

Denzin and Lincoln (2000, p. 3) define qualitative research as an activity that ‘consists of a set of interpretative practices that make the world visible’. Through these practices, which include making field notes, interviewing, talking and recording, interpretations of the world’s phenomena are made (Denzin & Lincoln 2000, p.3). Interpretations from a group such as the bipolar disorder group, with a focus on examining ‘how’ the life experiences of this group of people are created, are ‘value-laden’ because of the ways in which their personal experiences of being socially different are being constructed (Denzin & Lincoln 2000, p.8). Such experiences cannot be measured as being ‘value-free’ in the same ways as prescribed for the use of quantitative studies, as the value measurements are derived from understandings of social interactions and not causal relationships between variables as studied for quantitative research (Denzin & Lincoln 2000, p.8). Therefore, because expressions of personal feelings about life experiences, as conveyed by people with a bipolar disorder, and the interpretations that are made from them, are derived from personal values, a qualitative paradigm is necessary. The values derived from personal constructs of life are what create a different perspective to understanding the society.

Narrowing the study using a small sampling procedure also affords more time for a deeper exploration of life experiences with people with a bipolar disorder in order to discover social conditions that cannot be fully understood from a larger sample size. Moreover, in a quantitative inquiry, meaningful results rely upon large-scale statistical comparisons not needed for inquiring about the feelings of people with a bipolar disorder where the emphasis is on the ways in which the disorder is understood to be socially constructed (Berg 1998, p. 10). The focus on a smaller and specific population sample allows time for an in-depth study of how a particular group with bipolar disorder experience their difference within the larger social world. Choosing a specific group of people sits well within a qualitative

methodological framework as the focus of the inquiry is confined to a specific topic that allows the researcher to explore in some detail and depth the experiences and feelings of those under investigation (see Berg 1998, p. 7; Dworkin 2012; Charmaz 1990). Therefore, a qualitative paradigm is suited to making the ‘world visible’ through the experiences and perceptions of people situated within their own particular social setting and their interaction with the internet.

#### **4.1.1. The personal progression**

The changes in society that have influenced the ways in which responsibilities for insurances have come about, and attitudes towards medicalisation that have influenced individual thinking, have already been cited and addressed in the literature review. These social changes have involved media and have coincided with social critiques that have formed theories that have emphasised the need for individual autonomy in health care. The political changes in health policy that have contributed to the social changes to medicine in general, and in psychiatry, have influenced my thinking about how to design my research project.

I was initially influenced by the Foucauldian concepts about governmentalities and the control of people for the sake of citizen welfare. Within such control, were practises of institutional surveillance that ensured the behaviour and wealth of everyone (Foucault 1991, p. 10). Since governments were seen to be tied up with economic concerns, the welfare of populations became integrated with the concept of ‘political economies’ (Foucault 1991, p.10). Where medicine and psychiatry were concerned, these economic forms of control included what Foucault (2004, p. 16) referred to as ‘political economies of medicine’. Within ‘political economies of medicine’ were social controls that ensured the ways in which some

individuals met their destiny within the care of the institutions of psychiatric medicine (Foucault 2004; Goffman 1961, p. 129).

I continued to think around the need for ‘political economies’, the welfare of all, and the control of the individual. I felt that although the internet may be viewed as a ‘democratic’ form of media, it is also a technology that makes it possible for some institutions to control individuals. That is, the internet may contribute to the ‘political economies’ through exercising control over what is produced, including online contributions made by individuals. In this sense, individuals have also become contributors to ‘political economies’ through forms of ‘empowerment’ that allow them to contribute to the society through the use of the internet. At the same time, privately-owned/sponsored internet sites that provide the space within which individuals may contribute, have the ability to control what messages are being made public. The internet, therefore, may be seen to be one institution that controls forms of ‘empowerment’ that induce individuals to contribute to ensuring that the ‘political economies’ continue to function.

I began to reason that this may be a contributing factor to be aware of when examining data such as the Black Dog Institute’s written testimonies which have been topic-set and scrutinised for a ‘writing competition’, run by the Institute, before presenting them on the web site. It appeared to me that the ‘political economies of medicine’ may be reinforced through internet sites involved in providing mental health resources and promotion. My initial research design, therefore, focused upon mental illness, and medical and social control. I set about investigating websites and interviewing, with a broader perspective about mental

illness in general. However, much of the data I gathered was confounding, causing me to deviate from my original thinking.

Further background reading and the data I was gathering led me to believe that there had been a significant shift from the Foucauldian and Goffman experiences of the mid-twentieth century. So I, at least temporarily, shelved my fascination with the idea of the Foucauldian 'medical gaze' and its control over the destiny of the patient and turned my attention towards the flow of the newer background material as well as the material gathered in from the data collection procedure. Particularly, as I began to interview participants about the more general line of inquiry concerning mental illness, the clinical experience, and the internet, I began to realise the significance of the social changes. These changes concerned the individual destiny over the experience of living with mental illness and the act of discovering the self through personal investigation. This discovery became an essential reason for readjusting the initial line of questioning and analyses of interviews, and the type of interrogation to be employed when using the textual evidences as downloaded from the internet. The new and developing social changes prompted me to think that old well-used theory, while having an important place in current scholarship, could no longer stand as an overarching concept to a contemporary social problem.

Social changes in medicine from the previously conceptualised control of medicine over the body and mind (see Foucault 1973, 1995; Goffman 1961; Rose 2001, 1999, 1996 and Conrad 2007) have opened up an area of inquiry that should explore the related social effects. As pointed out above, one way in which such changes are reproduced and may be observed is through social discourse found within the internet. These changes have influenced my

facilitating an inquiry, including internet use, which would be able to initiate future concepts about the social effects of patient knowledge, even expertise, resistance to old forms of medical power/knowledge, the future clinical experience and social attitudes towards people with mental disability. The outcome of such an inquiry may include knowledge about the future direction of mental health medicine as well as how patients encounter future life prospects of living with their disorder.

Whilst the methodology for this study does not attempt to cross over clinical case studies, I have noted that mental disorders such as bipolar disorder are clinically under considerable investigation in order to expedite diagnosis and treatment. Knowledge from a clinical level may be transferable to a social level, especially with the aid of the internet. It may, therefore, follow that from a sociological perspective, social attitudes about bipolar disorder, for example, may be dependent upon social understandings of the disorder as learned from internet reproduced medical knowledge. Due to the recent development in mental illness discourse within the internet (as above) and the ways in which clinical knowledge is reproduced through it, at this stage, it would be expected that little ground has been uncovered about social understandings of bipolar disorder. Therefore, the adventure of learning about what it is for someone to live with a bipolar disorder was to be rewarding in the investigative sense, as well as exciting due to actually being able to look for concepts previously unexplored within the context of living with a bipolar disorder.

#### **4.2. The research design: A grounding in grounded theory**

A qualitative grounded theoretical approach has, therefore, been employed so that the concepts arising from the data analyses could be built upon from the ground up in order to

form new theory (Davidoff et al. 2015, p. 2). This theory may then be used to explain a more generalised social understanding of the lives of people with a bipolar disorder and also their clinical experiences.

While grounded theory analysis employs an interpretivist and constructionist approach (see Charmaz 2006, pp. 130-1), I felt that this was doable within Foucauldian theory about the discursive formation of meaning. In Foucault's description of the history of the formation of subjectivity in, for example, *History of Sexuality*, meaning is formed within society by individual interactions of language and acts (Foucault 1978). Changes in community perceptions about what should be enacted and what should not, come about through discursive practices related to how communities are able to make certain judgments about individual behaviours. Discourses first formed by society have changed, due to arising power/knowledges that have introduced new ideas about how an individual should think and act, inventing ways of enforcing them within social discourse (Foucault 1978, p. 11). These new ideas have made objects of certain behaviours (for example, sexual behaviours) and have created subjects through what Foucault has described a 'web of discourses', comprising physicians, administrators, educators and families (Foucault 1978, p. 30). Thus, individuals are encouraged to learn from such sources of power/knowledge which effects individual 'modes of behaviour' (Foucault 1978, p. 11). While individuals may hold their own ideas of what they should be, they may be largely dependent upon social discourses that have determined 'modes of behaviour' (Foucault 1978, p.11). That is to say, the construction of the individual, by the self, depends upon how they have understood social constructions of 'modes of behaviour'.

When applied to the analysis for this study, the formation of meaning is acquired through the researcher's relationship with the self as well as the participants' relationship with themselves. These two subjectivities each depend upon how they have come to understand their world view, how this has been constructed by themselves as well as through their own particular social setting. As (Harrer 2005, p.81) explains, 'every entity is determined by something else with which it has, or whom it is in relation with'. Therefore, the construction of the subject, as arising from the researcher interpretation of data, must depend upon intersubjectivity that creates the combined knowledges, which have been brought about through the discursive formations of meaning.

Using such an analytical paradigm, therefore, also requires an awareness by the researcher of the production of theory through the process of phenomenology (understanding meaning from text, that is, from what it says to what it talks about) and hermeneutics (a method based on text interpretation) that includes a reflexive approach (Lindseth & Norberg (2004). The reflexive approach provides the additional awareness of how the researcher is positioned within the process of knowledge production. Breuer (2003) argues that most classical sociologists have used the constructionist (constructivist) method for qualitative research, regarding the object under study purely within the context of the object's culture, while failing to recognise the cultural constructions of the subject who is the researcher. The effect of this thinking and practice, as for Malinowski in his notes on his field research, was that the researcher tended to adopt a 'paternalistic' stance towards the cultural attitudes and practices of his objects (Breuer 2003).

On the other hand, as Breuer (2003) has noted from other studies, there is no such thing in field research as a fair exchange (economic exchange) of knowledges as this presupposes that both object and subject are expecting something equal in return from each other. For example, participants may feel obliged to 'accommodate' the researcher based on her/his perceived authority, and/or the notion that the research is in their best interest. As a way of overcoming such difficulties, which may be responsible for emerging biases throughout the methodological process and final thesis, Breuer (2003) recommends that constructivist research paradigms incorporate a reflexive methodological approach. Using reflexivity, researchers observe themselves as well as their participants and are involved in the production of the research, with the participants, at all stages of the research (Breuer 2003).

Barney G. Glaser and Anselm L. Strauss initiated the concept of grounded theory and wrote *The discovery of grounded theory* as a response to dissent within social sciences that qualitative research methods could not be systematic or legitimate (Charmaz 2000, p. 509). By the mid-twentieth century social scientists were preferring methods that were logical and could be verified by repetition, rather than relying on 'grand theory', which had lost its credibility (Charmaz 2006, pp. 6-7). In opposition to the rising use of the positivist methods, which tested hypotheses arising from existing theory, Glaser & Strauss worked on a method where theory could be derived from data. In developing grounded theory, Glaser & Strauss adopted Merton's 'middle-range' theories and developed the idea in order to provide a systematic way of analysing social phenomena derived from data to produce abstract concepts (Glaser & Strauss 1967, p. 32; Charmaz 2006, p. 7). Grounded theory analysis became a part of a methodology that would develop 'mid-range' theory that would enable scientific rigour without 'undue emphasis on verification' (Glaser & Strauss 1967, pp. vii-viii; Charmaz 2006, p. 7).

When I initially embraced the idea of grounded theory analysis, I felt ‘why not begin with the persons who devised the method?’ So my initiation to grounded theory began with Glaser and Strauss, *The discovery of grounded theory*. However, other leading theorists such as Corbin in Corbin & Strauss (2008) and Charmaz (2006) added the necessary descriptions for me to more fully understand the process of grounded theory. Taking advice from these three theorists helped me develop my theoretical framework from the data collection process through coding and analysis, and the development of theory.

The first question that arose for me when thinking about doing a grounded research project was “is it possible to think without a concept of something that already exists?” I already had realised that everybody constructs their thinking from what they have learned from their society and their own lived experience. Therefore, the development of a research topic relies upon certain known social constructions of ideas or concepts that enable the categorisation of a topic. Corbin and Strauss (2008, p. 39) argue that, while ‘predefined’ theoretical frameworks are not a preference in the use of grounded theory, they may serve to ‘complement’, extend or verify someone else’s research. The research topic of the internet and how people with a bipolar disorder use it is previously unexplored; however, to begin with, it does embrace theories such as communication and globalisation practices, medicalisation and individual agency.

Acknowledgement of arguments amongst peers about the originality of theoretical concepts and their generation has been made by Corbin & Strauss and Charmaz (Corbin & Strauss 2008, p. 39; Charmaz 2006, p. 48). These arguments have been specific to coding with the

intention of creating original concepts. While Charmaz notes Glaser's call for abandoning 'preconceived' ideas in grounded theory, I found comfort in the acknowledgements of both Charmaz and Corbin & Strauss to the reticence of 'novice researchers' towards the use of original interpretations of data, and that the use of 'open-ended' coding is difficult due to researchers' prior ideas and skills (Charmaz 2006, p. 48; Corbin & Strauss 2008, pp. 52-3). I found that, while my original ideas flowed more easily from the interpretation of the lower level concepts, such as how the participants for this study viewed their professionals and experienced their condition, forming the higher level concepts from which I was to organise categories, was often influenced by preconceived ideas about, for example, management, agency and medicalisation. In any case, as Charmaz (2006, p. 47) claims, we construct our codes according to our views, defining what it is and describing what is happening; that is, our codes and analyses constitute our views. Therefore, my personal constructions of contextualised events and feelings found in my data have informed my analysis. Nevertheless, some of these preconceived concepts proved useful in confirming that my earlier suspicions about social changes in power relationships had been right, as Charmaz (2006, pp. 130-1) claims, viz:-

The logical extension of the constructivist [grounded theory analysis] approach means learning how, when, and to what extent the studied experience is embedded in larger and, often, hidden positions, networks, situations, and relationships. Subsequently, differences and distinctions between people become visible as well as the hierarchies of power, communication, and opportunity that maintain and perpetuate such differences and distinctions.

Thus, using a constructivist grounded theory approach I could move forward, analysing the bipolar disorder discourse, with assurance that I could make visible some new concepts about

the experiences of the participants living with a bipolar disorder and the social conditions in which the experiences are situated.

In techniques of interpreting and coding, I found that Charmaz gave detailed descriptions about how to develop coding from concepts derived from content analysis and conversational analysis of textual material. For example, Charmaz recommends 'word-by-word' coding for the internet, a practice that aligns itself with the conversation analysis I used for investigating how people with bipolar disorder group are able to interact and share their experiences. Paying attention to in-group words and how they are used within the writers' settings allowed me to discover the bipolar identity and how people sharing that identity see themselves within the wider social world. However, while I sometimes felt it necessary to ponder over a line in the data, I found that the 'line-by-line' coding that Charmaz recommends unnecessary. I found it more satisfactory to analyse whole segments of data that explained events within specific settings, first coding the data by summarising the segments and labelling them (Charmaz 2006, p. 43). In this way, I could gain sense of when, where and how events affected the lives of people with a bipolar disorder.

According to Corbin and Strauss (2008, p. 56) 'The construction of theory necessitates that an idea be explored fully and considered from many different angles and perspectives'. In order to develop my theory from grounded theory analysis I went back and forth between the data forming a 'conceptual pyramid' in which higher level concepts, such as how people sought diagnosis, in order to develop the lower level concepts such as diagnostic steps (Corbin & Strauss 2008, p. 52). After considering the data from many angles I was able to form some mid-range theory by working through the higher and lower level concepts (Corbin

& Strauss 2008, p. 56). For example, in developing theory, I worked from the substantive theoretical area of, say, diagnosis, to form mid-range theories about how people with a bipolar disorder came to achieve their diagnosis through their individual experiences (Corbin & Strauss 2008, p. 56). As Corbin & Strauss (2008, p. 56) explain mid-range theories may then be used to develop more formal theories of higher abstraction by drawing from several studies of similar kind which, together, can be used more widely; for example, studies of how people with other mental illnesses achieved diagnosis, thus elucidating a range of diagnostic experiences.

Using the internet as an integral resource for this research project, the aim of the inquiry has been to investigate what type of mental health discourse people with bipolar disorder are engaging in through the internet. Placing the internet within its social context, the investigation also examines the ways in which the internet is ‘democratising’ and ‘empowering’ to health consumers and in what ways individual engagement with the internet has affected the doctor/patient relationship for people with a diagnosed bipolar disorder. The overarching question used for the investigation illuminated considerations of the internet in its role as a forum for talk and an information source, and how the internet media may influence social and medical understandings of bipolar disorder. In summary, using grounded theory analytical techniques, I have been able to develop some ‘mid-range’ theory about the ways in which people with a bipolar disorder learn to manage their lives.

#### **4.3. The data collection procedure**

Since I had decided that the personal experiences of those who have been living with a bipolar disorder would be likely to provide the best kind of material for this investigation, I

sought out groups of people who identified with the disorder by using a purposive sampling method (Berg 1998, p. 229; Krysik & Finn 2013, pp. 161-165). Using this method of sampling, I decided to choose three different data sources.

To begin with, since the internet was a key to my investigation, the data were collected from internet chat site content and written online testimonies in order to explain and explore how this particular group of people were engaging with the internet, and were learning to manage living with a bipolar disorder (Denzin & Lincoln 2000, p. 8; Arber, 2001, p. 61). The site content was downloaded to a computer and stored.

Being an Australian study and in order to narrow the focus of the investigation to a workable size, I focused upon websites that are Australian-run. Keying in the words “list of mental health organisations in Australia” returned 553,000 results. The search engine then directed me to a list of thirty most popular Australian web sites for mental health organisations within Australia. However, nearly all of these organisations failed to meet my selection criteria, which was for a sample of adults with a personal experience of bipolar disorder.

Organisations catered for mental illnesses generally. Some were directed towards people too young to fit the age criterion of ‘adult’. Others offered online self-help programs, advice, self-tests, information resources, and were engaged in anti-stigma campaigns. Although three, *beyondblue*, Headspace and SANE Australia offered a direct counselling ‘lifeline’ crisis support, only *beyondblue* and SANE Australia were open to online chat between group members, and only SANE Australia categorised a chat site for bipolar disorder. Some sites, for example, Grow Organisation and *beyondblue* displayed personal testimonies but these

were short: Also, these testimonies rarely could be identified to be bipolar disorder-specific. My discovery of the Black Dog Institute writing competition made it easy for me to identify, through their annually-set essay topics, the bipolar-specific content of personal testimonies. Thus, my final internet sample included The Black Dog Institute for personal testimonies, and the SANE Australia ‘bipolar’ chat forum.

The SANE Australia organisation is a national charity that provides online help and support services and information for people with a mental illness as well as being concerned with community awareness (see [www.sane.org](http://www.sane.org)). Their programs include suicide prevention advice, aged care mental health services and a ‘StigmaWatch’ program, which encourages people to report on stigmatising media representations of mental illness. I consider the SANE Australia site to be an active site because it provides online access to individuals through a direct help contact line and its chat site. Most sites, I found, could be called passive because they only display visual and textual content that are not spontaneously interactive, with only email or organisation phone numbers provided for personal contact. Because of its online activities, I chose the SANE Australia site to collect content from its chat site on ‘bipolar disorder’. Including content from a chat site allowed me the opportunity to explore the identity of a bipolar group and how they are able to communicate about their disorder as a common-interest group.

This chat site was open to public view meaning that I was not obliged to make my presence as an observer noticed. Ethics approval was not obtained as the data were publicly accessible akin to publicly available information in newspapers and magazines. I referred to Eysenbach and Till’s (2001) outline about how to determine the ‘publicness’ of this forum: (i) the SANE

Australia site required no registration or subscription to gain viewing access to the discussion threads; (ii) the number of users (as listed on the forum) were in the thousands, thus making it a large public forum; and (iii) the forum did not use any signage to discourage health professionals and researchers from viewing the content. As an added precaution, in line with standard ethics protocols, I have excluded all forum names of the participants and any personal identifying information from the analysis.

At its website, The Black Dog Institute refers to itself as a ‘not-for-profit world leader in the diagnosis, treatment and prevention of mood disorders such as depression and bipolar disorder’ (Black Dog Institute, accessed Jan. 2016). Professor Helen Christensen is the Chief Scientist and Director of the Institute and leads a team of approximately fifteen researchers. Professor Christensen is also a Professor of mental health at the University of New South Wales. The Institute is situated within the Prince of Wales Hospital, Randwick, New South Wales. The Institute is, therefore, strongly clinically oriented with affiliations to scientific research into depression and bipolar disorders. I chose the Black Dog Institute for the substantial amount of content of written personal testimonies about bipolar disorder, found at its ‘writing competition’ page. The written personal testimony offers an account of life experiences that have been carefully considered by the writer and edited, giving a different perspective of the accounts from the other two sources I used. I found the personal testimonies fascinating and interesting to read as they led me through the life experiences of the person with bipolar disorder in the narrative, chronological style.

In order to facilitate the interviews, I selected some mental health organisations to contact for the purpose of recruitment. A few of these were responsive and gave me assurance of

assistance with the recruitment. Previous public advertising for recruitment through libraries, community centres and professional suites did not yield any responses. I interviewed 10 people with a diagnosed bipolar disorder. The table lists the participants, using pseudonyms, and provides their demographic detail:-

**Table 1 Interview demographics**

<i>Pseudonym</i>	<i>Age (years)</i>	<i>Sex</i>	<i>Single/partner/divorced</i>	<i>Education</i>	<i>Occupation</i>
Graham	30	Male	Single	Academic tertiary	Unemployed
Helen	36	Female	Divorced	Academic tertiary	Public relations
Catherine	35	Female	Divorced	Academic tertiary	Financial services
Jim	48	Male	Partner	High school	Clerical worker
Maria	59	Female	Partner	Academic tertiary	Teacher
Mayra	35	Female	Partner	Academic tertiary	Doctor
Elyse	33	Female	Partner	Academic tertiary	Teacher
Jane	51	Female	Partner	Academic tertiary	Journalist
Zoe	34	Female	Partner	Academic tertiary	Teacher
Deryn	68	Female	Divorced	Academic tertiary	Teacher

Table 1 shows that data were collected from 50% of young people, that is, people under 36 years of age, two middle-aged participants (36-49 years), and three older people (50 + years). The ratio of female to male participants is high, which does not reflect the life-time prevalence for bipolar disorder female/male ratio of 1:1 (Altshuler et al. 2010, p. 710). The ‘partnered’ ratio represents those people who were partnered or ‘married’ at the time of interview and does not include re-marriage or previous partnerships. The occupations of all, except Jim who had completed secondary education, indicate a high to very high tendency for

academic achievement. However, ‘occupation’ does not represent changes in employment, time off from work, part-time ratios, or previous employment that was terminated.

The selection of chat threads:

Upon entering the online Sane site, links were selected, beginning with ‘forums’, then selecting ‘lived experience’ as being the most relevant term for the data collection, which was then followed by keying in the term ‘bipolar’. A link at the ‘bipolar’ page provided the ability to ‘select by date’ enabling the selection of chat topics from the most recent conversations. For this study, a 6 month time period was selected, occurring from 1<sup>st</sup> October, 2014 to 31<sup>st</sup> March, 2015. Threads of conversation within discussion topics were sorted for the most relevance; not all were about bipolar disorder and some only briefly mentioned bipolar disorder. The three most relevant threads containing the largest number of conversations within the thread, were finally selected (see tables 2 and 3 below):

**Table 2 Items selected from SANE Australia site chat threads under ‘bipolar’ between 1/10/2014 and 31<sup>st</sup> March 2015:**

Category of discussion\*

Title of discussion	Our experiences	Looking after our wellbeing	Enjoying time with others	Something’s not right	What’s new, research & technologies	About the forum	Special events
New member						1	
Anxiety issues				1			
Quitting smoking		1					
Getting creative energy to slow again	1						
ECT treatment	1						
Bipolar and work	1						
Work, family and play				1			
I am not invited	1						
First timer searching for hope	1						
Newly diagnosed with bipolar disorder				1			
Looking for friends	1						
How do you talk about your children?							1
What’s out there for bipolar?					1		

Meds can be so hard to take	1						
Bipolar type I with schizophrenia and manic depressive disorder	1						
Hi everyone	1						
Who do you turn to when you need help?				1			
A poem maybe			1				
Relentless imaginary conversations	1						
Just dropped in to say hello	1						
A life full of mental illness	1						
The joke's on us stand up for mental health	1						
How do we stop doctors neglecting physical illness?	1						
Weighed down	1						
Complex PTSD	1						
Being real		1					
Not sure				1			
Things not to say to someone with mental illness	1						
Good ideas thread						1	
So you had an experience				1			
What's the difference between voices and voices?	1						
Mania or manic?				1			
Depressed and manic				1			
Living with mental illness and making friends	1						
Being managed or let go for mental illness	1						
Apps to train the brain					1		
Medication and hospital				1			
Up vs downs	1						
Same e for depression anyone trying it					1		
Treatment options	1						
Changing minds						1	
Hya			1				
Welcome Wednesday			1				
Feeling lost	1						
Dealing with diagnosis	1						
Despair potential trigger: Abuse				1			
Ask anything Monday							1
Life sentence for a crime I did not commit	1						
The decision to take medication	1						
Anger management				1			

Managing schizoaffective disorder		1					
My life is an acronym	1						
More than my diagnosis		1					
Drug induced psychosis				1			
Relationship between trauma and other mental illness diagnosis	1						
Living with bipolar disorder	1						
Still a little confusing	1						
The effectiveness of treatment for mental illness	1						
Speaking about mental illness stigma		1					
BPD+ADHD+PTSD who am I?	1						
Q&A tonight on ABC							1
Organic and natural therapies					1		

\*Each discussion category, for example, ‘our experiences’ had been categorised by SANE Australia. These headings indicated to the viewer and contributors what type of conversation would be likely to be found. For example, I found that ‘our experiences’ led to material about people’s life experiences with mental illnesses including bipolar disorder, and I found material pertaining to ‘looking after our well-being’ was usually about the management of, sometimes, multiple disorders. The headings at the side of the table are the actual titles of chat discussion threads that were initiated by the contributors. These titles had been placed by SANE Australia under the set categories (marked ‘1’). The replies under each title then followed along the lines of the set discussion title.

**Table 3** *Those threads more specifically talking about bipolar disorder:*

Title of discussion	No. of replies
Bipolar and work	2
Bipolar type I with schizophrenia and major depression	11
Feeling lost – depression, anxiety and bipolar II	11
Dealing with diagnosis: Bipolar II	2
Life sentence for a crime I didn't commit	9
My life is an acronym (BPD, ADHD, PTSD and manic depression)	7
Relationship between trauma and other mental illness diagnosis	39
Living with bipolar disorder	3
A life full of mental illness	7
What's the difference between voices and voices?	25
Being managed or let go for mental illness	17
Treatment options	2
BPD+ADHD+PTSD+bipolar – who am I?	9

Table 3 shows how topic headings (titles) were selected to identify the number of threads with the most relevance to conversation about bipolar disorder. As the title of each discussion thread did not necessarily indicate an entire relevance to bipolar disorder, conversations were sifted for the most relevance and then countered by number of replies.

Collection of the testimonies: Twelve (12) online testimonies found at the 'writing competition' link were collected from Black Dog Institute site content. These testimonies, ten of which were taken from the year 2007 competition (entitled "The getting of wisdom: Managing the highs of bipolar disorder") and two from the 2009 competition (entitled

“Tackling mood disorders in the workplace”) were chosen because of their specificity to bipolar disorder and were, excepting two, written in the first person.

Collection of data by interview: Recruitment for interview about a sensitive topic such as bipolar disorder can be difficult and frustrating for the researcher. I found that the best way to recruit participants for interview was through some of the local Melbourne-run mental health advocacy sites. By contacting some not-for-profit organisations for mental health, and, in particular, those who supported people with a bipolar disorder, I was able to approach some helpful gate-keepers. Using gate-keepers is useful for ‘gaining entry’ into groups of people who are considered to be vulnerable, private and hard-to-access such as a bipolar disorder group (Krysik & Finn 2013, pp. 163-5). My initial contact with a representative of an NGO was then followed up by sending my flyer and explanatory statement. I made myself known to the ‘gate-keeper’ concerned, who then undertook to take action to recruit on my behalf. At the conclusion of an interview, after having formed a good rapport with the participant, I then asked the participant if they could possibly approach other people who would be able to contribute to the project, another purposive sampling method called ‘snowballing’ (Krysik & Finn 2013, p. 163). This method of data collection is often used until saturation is reached, a criteria already met by the tenth interview in this study (Krysik & Finn 2013, p. 163).

Interviews were conducted face-to-face, recorded and transcribed. Semi-structured interview techniques have been used in order to guide the participants’ narrative according to the information sought about their engagement with the internet and also their life experiences prior to and after diagnosis. Using the probing technique, I was able to explore each individual case in depth, by allowing the dialogue to develop, encouraging participant

recollection of their individual experiences, listening while each participant told their story in their own way (Berg 1998, pp. 61-3). I found my respondents keen to tell me their story and each was able to explore their past and present experiences in an extensive way. Therefore, by using the semi-structured interview method I have achieved a collection of rich and full data.

#### **4.4. Coding and analysis**

All data has been coded by choosing categories by way of a generating a list of ideas interpreted from the phenomena that lies within the data, in an inductive process that may be referred to as the first-stage of analysis (Braun & Clarke 2006). Coding was achieved using the qualitative research NVivo computer program. Selecting across the three data sets mentioned above, I am using three forms of analyses each best suited to the type of data being analysed, that is, the narrative testimony, chat threads and interviews. This next stage of analysis requires a broader interpretation of the phenomena under investigation, achieved by developing themes to form arguments about the phenomena (Braun & Clarke 2006). Placing meaning from data into themes may be used across a wide genre of qualitative inquiry and is an analytical technique which has been undertaken within this study (Braun & Clarke 2006).

Grounded theory analysis: In grounded theory the researcher looks for patterns in the data which indicate themes of similar ideas, much as for thematic analysis (Braun & Clarke 2006). However, where grounded theory differs from thematic analysis because of its commitment to generating a theory, thematic analysis seeks to identify and report themes within the data (Braun & Clarke 2006). A grounded theory approach for this study has been useful for,

firstly, categorising often recurring themes immediately apparent within the text and interviews analysed, as per Table 4:

**Table 4** *Categories and their properties derived from first level analysis of the data*

<b>Category</b>	<b>Property</b>
<b>Advocacy</b>	What telling the public does; the value of the narrative
<b>Agency</b>	Help-seeking, control of mania, resistance, denial
<b>Bipolar personhood</b>	Learning to recognise the bipolar self, knowing the label, performing the style
<b>Chronicity</b>	Age diagnosed; history of events
<b>Collective challenge</b>	Forming
<b>Diagnosis</b>	What the diagnosis brings to the person
<b>Diagnostic steps</b>	Amount of clinical consultations; time taken to reach diagnosis
<b>Disclosure</b>	Telling other people
<b>Friends and family awareness</b>	Witnesses to mood swings
<b>Social support</b>	Relationships in workforce, Friends, other community
<b>Social experiences</b>	Effects of living in community, workplace and with friends
<b>Helping others</b>	Sharing experiences
<b>Knowledge quest</b>	Information sought via internet, community or advocacy groups
<b>Scientific knowledge</b>	Information acquired that is scientifically based
<b>Lived experiences</b>	Phenomenological descriptions
<b>Management and containment</b>	Self-surveillance, techniques for controlling moods, institutional interventions
<b>Management and treatment type</b>	Pharmaceutical, psychodynamic or natural therapies
<b>Stigma</b>	Real or perceived social stigma
<b>Subjective experiences</b>	Experiences with providers or institutions
<b>Bipolar community</b>	Chat sites or face-to-face communities

In coding for grounded theory, categories and their properties are generated from the data, categories being a 'conceptual element' of theory and a property being a 'conceptual element' belonging to the category (Glaser & Strauss 1967, p. 36); for example, I generated the concept of 'management', under two separate categories, whose properties together explained how people with a bipolar disorder recognise and manage the manic and depressive episodes. The process of developing a 'term' into a conceptual 'category' transforms a mere descriptive term, for example, 'management', into a concept of what I mean by 'management', that is, management through, for example, 'self-surveillance' and management through treatment type (Charmaz 1990, p. 1168). These first devised categories are 'lower level' categories and are recognised easily from within the data.

Following the initial coding process, I began to revisit the data for further scrutiny of the categories generated, a process which leads to 'higher level' and more abstract concepts, which explain the kind of phenomena under investigation (Glaser & Strauss 1967, p. 36; also Corbin & Strauss 2008, p. 52). Checking and refining concepts already developed, pinpointing information about specific issues helps to reify and further develop theoretical concepts, a process referred to as 'theoretical sampling' (Charmaz 2000, pp. 519-520). This process then led me to develop ideas about diagnostic experiences and the personhood of people living with a bipolar disorder.

In order to form categories as above, I used some pre-conceived assumptions, referred to as 'informal theory' or ideas. These are ideas which are not as yet evidence-based theory, as developed later in grounded theory. Through examining the data, I made, for example, assumptions about 'diagnostic-steps' because of constant comparisons of the data that led me

to recognise that people with a bipolar disorder engage in a series of life decisions that lead them to seek out a formal diagnosis. My original pre-conceived assumptions about 'diagnostic steps', however, must be based on my own understandings that are linked to my 'substantive' interests (see Charmaz 1990). In other words, my assumptions are a product of my understanding of the world and how I form words which carry meaning or concepts and apply that meaning to my interpretation of the data. Therefore, when I am using a grounded theory approach to my study, I am doing it from a social constructionist approach because I have already formed my ideas from the ways in which I have constructed meaning of my world and how I use that meaning to inform my interpretations of my data (see Charmaz 1990). By the same token, in following this research strategy, I am able to build my concepts by asking myself a series of questions about how the text under examination is constructed, by whom is it constructed, and what does it tell me about their beliefs; and the consequences that are the result of their constructed beliefs. In this way, I am able to discover what people think, feel and do in order to form concepts about their social construction of their lives from the ground up (Charmaz 1990).

Considering, then, this reflexive approach to analysis, I refer to Breuer (2003) who argues that due attention should be given to the power/knowledge relationships that are used in the construction of theory from the field and text. Care should be taken with regard to researcher interpretation and the formation of meaning as it is comes to light through researcher/participant dynamics. The formation of meaning is constructed as a result of two different life experiences, that of the researcher and participant, that effect the power/knowledge dynamics present in any observation and interaction (Thorpe et al. 2017). However, power/knowledge is not always the privilege of the researcher. Thorpe et al. (2017) found that face-to-face encounters, in semi-structured interview, presented social

‘characteristics’ of the researcher and participant that shifted the power dynamics during the interactions that took place. Rather than trying to position the self or the other as having the higher ground, it was a matter of being prepared for a changing positioning of power/knowledge that could even change the roles of the researcher and participant. For example, as Thorpe et al. (2017) found, social ‘characteristics’ pertaining to generational knowledge could change the knowledge/power relationship between the researcher and the participant in such a way as to effect switching the questioning from researcher to participant (Thorpe et al. 2017). Thus, it could be considered that the same type of effect would be encountered within this study where there would be power/knowledge exchanges between the researcher and participant, according to cultural knowledges that formed social identities, based on age differences, economic status, cultural beliefs, and education levels, for example.

Conversational analysis - chat sites: For this study, conversational analysis (CA) complements the grounded theory used in the initial stages of coding as it provides an additional method for refining the ‘higher level’ of analysis: This is because it is used to consider ‘details’ and ‘subtleties’ that lie within human communication, such as found within the internet chat sites (ten Have 2007). Thus CA may be considered to be useful to the process of developing any ‘particular’ meaning embedded within the online talk, selected from the internet chat forums, into the broader concepts that will explain social understandings and attitudes about bipolar disorder. Since conversation is ‘organizational’ and ‘procedural’, as it follows an order of shared talk, rather than dialogical as in interview, or autobiographical as in written narrative, it is useful for showing how groups interact and therefore serves as an additional analytical tool for showing ‘how’ discourse about bipolar disorder is performed (ten Have, 2007).

Content analysis – testimonies: In contrast to conversational analysis, content analysis arguably offers a more rigid adherence to positivism because it is ‘objective’, ‘systematic’ and ‘quantitative’ and maybe limited to ‘counts of textual elements’ (Berg, 1998, p. 224). While conversational analysis looks for fine detail within data, content analysis focuses more on the broader picture and may be likened to reductionist science where the broader concept is used to narrow the findings (Mir 2010; Berg 1998, p. 225). Content analysis organises elements of text in much the same way as grounded theory is used for selecting content for categorising and organising data (Berg 1998, p. 225). For written testimony, content analysis offers a way of analysing what the subjects have said about their life experiences through the words they have chosen to explain the particular cultural context within which their experiences are formed (Berg 1998, p. 225). In this way, content analysis helps to understand bipolar disorder from the perspective of the writer and the ways in which he/she uses language, which is useful for explaining how the individual with a diagnosed bipolar disorder is situated within their particular social setting.

Narrative analysis – interviews: ‘Narrative analysis refers to a family of methods for interpreting texts that have in common a storied form’ (Riessman 2008, p. 11). Initially, the guided questions inform the type of story that emerges during the interview. Text, from interview, as for this study, may then be used, as in a grounded theory approach, to modify the questions in order to explore more deeply concepts arising from the stories (Burck, 2005). The concepts may then be developed, using the ‘feedback’ system, a ‘recursive’ and ‘iterative’ process, as in the grounded theory process (Burck, 2005). Using the text from interview, narrative analysis allows the researcher to explore ‘how’ and ‘why’ the particulars of the story are told, rather than focusing on the content in which words give meaning, as in content analysis (Riessman 2008, p. 11). Therefore, for this study, narrative analysis brings a

third perspective to the analyses used for the chat sites and written testimonies because it focuses on ‘plots’ and ‘plot-lines’ as used in a story (Burck, 2005). Narrative analysis, therefore, brings to this research a longitudinal perspective, assists in creating a sense of the place where living with bipolar disorder has been experienced, and it helps realise the significance of the relationship between the story teller and the audience (Riessman 2008, p. 11; Plummer 2001, p. 44). In this latter respect, narrative analysis could also be used for the written testimony, but has been chosen for interview in order to inform the research according to the particular line of inquiry for which the topic questions have been devised, not obtainable from a pre-written testimony. I thought it more appropriate to analyse the written testimony for content that had been pre-written for a broad audience thus permitting the analysis of the contextual setting meant for such audience. Also, the written testimony does not allow for the dialogue between the interviewer and participant that helps form the story around the guided questioning (see Riessman 2008, p. 23).

#### **4.5. Validity**

Glaser and Strauss (1967, p. 224) have strongly argued against applying quantitative-positivist methods of checking the accuracy of research, such as verification of ‘sampling, coding, reliability, validity, indicators, frequency distributions, conceptual formulation, hypothesis construction, and presentation of evidence’. In fact, the ‘flexibility’ applicable to qualitative grounded research cannot be verified in the same ways as for traditional empirical quantitative research (Glaser & Strauss 1967, p. 224). Instead, Glaser and Strauss (1967, p. 224) suggest judging the ‘detailed elements of the actual strategies used for collecting, coding, analysing, and presenting data when generating theory, and on the way in which people read the theory’.

Referring to the writings of Steinke (2004), Flick (2004) and Glaser and Strauss (1967) as a guide, I used six methods of checking the validity and rigour in my research. These are (i) a constant comparative analysis; (ii) member checking, (iii) triangulation; (iv) negotiating and reviewing the working relationship between each interview participant and me; (v) a detailed and structured sampling method; and (vi) reflexivity in interpretation:-

The procedure of constant comparison analysis is used for generating theory from the data for coding and analysis jointly (Glaser & Strauss 1967, p. 102). Using this procedure, I systematically scrutinised the data from the three sources I used for similarities and differences in the text that may indicate, first, a category for coding a segment of data, such as life experiences, and, second, for any material that related to the properties of a category, such as how individuals experienced life. As the material became more abstract I then compared the types of abstraction, for example, in what ways people with a bipolar disorder viewed 'being normal' and measured normality. During this process, I was able to verify what I found, within the material collected, by the numbers of times the same or similar forms of discussion arose, and by comparing the ways in which language was used to express similar feelings.

Using participants to check my theoretical findings was not possible for this research project, since interviews were organised on an ad hoc basis and internet text is protected by the organisations that place it. However, I did cross-check my initial coding with my supervisor as a way of validating my scrutiny and overall interpretation of the data. Selecting one sample of datum from each of the three sets of data, as a guide, we each read and marked categories

of concepts visible within the data. Then we each brought together our markings and discussed our interpretations of these texts, until we could reach some mutual agreement.

Flick (2004, p. 178) defines triangulation in sociology as a term used to ‘refer to the observation of the research issue from (at least) two different points. I used the ‘within’ method of triangulation by cross-checking material from the three data sources that had been contextualised at different times and with different people in order to check for consistency within the data, or to note what differences made sense according to the particular context within which they were observed (see Flick 2004, p. 178). I also used triangulation of data in order to ensure a deeper understanding of the data as it is a way of consolidating knowledge by accumulation of it, rather than merely a way of validating people’s experiences (see Flick 2004, p. 179; Steinke 2004, p. 185).

Steinke (2004, p. 187) recommends documentation of the entire research process as being a way of ensuring validity of the research as it is made available for ‘public’ scrutiny. My thesis has included a statement of the issue under study, the sampling methods that indicate a systematic adherence to data collection including observation of time span, how the selection procedure was carried out, the type of material collected, and how it was analysed (Steinke 2004, p. 187). Throughout my thesis, I have tried to make my evaluation of the data transparent so as to invite additional response to my interpretation.

For qualitative research paradigms philosophies have been derived to expound validity as representing the seeking of ‘truthfulness’, ‘rigor’, and ‘goodness’ (see Corbin & Strauss 2008, p. 297; Whittemore, Chase & Mandle. 2001). Qualitative research is often seen by

social scientists as being ‘creative’, ‘artistic’ and ‘interpretative’ while maintaining the quality of a scientific approach (Corbin & Strauss 2008, p. 298; Whittemore, Chase & Mandle 2001). Since qualitative research is all these things, and from the point of view of interpretation, I can only say that I have endeavoured to adhere to quality of research by revisiting the texts I examined many times to make sure that I have really seen what has been the intended message of its authors. Also, I was careful when interviewing my participants that I did not influence their responses by suggesting a particular line of thought in order to elicit more talk. I am well aware that there will always be tensions between rigour and creativity in qualitative research and, therefore, I must depend upon the disciplines of the reflexive and critical approaches to my research from the beginning to beyond the end of it. Critical reflexivity requires self-evaluation during and after the research process which is, according to Corbin & Strauss (2008, p. 300), a ‘tricky’ process that requires ‘sophistication and experience’ in order to remove researcher bias. Nevertheless, I expect that the combination of ideals and methods I have used (as above) have diminished any threat to the validity of this research (see Whittemore, Chase & Mandle 2001).

#### **4.6. Ethical considerations**

As my research was to involve people with a diagnosed bipolar disorder ethics approval was sought. An ethics form was completed and sent to the Monash University Research Ethics Committee, which issued ethics Approval No. CF13/2040-2013001060. As all of the NGO site content I was viewing was open for public scrutiny, no ethics approval was sought or required for collecting the internet site content (refer Eysenbach and Till (2001) on public forums). I was not contributing to or taking part in any chat site activity, rather I was viewing the content of the internet sites for collecting text as evidence for my research (see also

Stepeney 2014; Kendrick & Costello 2000); therefore, it was considered that there was no need for 'informed consent' to be obtained from the NGO site managers or chat site participants. However, I was required to and was granted approval to interview participants with a diagnosed bipolar disorder.

Inquiring into the private lives of people who bear the 'burden' of mental illness requires a sensitive approach by the researcher. Careful consideration needs to be given even to researching public spaces such as the internet as this could be considered somewhat voyeuristic, so I felt that I personally needed to explore the internet sites with the inquisitiveness of a researcher and yet with a compassionate, open-mind towards what I was viewing. I always bore in mind that people tell each other personal and private stories because they live in hope that by doing so they will be able to personally gain from it, either through receiving help or the personal satisfaction of helping others. In interviewing people I kept in mind that I needed to be friendly, approachable and sympathetic, rather than judgmental and authoritative. During conversation and interview with my participants I realised that they had agreed to help me with my research because they believed they were helping to contribute to the social understanding of mental illness. Therefore, I felt that I needed to honour their beliefs about my research by rewarding them with the best possible results by being true to myself and them.

For either viewing the NGO sites for content or interviewing participants I was aware of the need to be 'true' to the purpose of the research by remaining impartial to my subjects' discourse. By impartial I mean that I was careful to check myself for any internalised judgments I might find myself making about the content I was examining as I needed to be

aware of the values of the group of bipolar people I was studying. Checking my own judgements is important to the interpretation of the bipolar world as, according to Brewer (2001, p. 221), the moral evaluations we tend to make that pre-empt our judgements often, upon reflection, do not have the same 'reason-giving force' we initially think they have. By checking the 'maxims' we use in our moral judgements, the sympathy I intended to extend towards my participants could only be achieved through careful reflexive consideration of my interpretations of the text I examined (Brewer 2001).

As per Steinke (2004), Flick (2004) and Glaser & Strauss (1967), I refer to my points (iv) and (vi), above, to further explain the researcher role in the power/knowledge relationships that occur within researching and representing the lives of others. While the dynamic power relations may change between researcher and participants, and also within the entire research process, the construction of knowledge requires shifts in information outputs between the two (Ben-Ari & Enosh 2012). Ben-Ari and Enosh (2012) argue that while the exchange of power/knowledge may be a source of detriment to the construction of knowledge, through difference of opinions, it has also been noted that the exploration of differences may be profitable in the sense that differences become the source of knowledge.

Therefore, I had to make sure that reciprocity in interview was conducted as smoothly as possible. In addition, it was necessary to make sure that the art of my interpretation and writing did not destroy the compassion needed towards my subjects, and that I recorded the meaning of their experiences, as constructed by them, as accurately as possible. To this end I hope I have honoured my interview participants as well as the writers who were the subjects of my online research.

#### **4.7. Conclusion – Finding the way and contributing to society**

I initially set out to explore social discourse about mental illness as a more generalised study because I had an ‘informal’ theory or hunch that talk in the media was not quite the same thing as talk in the community. Beginning with an exploration of research, already documented on media and social stigma, I had formed ideas derived from Foucault’s concepts about governmentalities. However, through my initial face-to-face interviews my participants showed me that I was leading my investigation down a track that could not be validated because of some social changes that had taken place and the growing use of the internet in Australian households for health-seeking information.

What my participants were telling me was that by engaging with the internet they were reading and learning about a mental condition called bipolar disorder. This engagement with the internet, in fact, was precipitating a change in the relationships between the clinical professionals and the persons seeking a diagnosis for mental illness. People were often challenging their practitioners while making remarkable efforts to reach a personal diagnosis, sometimes completely on their own. I furthered my inquiry around this interesting discovery and altered my conceptual thinking. I then decided upon a grounded theory research paradigm that would allow me to let the text and interview participants lead me through their experiences in order to discover some new theories about living with a mental illness (bipolar disorder) in a contemporary society.

The three data collection techniques I used allowed me to examine the data from different perspectives that gave me a clearer analysis through constant comparison and reflection. I found that the narrative testimonies provided some text that documented a life with bipolar

disorder over time. The narrative from interview also gave me a longitudinal perspective but directed the data to speak about deep personal feelings. The chat sites revealed another perspective about being bipolar that embraces life as a member of a bipolar disorder identity, demonstrating to me how people understand each other within a like group.

The internet provides public spaces where individuals can be seen and heard or read, and yet remain bodily apart from the natural world. 'Imagined communities' (see Benedict Anderson 1983; Beck 2011) come together through electronic images and text to show the world their identity and enter into social discourse about, for example, bipolar disorder. Examining how and why people engage in internet discourse to identify their problems and communicate them publicly, I believe, will help us to understand some difficulties that are encountered by individuals within the society. Ultimately, knowing how people experience bipolar disorder, for example, can lead professionals and the communities to learn how to help people manage their condition and overcome socially stigmatising attitudes.

## Chapter 5 Normal is the cycle on a washing machine

### 5.1. Introduction

...When asked 'do you hear voices?' I said 'yes, but doesn't everybody?' You know like the inner voice. The last couple of days I've been contemplating what exactly is the difference; what is considered a regular inner voice and what constitutes voices that perhaps aren't meant to be there?... I have more than one inner voice; they have different accents and they argue with me and with each other. I'm not suggesting they impact on my life or anything but how can I respond accurately to the question if no one tells me what the norm is lol? Jo, SANE forum contributor.

...normal is the cycle on a washing machine and nothing more for me. I think I mean 'normal' in the regular sense of the word. More black and white as what is right or wrong. Though in that sense there's nothing necessarily wrong with hearing voices either. I think I am wondering more about how I can draw comparison on something that has been there for so long that for me could be seen as normal rather than something that shouldn't be there? Dale, SANE forum contributor

My psychiatrist says the difference is how you hear them, in your head or through your ears, that is, aurally. When I was really sick I actually heard them like you hear a TV. Although it was more like a kind of whispering. For me it was quite different.

Jodie, SANE forum contributor

Darned if I know how to work out if it's aural or inside. To me I can hear them and they interrupt me. I know I hear noises that aren't there and I see things that aren't there so perhaps that is the questions they should be asking me instead lol. They're real to me and always have been since childhood. They interrupt me and they keep me awake at night.

Jo, SANE forum contributor

These conversations have been taken from a SANE Australia internet chat thread where people are discussing bipolar disorder and hearing voices. This part of the SANE Australia forum is allocated to people who want to contribute to discussion about bipolar disorder. The people demonstrate their interest in knowing about the disorder through a particular text that talks around symptoms related to testing for bipolar disorder. To engage in such conversation people need to sign in; however, the forum is open to the public view. The forum does not invite comment from professionals but occasionally a moderator joins in to welcome a newcomer or to keep the conversation on topic.

The central concern in this text is about how to assess what is normal. The participant, Jo, has opened the conversation, and has expressed these concerns which have arisen as a result of a clinical consultation wherein the question was asked, 'do you hear voices?' Jo has been left with the quandary because the normality of voices heard was not sufficiently addressed within the consultation and has caused him/her to wonder about a phenomenon lived with since childhood, which is therefore normal to Jo.

Jo's contributions exemplify what several other participants articulated; how difficult it was to know when something was problematic, or not normal, and when to seek help. In fact,

help-seeking often involved coercion by family or community members who recognised problematic behaviours that they could not address. When a husband, for example, realised that life was becoming problematic due to his wife's behaviour, action was taken to find help. Sometimes, participants sought help themselves when life became unmanageable for them. However, even when finding help, satisfactory answers were not readily obtainable and individuals were left wondering about themselves for some time.

Participants expressed concerns about their accuracy in providing descriptions of the self within the clinical setting, how one should explain certain characteristics to the doctor, and how such explanations are intrinsically linked to self-knowledge and the ability to articulate. '...How can I respond accurately to the question if no-one tells me what the norm is?' was a refrain that resonated among my participants. The online replies to the quandary are about defining 'normal'. So, two main observations arise out of the conversations, one is concerning what is socially normal, and by what means does an individual assess their own normality? And, the second, what are the clinical definitions of normal and how are those definitions made clear to the patient, so that they eventually realise that they are not normal?

Within this chapter I will discuss how participants came to consider the difference between normal and what is not normal, and, also, how normal is understood within a social context. I will explain how a part of knowing normal is to understand what is real and how individual perceptions of real and normal become linked to common social perceptions that have become a social reality. For the individual, understanding behaviour and how to measure such behaviour within a social context, often requires the ability to be able to foresee the possible social implications which may arise from problematic behaviours. It is when

behaviours are recognised as problematic that people seek to pathologise the problem and seek clinical expertise. However, as I will explicate throughout this chapter, there are difficulties for participants in coming to know the difference between normal and problematic behaviour. Gaining knowledge was integral to coming to terms with disturbing behavioural episodes. Participants revealed that achieving diagnosis can take a life-time to resolve.

## **5.2. A protracted pathway to diagnosis**

The journey towards recognising what is not normal and how to process that realisation is lengthy and difficult for the individual with a bipolar disorder. Written testimonies and narrative interviews demonstrated the length of time it took to self-assess a problem in order to reach a clinical consultation, and, furthermore, to produce the type of discussions with clinicians that would ultimately result in bipolar diagnosis. Participants recalled, often as far back as early childhood, questioning their own feelings in relation to their moods, measuring how they were situated as individuals within their family and extended social environment. For example, at age 11 years, a testimony writer recalls thinking that her feelings of unease were not due to her interactions with others, but were due to her own thoughts, a self-acknowledgement that caused her to ‘dismiss the feeling’. At age 35 years, by the time she had married and had children, feelings experienced had become suicidal. Writing about herself in the third person, she recalls the moment of realisation that urgent help was required:

When suicidal thoughts prevent her from catapulting to the top [of her imaginary staircase] again, she finally acknowledges, in the timeliest and haunting way, that something is terribly wrong. Suddenly she is afraid of her next thought, petrified of her next move...the mother is hospitalised for an illness she has always sensed, but

never been able to grasp. It isn't until the mother's third hospitalisation that she is diagnosed with bipolar disorder. Testimony 7

Initial clinical help for older people (above fifty) had been at a time when the convention was to hospitalise a person presenting with mental illness in order to make a 'social reworking' upon them with the purpose of bringing them into a 'common character' (Goffman, 1961, p. 129). To be hospitalised meant that the psychiatric view of a person would have bearing on their social 'fate' confining them to the 'heavy machinery of hospital servicing', or rigid conditions enforced within the mental hospital that ensured the inmate would achieve a 'uniform status' (Goffman 1961, pp. 128-9). An example of this rigid clinical view was drawn to my attention by one of my participants, Maria, when she told me of a particular visit to the family doctor she made with her mother. Maria was eighteen years old, in the 1970s, when her visit to the doctor met with a negative clinical result. This had happened because she had complained about 'sadness and lethargy', to which the doctor had replied to her in threatening terms about sending her to 'Oakleigh', a renowned and very 'austere' mental asylum. Treatment was, therefore, not given or accepted, and the doctor never revisited. Even younger persons reported having had dissatisfaction with the clinical experience. One younger woman, called Zoe, related the time in her childhood when her mother had taken her to the family doctor because she was complaining about experiencing feelings of 'insects crawling under [her] skin': In that case the doctor had been dismissive of the symptoms, causing her to feel that they were a figment of her imagination. Such clinical conceptions about mental health, and resultant individual experiences, had inevitably led to longer life duration of living with the disorder while dismissing the reality of worsening symptoms.

When finally professional help was accessed, diagnosis was not a straight forward procedure either, often amounting to what may be thought of as a trial and error period in life for the person with a bipolar disorder. People interviewed narrated their clinical experiences which consisted of several different professional consultations, even amounting to as many as eight different professionals visited. Diagnosis usually took several years to reach for participants in their thirties, and much longer for older participants. The following sections demonstrate some difficulties associated with recognising when life was not normal, how help was sought, and some different pathways that led to a clinical diagnosis for bipolar disorder.

### **5.3. The problem of normal**

Dale (quoted earlier) understands normal 'in the regular sense of the word', that is, when used to label a cycle of a washing machine. Normal for Dale is something that is 'black' or 'white' like a commodity with which everyone is familiar. Constructing normal for Dale, is connected to something material and serviceable, and, therefore, means that a social norm cannot be associated with 'right' or 'wrong'. In this way, Dale has found a way of avoiding accepting voices as being wrong, eliminating any moral obligation to overcome hearing them, viz. '...there's nothing necessarily wrong with hearing voices either'. The preference for black and white over right and wrong for Dale may, therefore, be indicative of a process of denial of personal internalisations which otherwise would cause him/her problems. The self-denial of such internalisations may then be responsible for preventing the individual from being able to know when 'normal' is not right, and when to seek help.

In addition, one of the difficulties in obtaining a bipolar disorder diagnosis may be in the differences between clinical and social constructions of normal. While clinicians refer to a

collection of evidence-based criteria (as detailed in the Introduction for this thesis), for assessing what should be categorised as a disorder, individuals rely upon feelings associated with sensory perceptions. As I will explain further within this chapter, these feelings were usually measured by participants according to what they understood about their personal social environments and their own conduct within them.

The ways in which people come to understand and ‘conduct’ themselves can be interpreted through the philosophical writings of Michel Foucault. Foucault used the metaphor of Bentham’s prison design, the panopticon, to describe how societies use surveillance methods to govern themselves and in turn cause the individual to practice certain ‘disciplinary technologies’ upon themselves which are derived from methods of ‘self-inspection’, ‘self-suspicion’, ‘confession’ and ‘self-disclosure’ (Rose 1996, pp. 26-7; Jones 2003, p. 136; Rabinow 1984, pp. 18-19). Such practices are difficult for the person with a bipolar disorder, and may be understood better through concepts about biopolitics, biomedicine, normalcy and surveillance. If feelings as experienced by the person with a bipolar disorder are interpreted by them to be normal and life is continuing along a tolerable trajectory, then, as the above excerpts would suggest, definitions from biomedical categories and medicalisation may not be a consideration. In that case, it is unlikely that the individual will attempt to make any approaches to seek help offered from knowledge of biomedical models of bipolar disorder.

One major purpose for the need to compile a set of categories for psychiatry has come about because of some social regulations that are used to govern the health and wellbeing of the society. The functioning of society depends upon ensuring that its individuals are well and able to act within it. In order to understand how the social control of the health of

individuals is managed, Foucault has used concepts such as ‘bio-politics’, to explain how biology has become politicised; the ‘problematization’ of normal, or making health and wellbeing a ‘problem’ in order to separate out the socially desired normal from the abnormal; and ‘surveillance’, the means by which every individual must subject themselves to self-inquiry and also be subjected to scrutiny by society (Rose 1996, 2013; Lemke 2001; Jones 2003; Jaye, Egan & Parker 2006; Foucault 1988).

For Foucault, the governance of medicine, or ‘biopower’, is responsible for the establishment of ‘norms’, which are categorised as the result of ‘surveilling, measuring and reporting the population’s health status’ (Jaye, Egan & Parker 2006, p. 142). Foucault thought that the analysis of any action or attitude could be thought of as an element of a problem or what he termed ‘problematization’, and that such object of thought could be used to seek ‘truth’ by means of, for example, moral reflection, scientific knowledge or political analysis (Rabinow & Rose 2003, pp. 12-13). Thus, moral reflection, scientific knowledge or political analyses may be considered to be forms of ‘surveillance’ in that they all require an object to be surveyed, measured and reported in the pursuit of attaining the truth and establishing ‘norms’. However, the ‘problematization’ of normal has become more difficult to determine as society has moved into the twenty-first century. By the twentieth century, ‘surveillance medicine’ had ‘problematized’ normal in such a way as to lessen the distinction between normal and abnormal (Lauritzen & Hyden 2006; also see Conrad 2007, p. 87). Therefore, while the categorisation of a mental illness in the DSM-V, such as bipolar disorder, may serve ‘biopolitics’ and the potential wellbeing of the state, difficulties in using ‘surveillance’ arise when relying upon individuals to make correct assumptions about themselves according to new and developing ways of ‘problematizing’ normal.

Following the anti-psychiatry movement of the mid-twentieth century, there has been critique about ‘illegitimate medicalisation’ of the social world (Williams 2001). This critique, is no doubt adding to the complications regarding the problematising of normal. The critique has been concerned with the ‘imperialism’ of medicine which has served to, for example, ‘professionalise’ social problems, ‘monopolise’ medical services, ensure professional control over the management of disease, build medical ‘empires’ through the medicalisation of new ‘problems’ and redefine existing problems (Williams 2001, p. 137). In effect, it has been argued by others, for example, Strong (1979), that such medical ‘imperialism’ has been responsible for people becoming ‘addicted’ to medical products and, therefore, dependent upon medical professionals (Williams 2001; Strong 1979).

Medical constructions of normal as situated within a technological society also tend to change as the society moves towards using new technologies, such as IVF procedures and new forms of mental therapy, to alter bodies and minds, further problematising social and medical definitions of normal. Decisions to use medical technologies are usually based upon how ideas of normality may be enhanced, the types of individuals within a population, the numbers of people who are alike within populations, encompassing ideas about where the ‘normal variation ends and abnormality begins’ (Lauritzen & Hyden 2007, p. 9). Indeed, as Conrad (1992, pp. 12-13) argues, medicalisation (the process by which a medical frame or definition has been applied to understand or manage a problem) encompasses ‘deviant behaviour’ (for example, madness, drug addiction, infertility), and ‘natural life processes’, (for example, childbirth, child development, ageing and death). Consequently, problematising normal extends from what has been recognised to be socially deviant behaviour, to making checks and observations about human growth, ageing and dying. As problematising general health has extended to so many newer definitions, so has the problematising of mental health.

As a mental condition, bipolar disorder has been problematised to fall within the framework of deviant behaviour and has been medicalised and categorised within the DSM-V (see Chapter 1 'Introduction'). Such categorisation of mental conditions are based upon what has been recognised as the 'biomedical model' of illness, where mental disorders are characterised as 'brain diseases' (Deacon 2013). As Deacon (2013) has argued, such definitions then, have become collectively understood within social institutions such as the pharmaceutical industry, psychiatry, government agencies, patient advocacy groups, media and the public.

For the participants for this study, concepts about normal were assessed according to personal feelings about coping with life, based on ideas such as how they measured themselves within their social context; how they defined reality; how they recognised and evaluated their mood cycling associated with the intensity of feelings, or were able to measure an imbalance of feelings. For the individual, finding ways of recognising and accepting that life experiences and feelings may fit into the biomedical model of 'deviance' or mental illness, is almost certainly made difficult due to individual lack of medical expertise and fear of self-disclosure. Problematising behaviours become a matter of knowing when personal checks indicate feelings are deviant rather than natural life processes. In fact, participants revealed that in order to make such discovery, they needed to learn to engage in procedures of self-surveillance, exercising certain social and personal knowledges in order to measure their condition. However, as Weiner (2011) argues, there are 'paradoxical forms of agency' where the person with a bipolar disorder is expected to be able to exercise such procedures due to their perceived competencies (see Weiner 2011).

#### **5.4. Reality and its relationship with being normal**

Initially, for the person with a bipolar disorder the idea of a social reality may, in fact, differ quite significantly from other people around them. Until they can come to terms with what is happening in their lives, knowing normal and what is not normal, what is a social reality, and what is an individual reality may be considered to be complex and difficult to achieve.

The philosophical understanding of social reality is best understood as a set of facts that have been constructed due to a consensus of opinion which has been formed by a process of mental cognition (Finn 1997, pp. 2-3; Searle 1995, p. 1). However, some facts when objectified cannot meet mutual consent because they are not known to exist by all of society and may be open to different interpretation by moral judgment or cultural consensus. In other words how we derive the notion of reality from facts is highly contentious and largely depends upon the context in which it rests (Searle 1995, pp. 1-29). Therefore, making judgments about 'normal' and 'reality' for people with bipolar disorder may depend upon the society from which they form their own interpretations and understandings. In any case, to form one's own interpretations of what is a normal condition is also dependent upon knowing the self and making personal judgments about one's own thoughts. Sometimes, when practising self-surveillance, people tend to try to find others who share their feelings so that they can reinforce understandings about what is real and normal.

#### **5.5. Establishing norms through group identity**

The idea of normal may be dependent upon group identity and how a person is situated within the group. There has been much anthropological and social research about the relationship between how people perceive themselves and how others assess them, and that self-concepts are the result of how others regard them (McNulty, Swann & William 1994;

Goffman 1963, p. 12; Blumberg, 1972; Cole 1991; Katz & Joiner 2002). For the person with bipolar disorder, contact with bipolar groups may help to reinforce a kind of normal that is derived from commonly shared concepts of life experiences or personal traits. These commonly shared experiences may produce understandings about 'normal' that then become the group's social reality. For example, the development of the group 'norm' and shared reality was revealed by members of the SANE Australia chat site, as they discussed 'voices' they were hearing, viewed as normal life occurrences:

Well it seems to me that I have similar experiences to all of you who have posted which makes me feel like it is normal lol. Headphones to quiet them [the voices] and I do always play loud music when I drive. I don't know if I am sick or not as I am having a lot of trouble deciphering what is reality and what is not, or better put, what is real and what is fake. Kylie, SANE forum contributor

Kylie recognised that she has common life experiences with her group members which make her feel normal. For the group, this commonality of hearing voices had become a social reality through sharing experiences. Using headphones when driving may be regarded as a normal practice within any contemporary society. For members of the SANE forum, using headphones to cover over voices was a technique engaged in that was useful for overcoming manic symptoms, making them an acceptable 'norm' agreed upon by shared experience.

Weiner (2011) found similar attitudes within a group she studied wherein some members of the group talked about 'responsible cutting' and 'cutting' the body in order to be taken to hospital. In that scenario, cutting to go to hospital was a way of self-managing the bipolar condition; as above, using headphones was also a way of self-managing the chatter of internal

voices. However, as Weiner (2011) has pointed out, there is disharmony here between self-knowledge, self-control, rational judgment and rational decision-making. Therefore, although the voices were felt to exist, the techniques for dealing with them, for the participants within the bipolar forum, may indicate some differences from usual understandings of what 'voices' should be. Usual social approaches to techniques of control would be based on understandings of biomedical definitions of normal that support a socially collective understanding of reality - different from that of the bipolar forum participants. For those participants, ignoring the voices by covering them up with the use of headphones was an agreed upon practice that reinforced the hearing of voices to be a normal part of life experiences.

Therefore, to the person who experiences the chattering of voices, learning to live with a psychosis is a reality that may not be perceived by them to be impeding upon their quality of life. The quality of life is ensured by rationalising the use of headphones when driving as a way of normalising the condition. The establishment of a bipolar reality has been mutually shared and understood by the contributors within the SANE Australia chat site. Together they acknowledge the presence of voices but simply rationalise them as being inconsequential to their condition, so long as the condition is not an impediment to life. In view of social attitudes and regulations outside of the bipolar group, however, behaviour caused by hearing voices may still remain a problem because of the possible effects, for example, on driving skills.

## 5.6. Using a bipolar yard-stick for measuring social norms

While the perspective of normal and real may be agreed upon within a bipolar group such as the SANE forum, normal can also be understood in terms of how an individual imagines other people within the society to be feeling and how they make judgments about their own feelings in comparison. Svenaeus (2007, p. 168) refers to 'normal' and 'normative' as interrelated states that signify a world-engagement and embodiment of feelings within a person that include being able to engage in 'social processes, patterns of self-formation and matters pertaining to the good life ...' However, comparisons people make in accordance with others around them are dependent upon how they interpret and understand the social processes to which they are all contributors, as exemplified through two texts below.

Jane and the testimony writer imagine the social norm to be the same as their personal norm and thus failed to recognise the problem:

Diagnosis was at 29, so I don't think that I recognised that I had a real issue before that. I think that I thought I was coping like everyone else, which was, at times, not terribly well, but I think that I assumed that was the same for everybody, do you know what I mean? So I wouldn't have said until the diagnosis that I recognised it. I think that was why the diagnosis was a shock. Interview, Jane

[I dismiss] the feeling and carry on through [my] teens thinking that everyone feels and sees the world as [I] do. Testimony 7.

Comparing the bipolar self with the rest of society is made difficult if the self is to be understood solely upon the imagined (or real) social definition of normal. Jane and the testimony writer, for example, formed ideas of social ‘norms’ by observing people around them. Jane’s feeling was that other people were coping with life in the same way, which was the way she accepted life to be. Thus, comparisons between self and others within ordinary social settings, may be seen to be obscuring the detection of problematic feelings. However, people with bipolar disorder sometimes make checks with others about their own rationality:

I had a discussion with my mum regarding the night and day of my episode (I will call it) in September. Her story differs a lot from my memory of it, which makes me wonder how much of what I think has happened has actually happened and how much is a twisted form of what didn't happen. But I think I will discuss this further with my psychologist and get her view point on it as well regarding what I experience and then also what is reality and what is not... Kylie, SANE forum contributor

As described, Kylie had arrived at a stage in life where she had questioned her rationality, and she had conceded that she had a problem with knowing what is ‘normal’. The discussion with her mother showed that she needed to clarify her own feelings about her manic episode in relation to social reality. Furthermore, the difference between Kylie’s account of events and her mother’s has caused Kylie to seek professional advice where the biomedical model of normal would be used to explain reality.

From the above examples, it may be seen that there are difficulties for the individual when trying to make assessments about themselves through relying upon perceptions of their own in relation to those around them, and others’ perceptions of them. Using these examples in

relation to the Foucauldian concept of ‘problematizing’ normal may help to explain the complexities between deciding what are ‘natural life processes’ and what may be thought of as ‘deviance’. Such concepts are difficult to separate and extract from social action within everyday life, and rely upon individual abilities to assess reality and measure it within the social setting. For people with bipolar disorder ‘voices’ may be ignored and readily regarded to be normal when they are considered to be unimposing upon life. A further extension of this idea is that manic episodes can easily be ignored due to their tendency to actually enhance feelings of self-efficacy:

Yes, well I guess I have had so many up and down periods, and when I am down I don’t want to get help, I don’t even want to leave the house. And when I am high everything’s fantastic, the world’s made for me, I don’t need help. Interview, Helen

Of course I’m not manic, I am fine. In fact I’m better than fine. I feel fantastic...There’s absolutely nothing wrong with me. I’m not ill. Testimony 8

### **5.7. ‘The world is made for me’ – or crunch-time for a reality check**

Realising when thoughts and actions are not normal can depend upon how often they occur and the social consequences that are incurred as a result of the actions. Participants revealed that their manic behaviours were not understood by them at the time they occurred.

Moreover, senses that inform about adverse feelings and behaviours were often ignored in preference to the performance of mania. Believing thoughts to be rational and actions normal, regardless of being a social reality, can present opportunistic moments for the person who wants to pursue an active and eventful life. Testimonies and interviews revealed periods in participants’ lives wherein while experiencing manic episodes much could be felt to be

achieved. Participants described their mania as permitting them to be very creative, and capable of paying excessive attention to daily routine. Due to such positive feelings about mania, the disruptive reality of mania was often brought to their attention by someone else.

Helen describes a sequence of events that led her sister to have to act on her behalf:

So that was late last year – my whole world just came crumbling down, my marriage ended and I just – I should not have – I took myself off overseas for two months and had this most crazy time and I think that was the most manic that I ever felt. You know, I didn't know that I was, I was kind of seeing meaning in things that really wasn't there and it was compelling me through this solo adventure through Europe. And then when I got back – I came back and I realised, “Oh, my God, I should never have left”. And I was so irresponsible. I had bills that I hadn't paid that I thought I had, and, you know, people – it had just got out of hand. Interview, Helen

Helen saw an opportunistic moment in her life at a time when negative experiences had left her with a space to fill. However, the rush of mania that drove her ambition at the time, left her with no time to plan for the events that followed, and after she returned from her trip, it was necessary for her sister to take action to find her clinical assistance.

Not coping with life became a reality to participants only when they were able to recognise the disruption to their lives caused by manic episodes. As Helen explained, the reality which exists at the time of a manic episode is often accepted for what it is and recognised, only upon reflection, as a vulnerable or unreasonable episode in life. Manic behaviour, as described by Helen, can be ‘crazy’, meaning disorderly and uncontrolled, and, while often disconcerting at the time of experience, sometimes produces elements of much risk that can

also exceed lawfully-defined social boundaries. For example, Mayra describes how she came to realise that her actions were not in compliance with the law, and that her hospitalisation and subsequent diagnosis were a confirmation of that realisation:

So there was a leap in hindsight; there was a lead up of, um, a couple of days of sleeping very little; lots of thoughts going through the head, and a bit of hallucination but also delusional thoughts as well...I actually basically ran a red light in the middle of the night. The police chased me down and signalled me to stop, and I just waved at them. And then they knew that it was not quite right. So, I was brought in by the police. Once I was in the hospital they recognised that it was a manic episode. So they had to physically restrain me, not because I was causing any harm but because, I suppose, I was running around the hospital department. So they had to medically restrain me with a [tranquillizer] to calm me down. Interview, Mayra

Mania has risky consequences. Participants often described their mania as beginning with euphoria and escalating to the extent where they lost control of their demeanour. The following narrative testimony describes the pace and sensual pleasures of a manic episode:

Mildly spiritual feelings emerge. I'm suddenly reading star signs and buying books on astrology. I feel a bit unusual and decide to buy a book on the matter. It's called "Are you getting enlightened or are you going out of your mind?" I'm so out of my mind by then that I decide I am getting enlightened. Soon after I am having messianic delusions with a feminist twist (why wouldn't God come back as a woman?). These are intermingled with delusions of reference (everything in the paper is about me), romantic delusions (a married man is in love with me), and grandiose delusions (I'll be moving to New York to set up a management consulting company). I was getting

delusions about bombs going off, about people I love getting hurt, and eventually persecutory delusions (people are out to get me). By now I am completely disoriented and terrified. I can't dance. I can only run. And run I do. From two hospitals, one public, one private. I am on the missing persons' list for a time. I sleep in parks, in 'new' friend's houses. I have two trips in the back of police cars, the final one to hospital, where I belong but do not know it. Testimony 1

From the previous examples, participants have revealed that the reality of living with bipolar disorder is that delusions are associated with being the normal self. Manic delusions did not present a deterrent to the ways in which their lives were conducted; mania, in fact, heightened the senses and enabled the emergence of normally suppressed desires. Life became a 'dance with the devil' or an over-exuberant overseas trip, or a moment of erratic driving, all prospects which could quite well be entertained, although not necessarily carried out, by many 'normal' people.

This latter point further explains the type of difficulties people with bipolar disorder may experience when trying to make judgments about their own behaviour based upon beliefs about social 'norms'. It may be argued that contemporary societies have constructed social 'norms' that permit living in the fast lane, for example, driving fast cars, going on overseas trips, and fulfilling the senses through excessive spending. Thus, for people with bipolar disorder, experiencing mania may be interpreted to be engaging in self-conduct that is much the same for everyone else. Social 'norms' may add to the difficulties when making self-judgments for people with bipolar disorder as manic behaviour engages with all the available pleasures of life. As Bauman (2007, p. 187) has argued, the Freudian idea of the 'reality principle' and its boundaries that admit trespassers at their own 'peril' has been transformed

by modern capitalist ideas of production and consumption that rely upon the 'spontaneity' of individual desires. Therefore, it could be said that contemporary social practices of consumerism encourage acts of 'impulse', relaxing boundaries of personal constraint in such a way as to alter concepts about normalcy that could be argued to embrace manic behaviour (see also Martin 2007).

For the participants, extending the boundaries of reality was usually realised only upon reflection of a manic episode. As usual understandings of reality were blurred by mania, it is with the assistance of others within the society that participants experiencing mania were encouraged to know that their behaviour had not been normal. For example, in Helen's case, after she returned from her overseas trip, she agreed with her sister's decision that she was in need of help. For Mayra and the testimony author, the decision to be helped during mania was made by institutional interventions enforced by the police and the hospital.

With experience, participants gradually came to realise that manic episodes were delusional and disruptive to life. The following section further explores the ways in which participants became aware of their condition. It also explains some of the complexities participants experienced when trying to identify their problem and place its symptoms accurately within a biomedical category, giving them the label they needed to enable them to understand their feelings and behaviours.

### **5.8. Pharmaceutical use as the litmus test: ‘I switched into hypo-mania due to an antidepressant – that’s one way to find out’**

Several of the interview participants discussed having been diagnosed and treated by their physicians for depression. However, when they took the prescribed anti-depressants they experienced a manic episode, which was the clinical indication that the diagnosis needed to be changed to bipolar disorder.

For example, one interview participant, Graham, had experienced ‘distinct euphoria’ but it had only lasted a short time, so he had not at first recognised it to be a problem. He had also been experiencing for some time melancholic symptoms, which he had been discussing with his GP who referred him to a psychiatrist. Finally, during the psychiatric consultations, both the psychiatrist and Graham became more aware of the manic episodes because they were becoming more frequent and ‘severe’. This had caused both Graham and his psychiatrist to suspect bipolar disorder, but still not actually arrive at a firm diagnosis until Graham experienced severe mania, resulting from a change in medication, viz.:-

...I went to a psychiatrist for a few years, and I was having quite severe episodes and they were happening a lot, and I think gradually we came to the conclusion that it was bipolar, and that was confirmed when I had a switch [of mood] from an antidepressant – I switched into hypermania, from an antidepressant. That’s one way to find out. And I had thought that we had found what worked, because for three weeks I thought “I am so much better”, and then crash. Yes, that confirmed it... Interview, Graham

Another participant, Mayra, consulted her doctor because she was feeling ‘very anxious’ and was experiencing what she later realised was a panic attack. She also had been experiencing

depression. Like Graham, Mayra was prescribed an antidepressant that brought on a hypermanic episode:

So he gave me an antidepressant, so I started taking it, so six weeks later I had a manic episode – hypermanic episode. It was very clear six weeks later, I know, I was with a partner at the time and he said “This is not right, call your GP by Monday”, and when I called my GP he said “Stop the medication” and then I crashed in a way that I fell into a deep sleep for a long time because I hadn’t needed much sleep because I had been hypermanic. So that’s the beginning of this diagnosis or the search for it.

Interview, Mayra

The above examples demonstrate the difficulties that people with bipolar disorder experience in defining their problem and being able to achieve diagnosis. For individuals like Graham and Mayra, assessment for bipolar disorder comes from experiencing adverse consequences from clinical treatment as much as it comes from trying to come to terms with personal emotional feelings that are problematic.

One observation arising from the above two excerpts is that participants were usually, at first, more inclined to think of a diagnosis for depression as being the answer to their problematic feelings. It would also appear that there was a tendency for the clinical practitioner to investigate symptoms for depression rather than for bipolar disorder, possibly on account of the high population prevalence of the former, and low population prevalence of the latter.

But as Graham's account indicates, there is some length of time and personal effort made when trying to reach diagnosis:

So we had the episode in 2006 which was really, really severe and so the next couple of years there was cycling. So from 2007 to 2009 I probably, maybe three or four times a year I would cycle in and out of a depressive episode, probably at a moderate level and so it was difficult but it wasn't a huge impact on my life. But it got worse in 2010, and I was seeing a therapist at work which was quite handy, and I was seeing my GP, and I had actually brought up 'bipolar' because I had, basically, read as much as I could to try to figure out what was happening. In 2006 and onwards I was extremely well informed, as much as one can be, so I had some idea it was bipolar and had discussed it with my GP and a psychiatrist who were just dismissive of it.

Interview, Graham

Through Graham's narrative, it may be seen that the more severe cycling had brought him to do his own search for information that would lead him to consider that his condition was bipolar disorder. In this case, it was not clear why the GP and psychiatrist disregarded bipolar disorder as a diagnosis, only that they were 'just dismissive of it'. However, earlier in his clinical experiences, Graham had rejected the possibility of bipolar disorder himself, possibly because he had identified his feelings with depression, expressed as cycling 'in and out of' depression.

Like Graham, Catherine also came to her own conclusions about the fact that she had bipolar disorder before she was able to clarify it with her doctor. Before that, Catherine had consulted two psychologists: The second one she had provided with a 'very detailed history'

but a diagnosis of bipolar disorder was dismissed. Catherine had noted that her condition 'wasn't resolving' so she talked about it to a friend who had worked with people with bipolar:

I only really knew about depression and anxiety and I hadn't heard of that [bipolar]. So I went and looked up the Black Dog Institute and looked that up [bipolar] and I spoke to a psychologist I was seeing and I said "I think I might have bipolar. This is the closest thing that has ever fitted me". She said 'you might have before but you don't have anymore'. So, a year later I spoke to my friend, and then I spoke to my doctor who just went "ah, yes", and put me on medication. Interview, Catherine

The above two examples demonstrate that participants were in search of knowledge about biomedical categories of mental illness before they were able to decide where they should fit according to their symptomatic feelings. The excerpts also demonstrate that the more participants knew about themselves and were able to problematise their feelings, the more likely the outcome of a diagnosis for bipolar disorder. Both Graham and Catherine had their suggestions to their clinical professionals initially rejected until their own knowledge helped produce a satisfactory clinical outcome. For Catherine, it took a further year to find a doctor who was able to concur a diagnosis of bipolar disorder. Trying to obtain the 'right' diagnosis involved several consultations, a process that was frustrating, according to Zoe:

I'd been to four psychiatrists, I think, and three psychologists and a counsellor. So, I think I have been through maybe eight medical professionals plus doctors in between that, and I never ever got any diagnosis for bipolar: Like they never talked about bipolar. My mum talked to me about bipolar when I was in my early twenties. She said to me, 'I think maybe you have bipolar'. And I didn't listen to her, I said, 'No, I've got depression and that's that'. I don't know why - I can't remember why, but I

did that. And then it was only 2012 when I actually admitted that, yeah, something is really not right and I need to go and really press for more help. Interview, Zoe.

Zoe had initially accepted depression as a satisfactory diagnosis for her feelings. She had told me that her mother 'sort of knew a little about bipolar' but Zoe had left home shortly after her discussion with her mother as the relationship between them had deteriorated. Although Zoe later came to realise that some family members most likely had bipolar disorder, the fact that her health professionals did not discuss bipolar disorder could have been either due to Zoe's own reluctance to talk about any manic symptoms experienced, and/or that there was insufficient evidence of mania presenting within the clinical setting. An interview with Maria also elucidates this point:

In 2000 I had a very severe depression after having a very long, high manic episode in 1999, and that's when I realised that I was really unwell, and my husband also, and I went to my family doctor. She thought it was just depression because I never told her about the highs, because I only used to see her when I needed some time off, a week here or there through depression. And she put me on an antidepressant and, when I got suicidal with that, she realised that it was more than that ... Interview, Maria

My respondents frequently told me that while they were experiencing a manic 'high' they felt that they were able to achieve many things in their daily lives. Therefore, unless mania was causing disruption to their lives, they tended not to mention it to their doctor, or, indeed worry about it themselves. Participants tended to only describe their depressive symptoms to their doctor because their depression was debilitating, sometimes presenting suicidal thoughts. Therefore, the clinical tendency to prescribe antidepressants, which, as I have

noted, sometimes became the determining factor for a diagnosis of bipolar disorder. Maria's reaction to the anti-depressants was enough to inform her doctor that there was 'more than that' to her condition.

Clinically, it is well recognised that there are difficulties in detecting mania amongst depressive episodes:

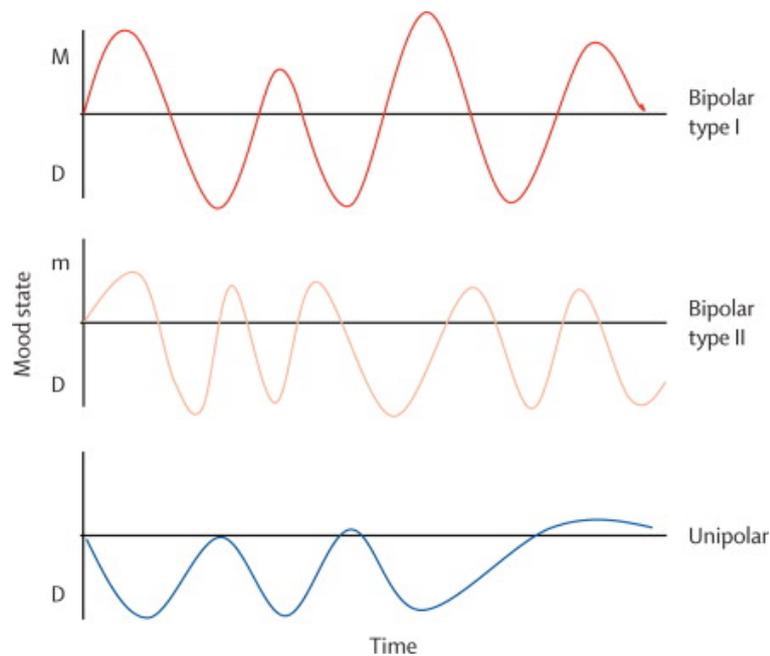


Fig. 1: Mood changes over time in bipolar disorder type I and bipolar disorder type II and recurrent unipolar depressive disorder (Phillips & Kupfer, 2013).

Especially in the case of bipolar II disorder, there is a tendency to diagnose unipolar depression because of the difficulties associated with differentiating these two categories (Phillips & Kupfer 2013). Phillips & Kupfer (2013) have noted that only twenty per cent of patients will be diagnosed with bipolar disorder within the first year of seeking treatment.

There is a mean delay between the onset of symptoms and the diagnosis of around five to ten years (Phillips & Kupfer 2013).

Clinical difficulties associated with diagnosing bipolar disorder is consistent with the experiences of my participants and may explain why their clinicians were reluctant to diagnose bipolar disorder. It may help to understand some of the difficulties my participants were experiencing when they were doing their own research, gaining information, and putting forward their ideas about their own condition within the clinic. As noted, participants took some time to reach diagnosis and spent time visiting several clinics before they actually could identify their problem and have it confirmed within the clinic.

Participants were generally more aware of depression than bipolar disorder. For example, as Catherine said, she had heard of depression but not bipolar disorder. Nevertheless, the idea of lack of awareness cannot singularly explain why people tend to be more accepting towards a diagnosis of depression than bipolar disorder. For example, fears of stigma could be an issue for most people, where bipolar disorder is not known about, let alone understood.

However, studies have revealed that there is no difference in public attitudes towards bipolar disorder and depression. Some recent studies with youth and children have found that there is public disrespect towards young people who have been diagnosed with either depression or bipolar disorder (Martin et al. 2007, p. 57; Pescosolido et al. 2007, p. 616; Moses 2014).

Other studies about depression, covering many countries, have also found that there is a significant amount of stigma and discrimination towards people with depression (Calear, Griffiths & Christensen 2011; Jorm & Reavley 2013). The factor left to consider would be

the individual perceptions that mania may be a more tolerable condition to live with than depression. As mentioned, there are characteristics associated with a mania that are mostly enjoyed by those who experience it and who, at the time of an episode, do not realise their vulnerability or the potential risks associated with it. As Maria and Helen related, they failed to mention their mania because depression was the intolerable part of the condition, whereas manic ‘highs’ felt right within their experience of life.

### **5.9. Agency and self-knowledge leads the way to diagnosis**

The following extract was taken from an interview with Jim (aged 48 at the time of interview). Jim had used the internet to search for answers to his ongoing problem. He had also been accepting of a diagnosis for depression, except that he and his wife had noticed his mood swings and were both still worried about his condition. Jim had, in fact, accomplished a significant amount of reading, including reading academic journal articles he had found by following links from some of the sites he had visited. It was his reading that finally helped him to discuss his problem with a third psychiatrist in order to reach a diagnosis of bipolar disorder:

I went back to the same psychiatrist. Shouldn't have but did and so I've been taking antidepressants during this time, so I've got onto medication. And, although that was helpful, it certainly wasn't curing anything. When I went off them, that's when I think I had the second breakdown. And then, in late 2007, I had another breakdown which led me to go to a different psychiatrist who almost diagnosed my condition but he wasn't quite on the mark. The second one, who was actually probably the [one], I should have stuck with him because he eventually would have worked it out, what was going on; but I thought, "Nah, he doesn't know what he's talking about." So I

went away again and, in 2011, had yet another major breakdown. And that was when I decided that, “Okay, I think I know what I have. Let’s confirm it.” I went to a third, different psychiatrist who pretty much, based on what I told him, said straight up, “Yes, you have bipolar II.” Interview, Jim

Jim’s story demonstrates how self-knowledge can help the individual to reach a diagnosis for bipolar disorder. Jim had begun searching for information through the internet that would help explain his feelings. Through self acquired knowledge, Jim was able to make assessments about the ability of his clinicians that caused him to challenge their knowledge and led him to doctor shop. Jim’s experience with his first psychiatrist had proven to be unsuccessful as it seems to have depended upon medication without sufficient supporting information that would help him to understand his problem. This lack of information had prompted Jim to decide not to continue with his treatment or medication, with serious consequences (a mental ‘breakdown’). In view of his past clinical experience, Jim had doubted his second psychiatrist. By the third time around, he had achieved an amount of reading through engagement with the internet, so that he felt that he had become the expert of himself. As a result of this self-knowledge, he only then needed a confirmation of diagnosis from his psychiatrist. In this case, it may be seen that the management of Jim’s condition had changed considerably from the experience with the first psychiatrist, where knowledge was believed to be in the control of the professional ‘expert’. According to Jim’s interpretation, later control over the outcome of diagnosis had been directed by himself, due to his acquired knowledge that had the effect of changing the power relationship between the doctor and the patient. As Anderson, Rainey and Eysenbach (2003) argue the internet has become a ‘mirror’

of the real world reflecting a consumer movement towards ‘self-reliance’ and ‘patient power’, an argument to be built upon in Chapter 8.

### **5.10. Discussion and conclusion**

Several considerations have arisen from the data analysed for this chapter. The overriding consideration is the length of time given to self-detection and clinical diagnosis of a bipolar disorder. Some deterrents which hinder the possibility of early diagnosis have become apparent from the data which concern how participants learned to ‘problematise’ normal, and come to learn about ‘reality’ through disruption. Being able to recognise what is ‘reality’ and how that reality fits into the boundaries of social normalcy required participants to be able to observe, reason and self-reflect. All those actions needed to be measured within social settings and participants made judgments about their own feelings according to their own interpretations of those social settings.

Biomedical models of mental conditions such as bipolar disorder define and give categories to such disorders – the ‘problematization’ of mental illness. Living in a neoliberal society, such as Australia, people use such biomedical models to seek information about their problems so that they may define them and learn to understand what it is that they are feeling. As Gardner (2007), Fullagar (2008) and Rose (2007) have argued, information seeking and problematising the self is a part of normalising responsibilities that have become a practice of somatic ethics as a key value associated with avoiding personalised health risk. However, as the participants for this study have revealed, individual action to come to the clinic has relied upon learning about a problem through personal or social judgments about ‘normal’. As the

participants have revealed there are difficulties in making such judgments when they have needed to measure their own account of 'reality' with social 'reality'.

Because social constructions of 'reality' are related to social constructions of 'normal' there have been difficulties for participants when trying to assess what is 'normal'. As I have discovered, participants were not able to assess what is the considered social 'norm' because of their confusion about their particular 'reality'; nor did they even contemplate it until their mood disturbances become too difficult to understand or manage. 'Normal' may be discussed within groups where people are experiencing similar kinds of realities. For this reason, participants found their kind of normalcy through shared feelings about reality and normalcy within bipolar-specific groups. However, shared feelings tended to have a bonding effect which may not necessarily have altered in-group perceptions of social reality or normalcy.

Sometimes participants came to realise that they may have a problem through learning about their behaviours that were being observed and discussed by people within their personal social settings. Therefore, learning to decide what is normal was dependent upon the particular social setting in which the participant resided; also, their trust in the judgments made by people within their social setting. In part, such social settings were able to provide the evidences that participants needed from which to draw conclusions about their own normalcy.

Biomedical models of bipolar disorder have defined and helped participants to understand their condition. However, some interesting evidence has arisen from the analysis regarding the clinical diagnosis. The readiness of the clinician to diagnose a depressive disorder and the

initial preparedness of the patient to accept it as a diagnosis has been noted within the findings of this study. Initially, participants found that their knowledge about bipolar disorder was difficult to discuss with their clinician. In addition, participants were reluctant to consider bipolar disorder in lieu of depression. Therefore, both the clinical tendency for a diagnosis of depression and participant attitudes resulted in having to wait for a long time before a diagnosis for bipolar disorder could be reached. From the clinical point of view, reluctance to diagnose bipolar disorder often meant diagnosis was reached through patient reactions to pharmaceutical treatments for depression: Then, it was the manic symptoms that ensued that prompted the resultant diagnosis for bipolar disorder. The reasons for why people with a bipolar disorder are inclined to accept a depression diagnosis are more difficult to discern. There is not enough evidence about stigmatising attitudes towards either depression or bipolar disorders that would indicate preferences towards a depression diagnosis because of fears of greater social judgements made about bipolar disorders. Nevertheless, participants for this study tended to seek medical advice based on their feelings of depression rather than the manic feelings. From the participants' perspective, mania could be life enhancing rather than debilitating. However, the severity and more frequent reoccurrences of mania were found to be the turning point for bipolar disorder diagnosis.

Particularly from interview, it became apparent that participants were frustrated because of the length of time it took to reach what they considered to be the right diagnosis – the bipolar disorder diagnosis. While the effect of these frustrations were negative for the clinician due to declining participant respect and consequential challenges to medical knowledge, there were positive outcomes for participants through exercising individual autonomy. Using socially-embedded notions of self-surveillance, including moral reflection, scientific knowledge, and analyses, participants were able to engage in health-seeking attitudes that permitted access to

medical knowledge outside of the clinic (Rabinow & Rose 2003, pp. 12-13). Whether engaging in chat sites, downloading information from the internet, or reading written material, participants were able to come to self-determining conclusions about their bipolar disorder diagnosis.

Participants found initially that the kind of reflection upon the self that revealed they had a problem was something to be avoided. However, living with bipolar disorder was a problem that at some time they realised needed to be identified. Many participants supported the idea that obtaining a diagnosis was a way of being able to 'move forward'. Moving forward enabled participants to plan an action towards a management regimen that would guide them towards social reality and being 'normal'. The following chapter discusses individual choices around gaining control of life for people with bipolar disorder.

## **Chapter 6 Mastering the self with clinical control**

### **6.1 Introduction**

Considerable research exists on the sociological and clinical experiences of people who participate in psycho-pharmaceutical treatments for their respective mental illnesses (for example, Parikh et al. 2015; Schneck et al. 2008; Malpass et al. 2009; Jenkins 2015; Jenkins 2010). As Janis Jenkins (2010, p. 17) argues, since the development of neoliberal market forces, there has been much interest in the anthropological and sociological understandings of the 'pharmaceutical self'. The term 'pharmaceutical self' refers to the ways in which people have engaged in the use of scientifically-derived treatments that are meant to enhance the performances of body and mind. The extent to which pharmaceutical products are being used in contemporary society in the management of health, and, also, in self-enhancement, is due to historical and cultural developments regarding the ways in which human problems are understood and treated (Jenkins 2010:17). Hardly anyone living within nations such as the US, the UK, and Australia have been left out of the choice to pop a pill as an aid to the demands of everyday life (Jenkins 2010:17).

Additionally, according to Ecks (2005), the global spread of antidepressants has transformed what people understand to be 'true happiness' with true happiness perceived as a 'human right' associated with taking pills, at least in Western societies. Concurrently, within neoliberal societies a culture of 'enterprise' has arisen whereby entities are engaged in activities that amount to maximising national and individual well-being (Rose 1996, p. 153). This culture of enterprise incorporates interactions between autonomous entities such as business, schools, clinical enterprises and individuals (Rose 1996, p. 153, 1993, pp. 295-96). Within the concept of 'enterprising individuals', Rose (1996, pp. 153-4) emphasises the

organisational forms that are involved and that need to compete on the market, be goal-driven and risk-taking, in the pursuit of transforming themselves for their own advantage.

Induced by such markets, enterprising individuals have become engaged in choices about how to reflexively examine themselves and practice certain procedures for self-enhancement. To maximise self-enhancement individuals engage in practices, referred to by Foucault as the 'mastery of the self'. The practice of *arche*, 'mastery of the self', as translated from the ancient Greek, has been interpreted by Foucault to be a form of power or authority over the self (Foucault 1987 in interview). Since 'self-mastery' concerns the practice of choosing to control oneself from being a 'slave' to one's 'appetites', Foucault interprets the practice of *arche* to be a personal freedom or liberty (Foucault 1987 in interview).

This concept aligns with most self-management practices within contemporary society, where the individual is required to be a competitive, autonomous, enterprising citizen who must make certain choices about maximising their own performance. To achieve this requirement, the individual needs to engage with a network of capitalistic enterprises of scientific and pharmaceutical developments that together are geared to ensure the maintenance of social economies (Jenkins 2010, p. 17). In other words, individual social contributions sustained through the management of the self have come to rely upon interdependent networks of pharmaceutical corporations and industrial developments (Jenkins 2010, p. 18; see also Martin 2007). Therefore, individuals achieve their goals by using institutions such as schools, universities, hospitals, the GP's surgery, families, and welfare services, as well as these institution's materials – books, pills, treatment, care – to maximise their own benefits (Rose 1996, p. 154).

However, there are inherent social and individual challenges associated with the use of pharmaceutical treatments for bipolar disorder. Side-effects include problems such as weight gain, lethargy, and have generally been associated with changes in personality, iterated as ‘blunting creativity’ (Jenkins 2010, p. 9; 2015, p. 41; Proudfoot et al. 2009, p. 124). Also, the fluctuations of mood disturbances with bipolar disorder have been found to cause difficulties with balancing medications and finding the right medications for each individual. Since mood swings are difficult to calculate, individuals tend to be subjected to medication adjustments from time to time that often amount to what has been described as a ‘cocktail’ of pharmaceuticals (see Proudfoot et al. 2009, p:124; Schneck, et al. 2008, pp. 374-5).

One of the most commonly reported iatrogenic effects of medication is the feeling of mental dulling, or ‘blunting’ creativity. This experience produces a perplexing problem for the individual because of the need to be productive within the dictates of contemporary society versus the need to be free to create. For the individual with bipolar disorder the practice of the ‘mastery of the self’ means that the freedom to be creative must be curtailed in order to control mania. Contributing to society, therefore, often comes with a personal cost, since often sought-after forms of creativity that are associated with mania, are substituted for control of mania (see also Martin 2007).

Therefore, there is an inherent tension between mastering the self to be productive versus the personal driving force to be creative. This tension forms the crux for the chapter as I explore how people with bipolar disorder negotiate their identity vis-à-vis the need to socially conform, the benefits of mania, and the search for the true self. I use the Foucauldian concept of ‘strategic freedom’ in my analysis and begin by describing the concept, and then discuss

what practising 'strategic freedoms' involves for the person with a bipolar disorder. This will be followed by some discussion about the needs for using pharmaceutical treatments, what it is like to be on such medications, and finally, why some people quit using medications for their illness.

## **6.2. Strategic freedom**

'Strategic freedom' is a term used by Clifford (2001, p. 137) to explain how Foucault's account of power relationships may be interpreted as ways of practising autonomous freedoms. According to Foucault (see interview dated 1984 with Gallagher & Wilson), power is not always dominant but rather a network of 'strategic' power relationships. As Foucault explained, 'strategic' because of the relationships of power 'struggle' with one another; that is, people are in a 'strategic situation towards each other' (Foucault 1984, p. 28 in interview; Foucault 1980, p. 142). These relationships are inter-dependent upon one another and, therefore, one relationship is unlikely to be 'trapped' by the continual dominance by the other (Clifford 2001, p. 137; Foucault 1984 in interview; Foucault 1980, p. 142). Being inter-dependent upon each other, power relationships are apt to change, affecting statuses between each other. As Foucault argues, if there were no 'resistance' to the power relations there would be only 'obedience'; so, resistance is what changes power statuses (Foucault 1984 in interview; Foucault 1980, p. 142). It is because of this flexibility in the relationships of power that freedoms are able to be expressed because there is no remaining or consistent dominant power. Individuals within such a system of power are able to negotiate their identity to have it received as being a part of their culture (Foucault 1984 in interview). However, as Foucault affirms, since power has been 'institutionalised' it has 'codes', and has been made 'rigid' by laws, which means there are limits to the ways in

which people are able to use their freedoms (Foucault 1984 in interview). Therefore, the choice to be free to perform the self within any social context has its limitations, even where power is being negotiated.

To date, Foucault's 'strategic freedom' has had limited applicability in the sociological literature on mental illness. The closest topics for academic discussion about freedoms and power relations within the realm of mental illness are found in Kelly's (2006) work which uses 'the three dimensions of power' as a theoretical explanation for the statuses of those with mental illness, and Bassman's (2005) work on refusing potentially harmful treatment and life-impairing sentencing decisions that have resulted when such individual freedoms have been practised. However, some authors, including Kelly (2006), do draw upon concepts that are analogous with 'strategic freedom' through their understandings of governance, power, autonomy, knowledge, subjectivity, agency, resistance, and regulating freedoms (Rose 2016; Verkerk 1999; Fullagar & O'Brien 2014; Fisher & Freshwater 2014; Danzer & Wilkus-Stone 2015, Rosenbaum 2016). For example, Rose (2016) discusses the association of freedom with choice and how choice may be regulated through resistance and strategies of governance. Fullagar & O'Brien (2014) discuss agency involving personal negotiations that are necessary when individuals are faced with having to make a choice between being the depressed self and being transformed into a much changed identity, without depression, through anti-depressant use. Kelly (2006) describes knowledge systems that present forms of reform to individual needs through collective social debate about current attitudes, for example, in psychiatric care.

My choice of the concept of ‘strategic freedom’ is unique in that I use it to analyse how people with bipolar disorder use their powers of freedom to choose their type of treatment, in order to negotiate their personal statuses (see Foucault 1987 in interview). The concept of ‘strategic freedom’ is particularly useful to explain people’s concerns when they have realised that the bipolar disorder has altered their marketable potential and changed their social abilities (Rose 2016 in interview; Ventura 2012; Rose 1996, pp. 150, 153-54, 158).

### **6.3. Practising ‘strategic freedom’ with bipolar disorder**

#### **6.3.1 Games of truth**

Foucault describes the scientific creation or understanding of a human subject as a being who ‘talks, ‘works’ and ‘lives’ (Foucault 1987, p. 112 in interview). Within such subjectivity, the individual is apt to practice ‘games of truth’ that involve variously imposed forms of control, whether as practised by scientific models, institutions or by the individual human subject on the self (Foucault 1987 in interview). To achieve certain ‘truths’, for the person with bipolar disorder, means that negotiations need to be made between institutions and the self as well as within the self, and it is the negotiations within the self that need to come first. For the individual, finding the ‘truth’ in the act of liberating the self means engaging in a negotiation between a ‘kind of self-love’ and the need to ‘master the appetites that risk engulfing [the self]’ (Foucault 1987, pp. 115-16).

Therefore, the practice of ‘Strategic freedom’ for the person with bipolar disorder may entail being aware of the self, recognising moods, and their consequences; practices that require self-reflection and self-knowledge. Self-reflection enables the detection of mood changes, assures personal recognition of when it is time to manage skills and personal economies, and,

it raises concerns about how to negotiate identities and deal with stigma. Self-knowledge is the knowledge gained through ones' own inquiry and by engaging in various resources such as print or the internet or self-reflection.

As discussed in Chapter 5, people with bipolar disorder learn to identify inner voices they hear, and they subsequently come to know how to recognise when they are problematic. Individuals come to realise the importance of this practice due to past experiences of manic or depressive episodes that affect their well-being. Dale, through the SANE Australia chat forum, describes the task of listening to voices so that appropriate action may be taken:

Some voices I need to listen to immediately – my intuition telling me something or someone is not safe for me (even when there is absolutely no apparent logical reason).  
Some voices I need to ignore or refute when in my rampant self-hatred, destructive mode. Some voices I need to sit with for a while for my own or others' well-being, when I'm asked to do something differently or change in a way that is challenging or frightening...That is when I need to be quiet long enough to hear the still, small voice that tells me I am loved and loveable.

As evidenced from this quote, people with bipolar disorder learn to recognise ignoring risky thoughts will have negative consequences. Dissociation with destructive and self-hating voices, focusing on being able to love and be loved, indicate that participants can learn negotiations of 'truth' to resist against doing harm to themselves and others. Moreover, by disciplining and restricting the more destructive aspects of mania, people with bipolar disorder do recognise the importance of being able to give and receive respect, affection and friendship. In this way, individuals are seen to be practising 'truth games' about themselves

that enable a change of personal status. Foucault (1980, p. 139) argues that ‘truth’ may be understood to be what is ‘censored’ and ‘forbidden’. As for Dale, participants surveyed their own thoughts and behaviours and recognised certain ‘truths’ about themselves. The practise of acknowledging ‘truths’ about the self, and choosing to comply to certain social understandings about being loveable highlights that participants exercise agency in choosing to accept social conventions based on knowing what is best for them. As Foucault (1980, p. 142) hypothesised, in the practice of strategic power relations there are roles that are engaged in by actors that are in accordance with a ‘condition’ and require ‘conditioning’. Thus, practising ‘strategic freedom’ entails negotiation when hearing conflicting inner-voices (the conditioning) and the need to be thought of socially as a worthwhile person (the condition).

### **6.3.2 Irrational pasts and the rational present**

Seeking out ‘truths’ from knowledge institutions such as scientific or clinical institutions has advantages for the individual. One advantage gained for the individual through having institutional power relationships with the ‘psy’ sciences comes with the ability to achieve diagnosis. With the knowledge that diagnosis brings, there are personal freedoms about making choices that have the potential to transform the self.

Diagnosis brings a containment label that draws a circle around actions that have previously been accepted simply as being a phenomena of a particular personhood. The ability to separate out irrational actions related to being bipolar, from the familiar aspects of personal identity can be transformative (see Malpass et al. 2009, p. 166; Paterson et al. 1999, pp. 791-93). However, Martin (2007) argues that rationality and irrationality are not clearly separable and that there are certain ambiguities between ‘performing’ being manic after knowing one

possesses manic traits (through diagnosis), naturally ‘performing’ mania, and rationally being aware of such performances. Also, there are tendencies to drag other people into performances within a particular setting that make it difficult to actually separate what is a ‘consensual reality’ or ‘scientific rationality’ from what is irrational (Martin 2007). In the below excerpt, Maria’s husband perceived her performances as being ‘what it is’ and accepted her actions as a way of life. The freedom to perform actions prior to any knowledge of bipolar disorder meant that life decisions were made that were considered to be rational at the time but were detrimental in hindsight. Therefore, the choice to seek a diagnosis and receive treatment was made on the basis of lost life opportunities that eventually were seen as an encumbrance.

So I agree that the negative effect of my bipolar was the fact that I didn’t necessarily think through things. And...I probably would have liked to have stayed teaching and I would have been able to plan my path a little more in consultation with my boss. That would not have been a problem. And the other negative impact, actually, was financially in that, due to my anxiety, I made decisions which I coerced my husband to be a part of, and we lost a house, financially, that we could have maintained – a rental house, so that’s impacted on our finances greatly. However, my husband is quite relaxed about that – he’s said ‘well, it is what it is’, and he does not have a problem about it at all, which is wonderful. If he had known of my diagnosis - that was before I was diagnosed - he would have taken charge and understood that I was making these rash decisions because I wasn’t well. Interview, Maria.

This quote is an example of where personal awareness about experiencing loss of life opportunities drives the necessary imperatives for seeking help (see also Lim et al. 2004, pp.

812-14). The subsequent knowledge gained through negotiation with the clinic helps identify and treat a problem (see also Proudfoot et al. 2009, p.125). It may be argued, therefore, that the knowledge gained through the clinic has a transformative effect upon the individual as they have been guided to re-interpret past events. Events, once viewed as normal, are subsequently noted to be failures and disappointments that have become emblematic of the condition and the irrationalities that the condition itself creates. However, it should be noted that the association of past events with a newly diagnosed condition may not necessarily mean that the correct connotations have been placed upon the events, as most people, irrespective of whether they have a mental illness, do make mistakes that they later come to regret. Nevertheless, the following participant self-reflection also supports the idea that knowing the symptoms of bipolar disorder enables the individual to take the necessary precautions towards their own behaviours:

I don't really go to work unless I am stable. I wouldn't go to work if I was unwell – that's the thing, I would never go to work unwell. I only ever went to work unwell one day in my life and it is the biggest mistake I ever made. You just can't go to work in front of children unwell. By the end of the day I really felt like this was a bad choice. Because I just didn't feel that I was giving my best. Interview, Zoe.

The above excerpt also shows that rational decisions about behaviours are able to be made once there has been some acquired knowledge about the consequences of a mood disorder. The experience of mania has brought about a reflective awareness that moods unchecked can produce performance-impairing results. Once again, the ability the individual has to recognise when they are not in a rational mood comes with rationally being able to identify

when manic symptoms are arising. The freedom to choose not to go to work comes with the knowledge gained from past experience.

Participants showed engagement in practices of personal negotiations that have resulted in gaining knowledge about their condition. Using that knowledge, participants have employed 'strategies of freedom' to make checks on themselves to assess rationalities. Participants' concerns for conduct that has impaired life performances was what drove them to 'master the self', limiting their actions and re-organising their lives to accommodate for their condition.

### **6.3.3 Seeking validation of the self**

Given that participants have revealed their tendency to be 'obliged' to 'master the self' to contribute to society, certain social coercions may be considered to have been a dominant feature in their lives. Some sociological evidence has found that people do seek clinical help and accept medications due to a sense of having to meet social demands (Malpass et al. 2009, p. 164; Garfield, Smith & Francis 2003; Maxwell 2005). For the participants of this study, managing the self as autonomous subjects within their particular social setting has meant that negotiations have been made within their clinic and their community. Therefore, institutional practices that make receiving diagnosis and treatment for bipolar disorder possible are important to the individual. The following testimony explains this point:

For the first time my symptoms were objectified as a medical condition rather than a failure to be any sort of decent human being. I learnt about the validity of mental illness diagnoses and welcomed the appropriateness of psychiatric drugs.

Testimony 2

As soon as past behaviours are recognised as symptoms by the person with bipolar disorder, a negotiation has taken place. The negotiation has incurred the acceptance of the clinical label, rather than acknowledging traits that have been associated with personal failure. Instead, through diagnostic labelling, symptoms may be related to the cause, bipolar disorder, and become associated with the need for medication. Thus, the personal failure is negated and behaviours are given legitimacy through receiving a diagnostic label along with treatment. Likewise, Malpass et al.'s (2009, p. 164) meta-ethnography of published qualitative papers revealed that, for some people, knowing the causes of a depressive illness made it possible to accept the 'appropriateness' of medication-taking (see also Grime & Pollock 2004).

From a Foucauldian point of view, the acceptance of a clinical label, rather than resisting clinical control, is due to individual centredness as a self-defining subject (Leask 2012). In this case, power is more related to the self and control over the self through one's own attitudes and values, rather than control from any kind of institutional conditions, for example, social or clinical coercions (see also Chan & Garrick 2003). Thus, it may be argued that accepting a clinical diagnosis of bipolar condition, was due to an individual freedom that enabled the choice to transform from a self-inflicted feeling of 'a failure to be any sort of decent human being' to having a medical condition, managed through pharmaceutical treatment.

Nevertheless, a further complication does arise that has affected some people in different ways concerning the validity that diagnosis has been said to bring with it. Individual attitudes and values about accepting pharmaceuticals as a treatment for psychotic disorders often depend upon the acceptance of the self as a diagnosed person with a stigmatising condition

(Luhmann 2010, p. 179; Malpass et al. 2009, p. 164). Some people have understood prescribed medication to be a remedy for a 'bad' person and have consequently associated their own illness as a badness that is in need of medicating, rather than an illness in need of medication (Luhmann 2010, p. 185; see also Fernandez, Breen & Simpson 2014; Malpass et al. 2009, p.164). Therefore, resistance to taking pharmaceutical medications may depend upon how deep the experience of being out of control and vulnerable has been for the individual (Luhmann 2010, pp. 180-5). For example, Luhmann (2010, pp. 179-83) found that personal feelings about the morality associated with taking 'good' drugs often comes from life experiences of being on the 'rock bottom', and realising the harm done to the self and others. In more severe cases of bipolar disorder, the idea that medications in themselves are stigmatising may be secondary to the promise of personal transformation and a better life. For example, an interview with Mayra revealed that the knowledge that diagnosis brings leads to predicting what future life might mean:

I wasn't ashamed of it. Since these things happened I needed to know 'Will it happen again?', 'What am I supposed to do to help myself in the future?' So diagnosis is good in that I can follow down this path – the future path. Interview, Mayra.

Therefore, the practise of 'strategic freedom' means that the individual may choose to accept diagnosis, based on their own particular experiences, and take pharmaceutical treatments, sometimes due to fears about recurrences of mania, or feelings about self-respect. The promise of autonomous control over the future life of the individual, assisted by the use of pharmaceutical treatments, may help mitigate any feelings of stigma associated with a bipolar disorder diagnosis. In other words, preference for being in control of the self may overcome

feelings of ‘badness’ associated with bipolar diagnosis and opens up the opportunity for treatments and new life opportunities.

#### **6.4. ‘Take your meds, get your life back’: Individual needs for pharmaceutical treatments**

The choice to use pharmaceutical treatments for bipolar disorder is related to fears of mania that have to do with being out of control and being associated with ‘scary’, ‘destructive’ and ‘life-threatening’ characteristics (Fernandez, Breen & Simpson 2014; Proudfoot et al. 2009, p. 124; Martin 2007, p. 90). Being in control of one’s own life may be argued to be a practise of freedom, whilst being out of control may be a form of constraint due to the inability to change one’s circumstances. Evident in the following interview, the choice to be free to control one’s own destiny is akin to having a life, whereas to relinquish control to mania is associated with a ‘living hell’.

I met people whilst in hospital who wanted to flout the rules a lot – they didn’t like medication. To me it makes sense. Take your meds, get your life back. It’s a living hell for me, so I don’t know why anyone else would want to keep it [the mania], but I guess they have fun with it occasionally, but I don’t...I want to take the medication, and I have from day one, and it’s been a relief. Interview, Catherine.

Catherine’s idea that to refuse medication is going against a form of social constraint may be consistent with someone who has adopted all the trappings of a pharmaceutical culture (see Jenkins 2010, pp. 3-4). Regardless of cultural attitudes, however, her desire to regain what she has referred to as a ‘life’ has been the cause of her choice to alleviate what has become for her an intolerable condition. In fact, it may be argued that, in this case, pharmaceutical

products have enabled the individual to return to a state of being more suited to the life she wants to live, within her given cultural understandings of how she should live. This, therefore, is an example of where the individual has chosen to accept certain social conditions that require subjectification to meet the social requirements. The ‘relief’ she finds is through the use of pharmaceuticals that provide the sort of social conditioning required for the individual to be, once again, a part of social life.

The following example further explains this argument and outlines how people understand the destructive effects of mania on their lives. It also indicates how individuals may understand the use of pharmaceutical products as an urgent method of treatment:

And this was a way of getting help quickly. With psychotic episodes, your tempers, your ability to return to a cognitive function means the quicker you get onto it the better. So, if you leave the psychotic symptoms going for too long, the worse the damage and the harder it is to get back to the functioning you were at before. The faster you are onto it – and that usually means drugs [prescription pharmaceuticals] – the better. Interview, Jane.

Jane has stressed her feelings about social values related to being able to function in life. There has been an urgency about returning to personal functioning that has meant engaging in strategies that involve the choice to use pharmaceutical treatments.

A testimony writer describes mania metaphorically to explain the personal feelings that brought about engagement with medical treatments:

Like someone losing control of a car – one second you're driving and the next second you're gone; it's the speed that does it. The higher, or faster, you've been travelling, the deeper you will fall...Now you are at the mercy of others: triage nurses, doctors, parents. Together they are attempting to pull the wreckage from the water...There were long months of sitting on the lounge, taking antipsychotics, and reading.

Testimony 3

Within Jane's understanding of society, contributing to social demands is linked to having to take part in a pharmaceutical consumer society which means taking medications (see Jenkins 2010, pp. 2-4). The testimony writer has realised the destructiveness of mania where there has been no alternative than to allow medical treatments, with the use of antipsychotics. The result of medical control for the testimony writer has been the return to being creative:

There was no work to show for the effort of losing my mind, no masterpiece to present to the world and confidently say "It was worth it". Let me state categorically that neither being high or low are very good conditions for focused creativity that brings results – something to display for your toil. Testimony 3

Fullagar (2008) has criticised the tendency for biochemical discourses to view people within a purely functionalist ideology that relates to relying upon pharmaceutical treatments for coping with life. However, the testimony writer, Catherine and Jane's approach certainly supports the idea that individuals understand their functioning as integral to society.

Catherine's and Jane's attitudes to taking medication were positive in that they felt that

medications allowed them to conduct themselves appropriately within the context of what they understood to be an acceptable and functioning life. The testimony writer has also accepted the need for pharmaceutical treatment as a means to returning to a functioning, creative life.

On the other hand, in opposition to views about the need for medications, there is considerable evidence about patients' 'low compliance' with pharmacotherapy as a treatment for bipolar disorder (Proudfoot et al. 2009, p. 124). This reluctance to adhere to medications has been found to be associated with pharmacological unreliability that has caused people to discontinue such treatment, even though they may have experienced extreme and 'terrifying' mania (Proudfoot et al. 2009, p. 124). Systematic reviews and quantitative clinical studies have supported the difficulties with the pharmacotherapy treatments for people with bipolar disorder in relation to mood cycling (see for example, Parikh & Huniewicz 2015), especially when not combined with cognitive behavioural therapy (Schneck et al. 2008, pp. 373-75). Therefore, the pharmacological way to attaining what the individual may expect of life is not always certain regardless of any positive beliefs about the efficacy of such treatments.

#### **6.5. Individual experiences with pharmaceutical treatments for bipolar disorder**

Even with the knowledge that diagnosis brought to participants, controlling the onset of mania remained difficult. The complexity of the disorder does mean that individuals will most likely need medication adjustments from time to time. Until such adjustments are able to be made, participants tended to experience disruption to lives due to uncontrolled manic episodes and mood swings. To explain the type of personal experiences encountered when the right kind of medication balance had not yet been reached, I quote from Catherine:

When I was diagnosed I wasn't taken off the depression meds, but I was started on the bipolar medication and I was also given Valium for the panic attacks. It turned out I was also allergic to the Valium so instead of getting better I consistently got worse...I just started cycling faster and faster and faster, and it was very exhausting. So, in a stupid mind I decided to take every single medication I had in the house as well as alcohol. Luckily that caretaker person [inner self] rang a friend of mine and said 'I'm doing something stupid, I can't stop myself, so please come and get me'. So, I ended up being in hospital for a month until they balanced the meds. I was exhausted!

Several participants reported that using pharmaceutical treatments to control mania was an essential part of treatment that needed to be adjusted for the continuing control of mood swings. The reliability of medications and their treatment efficacies, therefore, in the control of mood disorders were important for participants. As the excerpt above has demonstrated, it may be seen that problems do arise in the practise of 'strategic freedom' when the personal ability to exercise choice means that making the right choice is essential to controlling manic behaviours. For example, relying upon the 'caretaker person' to make the right choice was a risk-mitigating strategy for Catherine who may have suffered serious consequences when left entirely to her own self-management while experiencing mania. Negotiations with the self when feeling 'obliged' to be well have thus been revealed to be difficult by the fact that pharmaceutical treatments are unreliable. Sudden changes in moods, even medication-induced, have meant that hospital visits are sometimes unavoidable when medications need to be re-adjusted.

However, when pharmaceutical efficacy is reached, there are benefits to be gained for the individual. Proudfoot et al. (2009, p. 124) sought to understand the ways in which people might come to terms with the need for the ‘trial and error’ approach to medication-taking required for achieving such personal benefits. My participants revealed that when mania is severe, then they were prepared to choose to be controlled in whatever ways medical practice could help them. As Helen related during interview, feelings of being ‘out of control’ caused her to seek the advice of a general practitioner, and a testimony writer described mania as being ‘equivalent of being on [illicit] drugs’. As participants had experienced the disruption of depression and mania, they were aware of the need to keep track on the balancing of their medications. Therefore, in the practise of ‘strategic freedom’, the experienced effects of depression and mania were measured against the ‘trial and error’ effects of medications with the usual resolution that having to take medications was an accepted way of life. As one testimony writer put it:

It took me until the second psychosis before I got the message. I accepted my doctor’s mantra ‘If you want to stay out of hospital and lead a productive life, take your medication, sleep regularly and don’t drink or use drugs’. It’s a winning formula. Testimony 3

Thus, there was an imperative to stay on medications for my participants, even though choices about how to transform the self were dependent upon pharmaceutical treatments that are not entirely reliable. For participants, the negotiations that were practised by the self and within the self were only a first step to personal transformation. Positive outcomes from such negotiations were hampered by the fact that the clinical institutions they depended upon were dependent upon further scientific discovery into bipolar disorder. My data have shown that

the practise of 'strategic freedom' has been engaged in by participants to seek knowledge from clinical settings. The knowledge needed for the participants to practise control of the self has been impeded when they have relied upon pharmaceutical products that have not provided dependable efficacy. However, it should also be noted that insufficient self-management practices involving medication-taking, or medication-balancing, may also depend upon personal awareness and acknowledgement of the severity of the mood disturbances.

#### **6.6. The temptation to quit using pharmaceutical treatments**

There is an inherent dichotomy between the negative side-effects of medications and the negative effects experienced through the bipolar disorder (for example, Jenkins 2015, p. 41; Wisdom et al. 2008, p. 491). The main point to be taken here is that both the bipolar condition and the medications do, in effect, change an individual's sense of self – a point which will be revisited in more detail in the next chapter. The following extract indicates how, in the practise of 'strategic freedom' negotiations are made around establishing personal identities:

But it's fun [the mania]. And when I'm on medication I keep saying to my psychiatrist 'I'm not getting very far with this Master's Degree because I'm on these bloody drugs. If I come off the drugs I'll be able to do it in a night'. But I know what's going to send me right down. I just have to make sure I avoid it...And my psychiatrist doesn't claim to know it all either. Like, when we were having trouble with the drugs she recommended that I go back into hospital where there is a specialist in pharmacology. So I went to hospital and I saw him and the two of them nussed it out, and then it was fine. And I've been fine ever since. Take the pills and

I'm okay. And every so often I go off them just because I'm sick of them. Because it's a big, big thing taking them every single day. I just like to feel like I'm having a rest from them. Interview, Deryn

The above example exemplifies the inherent tension associated with exercising 'strategic freedoms'. On the one hand, personal achievement is related to the benefits of mania that are associated with high energy levels, creativity, and fun. On the other hand, personal achievement may only be attained when there is no fear of being sent 'right down'. Individual freedoms of choice then become a matrix for sorting out desires for a manic identity, and knowing the detrimental consequences when mania is not under control.

From the above interview extract, it is evident that Deryn recognises the benefits that correct balancing of pharmaceutical treatments have upon the control of mania. However, when engaging in clinical advice and accepting pharmaceutical treatments, the individual submits themselves to a long-term commitment of what is, in effect, a self-imposed, but conditional pharmaceutically-controlled personal environment (Martin 2007). The implication under consideration, when being entirely controlled by medications, is that there would be no room for negotiation by the individual. Mania and its energies are forbidden and the master, being the medication, overrides autonomous choices (Martin 2007).

However, Deryn has demonstrated that there is opportunity for the individual to have rapport with their psychiatrist and pharmacologist. Within this rapport, there has been a form of negotiation, or what Martin (2007, p. 92) has referred to as an 'alliance with psychiatrists who could "know" and manage [her] illness'. In effect, Deryn has retained her autonomy and used the practice of 'strategic freedom' to learn about her medications and their relationship

to her feeling well. Deryn has then been able to make decisions based upon her negative experiences of mania and depression, and has chosen to accept clinical advice which has promised to stabilise her moods.

Another participant reifies the need for gaining medical knowledge that enables an understanding of the condition as a requirement for its management:

Understanding your mood disorder is a strategic step in managing your illness, remaining well, and avoiding the extremes of mood elevation. One of your most useful tools for dealing with mania will be your learning about it. This includes as much medical knowledge as you can tolerate so that you will easily recognise signs and symptoms of mania. Testimony 5

Nevertheless, the concept of 'strategic freedoms' is a difficult approach in a culture of pharmaceutical treatment where resistance may, in fact, not be a consideration due to the consequences of mania. To practise the mastery of the self, where medications are needed, often means there are personal experiences of loss of identity due to the personality changes that medications cause. If pharmaceutical control is likened to the 'master' then the loss is incurred by the 'slave' who no longer has control of their own life nor can experience the benefits of seeing themselves as the master of their own 'true' identity. As Deryn has explained, beliefs in herself about her abilities to achieve are altered when the effects of medications diminish her personal performances. In the process of the transformation of the self, the manic identity has become lost in favour of a stabilised, controlled, and comparatively dulled person. The practice of 'strategic freedom' has brought about a kind of control over the self that brings with it some undesirable effects for the individual that may be difficult to relinquish.

According to Weir (2009), if we take the Foucauldian concepts about the care of the self in relation to who we are and whether we can categorise ourselves as deviant or normal, then we are submitting to ‘normalising’ and ‘coercive’ regimes of power (see also Foucault 1979). Weir argues that, within this kind of regime, people are apt to view their own characteristics as ‘fixed identities’ that fall under ‘binary’ terms of either normal or deviant (Weir 2009). It is, therefore, hard to imagine what kind of freedoms enforce individuals to make choices between ‘aspiring’ to characteristics that are placed as socially normal, and ‘resisting’ certain other characteristics, which may be defined as deviant (Weir 2009).

In fact, with bipolar disorder, dichotomies inevitably arise where there is a choice between what is the best personal outcome. In other studies about mental illnesses, Malpass et al. (2009, p. 166) and Wisdom et al. (2008, p. 491) have found that people are in constant conflict about the need to find a ‘restored’ or ‘new’ self, the real self that has been transformed by the illness, and the ‘chemically enhanced self’. As Deryn has pointed out, transformation of the identity into something that is acceptable within the context of individual accomplishment in relation to their society, is a daily commitment. Thus, ‘strategies of freedom’ enable individual negotiation to take place between what kind of personality traits to retain and what choices of institutional assistance need to be employed to maintain a sense of personal well-being. Transformation of personal identity is a life-long commitment of doing something that, in fact, may be considered to be not natural – taking drugs.

## 6.7. Conclusion

Much has been written on the culture of pharmacology and its relationship to the creative, productive, entrepreneurial person best suited to contribute to a contemporary, neoliberal society (Jenkins 2010; Martin 2007). Regardless of the much adulated view of mania that has been connected to celebrities and their high performing abilities, bipolar disorder has been noted for its life-disorienting effects (Martin 2007). For people with bipolar disorder, staying well enough to contribute to society, as well as preventing harm done to themselves or others is the reason for why they may engage in personal management techniques. These management techniques are ways in which autonomous individuals are able to ‘master the self’ and require the practice of ‘strategic freedom’.

When practising ‘strategic freedom’ individuals are engaged in making choices about knowing and accepting their condition, controlling their own destiny to fulfil their personal productivity requirements, and gain their social benefits. However, for the participants of this study, negotiations that were made when engaging in the practise of ‘strategic freedom’ were found to be complex. The choices made involve learning and understanding the disorder, testing self-awareness, and engaging in management strategies that usually involved accepting medication treatments that, in themselves, are difficult to control.

For participants, the inability to control life and plan for a future has led them to choose to find out about their condition. The validity that diagnosis brings has helped them in the understanding of their behaviours, identifying behavioural problems within a medically-treatable space. There was some personal relief to be experienced for participants when they received diagnosis and treatment because it enabled them to know about their condition.

Knowing about the condition meant that participants were able to be aware of disruptive behaviours in a new way, accepting them as belonging to the medical category of bipolar disorder. This awareness was the crucial first step in learning how to control manic and depressive symptoms.

The understanding that pharmaceutical treatments are beneficial was, for participants, related to their potential to bring about a stability to their life by controlling mood swings. The recurrences of mood disturbances brings uncertainty of life events. Once medication efficacies were reached, participants found that they could gain control over their life, meeting their personal goal-driven endeavours or daily routines.

However, while pharmaceutical treatments were helpful in controlling mood swings, difficulties were experienced with their efficacy. There were two main difficulties encountered that led participants to have to negotiate their life choices: These were (i) the effects of medications when trying to maintain a balanced person, and (ii) the changes to personal identities associated with the 'blunting' effects of the medications. Mania has been likened by participants to being 'out of control' and being 'on illicit drugs'. At the same time, prescribed medications have been made accountable for some similar effects. For example, the mentally dulling effects, caused by the medications, have been associated with loss of identity due to an inability to exercise usual personality traits. Therefore, the freedom to control one's destiny has been complicated by the choice to be manic/depressive or the choice to be medicated.

Ultimately, these become decisions about choosing what kind of identity loss will be experienced – that is, loss associated with personal identity through medication or loss associated with personal identity through illness. These are difficult decisions, always in flux, and inevitably have led to participants having to decide whether to perform mania or ‘master the self’. Since, the mood fluctuations experienced with mania and depression have been likened to fluctuations experienced from the ‘trial and error’ (Proudfoot et al. 2009, p. 124) approach to medication treatments for bipolar disorder, it may also be considered that identity is situated somewhere within a juxtaposition of the unnatural environment of medication and being naturally bipolar.

## Chapter 7 Mastering the self: Balancing moods and balancing life

### 7.1 Introduction

For many people living with bipolar disorder, the black dog yapping at their heels often morphs into a gregarious, colourful and excited toucan capable of flying high, fast and free. For those who experience the roller-coaster ride associated with this illness, life becomes a balancing act between avoiding the vicious snap of the dog's teeth, and not flying too high and untethered with the exotic toucan. Strategies are often discussed for managing the dark abyss of depression, but sometimes the soaring manic heights get overlooked. Testimony 5

This chapter builds upon chapter 6 and explains why participants often used self-management practises outside of conventional forms of clinical management. This study found that choices that were made by participants to overcome the disruption of living with bipolar disorder and to enhance life activities did not always mean that strict adherence to pharmaceutical treatments was achieved. Making choices that diverge from usual forms of clinical control in chronic illnesses or conditions such as the bipolar disorder means that individuals engage in practises of 'strategic freedom' that allow them to negotiate their way around problems and the way they want to be. Participants revealed that they engaged in constant self-reflection and intermittent revision of their treatments. As mentioned in chapter 6, the unpredictability of moods, and the difficulties experienced with balancing medications, means that treatments need to be adjusted from time to time, interrupting usual life performances and social contributions. Participants revealed that knowing how to detect the onset of mood swings, what to do to avoid them, and actually choosing to avoid mania

became a part of the complex set of negotiations as neoliberal subjects living with bipolar disorder.

Most of my participants combined ‘synthetic’ pharmaceutical treatments along with what they considered to be more ‘natural’ approaches to controlling the condition. In fact, management of bipolar disorder did not necessarily mean that participants had to rely solely upon prescribed medication-taking, and often there was the temptation to discontinue medications. For some participants the idea of continuing medications on a life-term basis was unacceptable. In such cases, participants chose to use ‘natural’ therapies, usually termed ‘complementary and alternative medicines/therapies’ (CAM), instead of adhering to prescribed pharmaceutical treatments (sometimes referred to as ‘synthetic’ or conventional/mainstream treatments, as controlled by the medical doctor or psychiatrist, for example, see Lakhan & Vieira (2008).

### **7.1.2. Definitions of CAM and use in Western societies**

According to the US based National Center for Complementary and Integrative Health (NCCIH, para. 1), complementary and alternative/integrative medicine/health is defined as, ‘...diverse medical and health systems, practices, and products that are not generally considered to be part of conventional medicine’. The Australian Government Health Department (para. 1) defines complementary therapies as ‘...used at the same time as other treatments; for example, aromatherapy...’, and alternative therapies as when being ‘...used in place of usual treatments, such as when someone chooses to take herbal remedies instead of prescribed medicines’. In addition, ‘integrative medicine’ has been used to describe when complementary treatments have been used in conjunction with ‘mainstream’ medicine (Grace & Higgs 2010).

There have been many studies about social understandings and usages of CAM. Studying satisfaction in medical care, exploring age, economic status and confidence in the medical practitioner compared to the CAM practitioner, Conboy et al. (2007, p. 152) found that younger and economically disadvantaged people were more likely to use CAM. The findings also pointed to growing social attitudes about wellness philosophy and its relationship to CAM that incorporate ideas about preventative medicine (Conboy et al. 2007, p.153). A study by Downer et al. (1994, n.p.) with cancer patients found that patients most interested in CAM were young, female and of higher socio-economic status. This study also found that patients were inclined to use complementary therapies when they were dissatisfied with conventional treatments, due to side effects and loss of hope of cure (Downer et al. 1994, n.p.). In Australia on women's health, in particular heart disease, hypertension and diabetes, Sibbritt et al. (2015) conducted a survey and found that disinterest in CAM was largely related to health risk, and cost-effectiveness. For such chronic and serious diseases there was found to be a low use of CAM. It was considered from the study that these patients gained little self-efficacy from CAM, and their extensive health consultation time with conventional clinics tended to affect their beliefs based on conventional clinical advice. In addition, in Australia, the government assisted health scheme was found to make refunding and access easier for patients with chronic and serious illness, acting as a deterrent to CAM (Sibbritt et al. 2015, p. 1694). Another study in Australia by Yen, Jowsey and McRae (2013), found that patients suffering from musculoskeletal conditions, chronic pain, and depression and anxiety were more likely to use CAM than those with diabetes, hypertension or asthma. Preference for conventional treatments was given to serious diseases where risk was high priority, and for CAM where risk was lower and chronicity given high priority. In addition, a recent study in Australia by Grace & Higgs (2010), using hermeneutic phenomenology and case study,

investigated the experiences of integrative and general medical practitioners, who were co-located, and their patients, regarding complementary and alternative therapies. The study was concerned with the ways in which patients use CAM consultations, with both general medical practitioners and CAM practitioners to evaluate the benefits of conventional medicine and CAM. In this case, efficacy of treatments was measured by the knowledge exchanged between the practitioner and the patient, and the ways in which patients were able to practice autonomy. Information was sourced from media such as the internet to make informed choices about the treatments thereby maximizing knowledge gained from the practitioner/patient relationship (Grace & Higgs 2010). These results showed a high interaction between client and practitioner that formed better power relationships between doctor and the patient, not typical of conventional doctor/patient relationships. The result of such interactions was that there was a client-centred approach to preventative health care and a prediction of better social health management in the light of rising older populations (Grace & Higgs 2010).

Alternative therapy techniques are often related to self-management, and sometimes thought to be opposed to pharmaceutical management. This is because of the ways in which individuals are considered to have more ability to take control over their own health management through exercising agency and gaining self-efficacy by taking control of their own thoughts (Chan, Rappaport & Kemper 2003; Weiner 2011; Bandura 1989). The use of 'natural' methods of management is related to tasks involving changing or maintaining behaviours and/or life roles that need a more 'creative' approach, as acquired by individual agency (Lorig & Holman 2003).

However, there has been much critique in the sociological literature about issues pertaining to the ability and right or competency of individuals to exercise autonomy and control over their own health choices (for example, refer Weiner 2011; Lawn, McMillan & Pulvirenti 2011; Pols 1989). Usually such issues have emanated from understandings about the type of control over the individual that has been accredited to clinical interventions based on the biomedical model of illness that include mental disorder as a biological condition (Deacon 2013; Wade & Halligan 2017, p. 996). This reductionist approach to health problems tends to separate the person from the disease and its symptoms and places them in a devalued status due to their personal functioning brought about by the illness (Wade & Halligan 2017, p. 996; Kleinman, Eisenberg & Good 1978). As this study has found, when this approach to bipolar disorder as an ‘illness’ was used, participants tended to rely upon their doctor’s direction about what pharmaceutical treatments to use. Conversely, when using ‘natural’ methods of management participants engaged in tasks involving changing or maintaining behaviours and/or life roles, as separate from the ‘illness’, that required a more ‘creative’ approach. However, this approach does depend upon individual capabilities for self-management (Lorig & Holman 2003). Therefore, this kind of approach has prompted inquiry regarding the ability of the person with bipolar disorder to carry out self-management since such tasks require rational thought processes.

As I will demonstrate in this chapter, mostly participants were able to make rational self-management decisions. Using the concept of ‘strategic freedom’, this chapter explains why people decide to use CAM in the management of mania and depression. The chapter also explores people’s understandings of their condition as problematic due to the need to monitor mood swings. Much of the discussion is around the efficacies of medications and the need for personal contributions towards self-management. Therefore, this chapter focusses on the

ways in which participants have needed to engage in alternative therapeutical practices to monitor their mood swings and balance life.

## **7.2. Autonomous decisions and mistrust in medications**

Initial reasons for why participants sought alternative treatment regimens related to the ways in which they experienced their first steps to managing bipolar disorder. As the following two interviews have revealed, participants formed doubts about the reliability of pharmaceutical treatments due to the experimental approach to their use within the clinical setting:

I was experiencing no euphoria, but a high level of energy, a high level of irritability, and, I am bipolar II, so I have never had manic symptoms that are strong. Later that year I was suicidal; so, just constant thoughts of suicide, like obsessive thoughts and moving towards kind of planning it. I'd been on antidepressants at the time, but nothing had really worked. Then I started mirtazapine and then I got ninety per cent better in two weeks which was probably the medication, or may have been just a natural turn in cycle. Interview, Graham

Doubts usually expressed by participants about the efficacy of medications were due to experiences of being swung over to mania through antidepressant use, and due to experiences that had led to complications of medication balancing. Finding the right kind of antidepressant medication was clinically difficult as not all participants were tolerant to the same type of medication. Graham's lack of faith in antidepressants grew out of the length of time it took for one to apparently work. In the end Graham was unable to recognise the

difference between being controlled by medication or what was the natural cycle of the bipolar condition.

Using a clinical review, Deacon (2013) draws upon much survey-based evidence to synthesise an account of how the biomedical model of mental 'illness' has been used by clinicians in the treatment of mental disorders. Deacon (2013) argues that, there has been no clinical evidence such as the discovery of a biological marker or gene with which to identify any specific mental disorder. The lack of such evidence tends to question the practice of the use of pharmaceutical treatments since mental 'illness' does not fit the pathological description of 'disease' (Deacon 2013). Prescribing medication for a mental condition, in fact, has been based upon using 'symptom criteria sets' that suggest the need for 'tranquilizers', later termed 'mood stabilisers', rather than any conferred scientific reason (Deacon 2013, pp. 850-52). It could, therefore, be considered that Graham's lack of trust in the efficacy of his antidepressants was because his condition was due to causes more complex than his pharmaceutical treatments have been able to remedy. Therefore, the lack of evidence about the causes of bipolar disorder and effect of medications in reaching treatment efficacy may determine why some people turn to alternative or 'natural' therapies.

Furthermore, there was some evidence pertaining to social attitudes individuals expressed towards taking certain medications. Social attitudes have tended to permeate feelings in individuals about mistrusting some commonly known medications, and have created doubts about the professionals engaged in such clinical recommendations:

And he [the psychiatrist] said, “Oh, you might benefit from lithium”, and I thought, “You’re not touching that!” So, you know, it was like I wasn’t listening - so didn’t trust [the advice], you know. Interview, Jim

Jim had a history of changing his clinical settings due to experiences concerning his psychiatrists’ slowness to diagnose the condition and the lack of adequate explanations made by them. Jim’s experience is exemplary of other participants who found difficulties in establishing their condition as bipolar disorder and being able to trust their medications and clinical experiences. The result of such mistrust was that individuals tended to have more than one avenue of clinical consultation to learn how to monitor and control their condition.

In addition to the clinical experiences, it may also be argued that Jim’s concern about ‘not touching’ lithium may be derived from other people’s experiential knowledge gained from the use of the same medication. Such individual experiences subsequently shared through social discourses may have helped form his preconceived ideas about a particular psychotropic medication (see Malpass et al. 2009, pp. 162-63). Malpass et al.’s meta-ethnography of sixteen academic papers (2009) found patient difficulties with beliefs about their condition and their adherence to medications. As with the practise of ‘strategic freedom’ people have been found to engage in ‘lay evaluation processes’ when trying to make choices about self-management. These testing processes engaged in by individuals have been inspired by uncertainties due to their own experiential knowledge and observations of others’ behaviours and experiences; and, also, a lack of trust in their practitioner’s information (Malpass et al. 2009, pp. 161-62). Such ‘evaluation processes’ involve strategies that have been derived from the need to evaluate risks, benefits, hopes and fears, and positive

and negative self-images resulting from their knowledge about their condition (Malpass et al. 2009, pp. 161-62). Other studies, Badger & Nolan (2006); Givens et al. (2006) and Grime & Pollock (2004), have found that preconceived ideas about medications are, in fact, due to social attitudes held within the larger social discourse about them. Some of the reasons given for such attitudes have been related to concerns about fear of addiction and feelings of helplessness due to the control with which medications have over individual life choices (Malpass et al. 2009, p. 163).

Although there was much readiness by participants to accept clinical decisions based on the biomedical model of bipolar disorder, there was also some mistrust about the safety and efficacy of pharmaceutical treatments. Such mistrust in the prescription and use of pharmaceutical treatments gave participants reason to want to take more control over their bipolar management.

### **7.3. The importance of being aware of the self**

Self-management with bipolar disorder, however, automatically enlists the individual into accepting constant practises of self-surveillance. This is mainly due to the need to achieve a balance to life through balancing moods. I found that most participants felt the need to be aware of their moods and the onset of potential extreme changes, even when they were using pharmaceutical treatments. The following testimony explains the importance of self-knowledge and awareness as self-management practices. Knowledge gained through personal experience was used to practise awareness of mood swings:

My stomach, and its resident butterflies, is an infallible barometer of tension. Being aware of such physical symptoms is very useful to me in being comfortable, and in

the last resort, in preventing mania. My most common cause of tension is not balancing solitude and gregariousness in my life. There are also other balancing acts that can benefit from attention: inactivity/hyperactivity; being self-contained/self-disclosing; self-discipline/spontaneity...My real protection lies in good, early self-knowledge and well-developed habitual stress-management. Testimony 2

Self-managing mood swings meant that participants became very aware of changes in their feelings. Participants referred to this practise as watching for the 'signs' of highs and lows. For example, testimony 6 describes the need of self-surveillance:

Management of the highs of bipolar disorder involves accepting that every high will be followed by a low and that this low will be proportionate to the high. Therefore, it is not worth it for your general wellbeing to let a high keep escalating. You can learn to recognise your warning signs and then take steps to cut the mania off in its tracks...

Martin (2007) has also made reference to the ways in which people with bipolar disorder have become aware of 'signs' of mania and have encouraged each other to monitor themselves. Being aware of the 'signs' enables people to make the appropriate choices of types of management for mental stability. As Martin (2007) argues, the freedom to 'manage' mania and depression is exercised by choosing when to increase medication levels and when to change personal daily living habits.

I found that participants used their experiential knowledge to manage symptoms, adopting a dedicated practise of self-imposed control of conduct. The intense way in which the personal

surveillance of moods was practised may be interpreted as a form of self-control that has, through personal need, become an obligation. As demonstrated within the above excerpt, this obligation may be enacted as a list of binaries in a process of close personal monitoring. Rose (1996, p. 100) also argues there has been some kind of merge between being free to choose in order to maximise one's own enjoyment of life, and being 'compulsorily enterprising' or 'obliged to be free'. For people with bipolar disorder being 'compulsorily enterprising' may be interpreted to be a strategy that allows the choice of certain management techniques for balancing life while satisfying personal needs. As above, this obligation may be met by inventing personal binaries that have assisted with the detection of mood swings that enable self-control.

#### **7.4. The 'nature of the illness': its chronicity and unpredictability**

My participants commonly described the chronicity of bipolar disorder along with its unpredictability and changeability. Moreover, the condition does not always reveal itself, as fluctuations of moods are not constant, producing episodes of either depression or mania that are cyclic but sporadic. Participants were constantly seeking a way to achieve a balance to life by trying to predict mood swings and control their feelings:

The thing is that with bipolar disorder you can be well, but you are always affected by it. Even when you are well, you might be feeling well for months but you never know when it's going to strike again. It will just come out of the blue, you will be happy living life the way you want, doing everything you want to do, feeling quite calm. A lot of bipolar people have times when they are very even and then bam, it just hits you. So I think that's the hardest thing about it, you're not always ill but you're not always well and you're always going to flip between the two, and it doesn't matter

what medications you take, or how well you manage it you will always have another bipolar attack. It's just the nature of the illness. Interview, Zoe

The above description of living with bipolar disorder explains the chronicity and dormant nature of the condition. The resurfacing of recurrent mood swings is unpredictable so that being able to manage bipolar disorder is difficult. There is certainty conveyed in this message that the condition will return even when adhering to a pharmaceutical regimen. In other words, the condition is not felt to be curable, living always within the person, although not always readily apparent. The excerpt makes it clear that no kind of management, whether using pharmaceutical management or CAM management, will be sufficient to guarantee control over bipolar disorder. Consequently, management tends to be complex and ongoing. The chronicity and unpredictability of the bipolar mood swings, therefore, were the reasons for trying to find a way to prevent mood 'flipping' and maintaining a balanced life.

As Jane (below) explained, through the metaphor of the tripod, there are sometimes extreme human feelings that become the subject of 'normalcy'; so, there are other legs or parts to the treatment regimen that need to be used to produce the balance that brings about 'normalcy'. Pharmaceutical treatments were not seen to be the sole solution for establishing personal feelings related to being balanced, and other forms of self-management were selected:

I see medication as just one part of treatment. So, it's like a tripod. It keeps a balance. You take away one and not so stable maybe and I have to rely on others. For example, I was in psychoanalysis for a very long time learning how to talk about it, because I was completely unable to. I couldn't even say the word 'disorder'... If you asked me to sign something that says 'bipolar disorder', I would just seize up.

So, yes, medication is one part of treatment; I think psychotherapy is another part. I think family support, friends support and group support is incredibly helpful. I think it is important to educate yourself. And I also think diet and looking after yourself physically is another thing. Interview, Jane.

The initial impact that learning about having bipolar disorder has on emotional wellbeing may mean that medication is just the Band-Aid for feeling well. In the first instance, as with Jane's experience, the acceptance of a new identity attached to a mental condition may be so difficult that emotional care is as important as pharmaceutical care.

According to Inder et al. (2008), the construction of the self as a person with bipolar disorder affects feelings about social status and how individuals imagine other people see them. For example, the redefinition of the self, through a diagnostic label, may cause feelings of embarrassment and shame due to concerns about how other people may redefine them as 'ill' instead of as a 'normal' person. Furthermore, according to Inder et al. (2008, 2011), accepting a bipolar disorder identity is likely to confirm personal inner conflicts already manifested by living with significantly different personality traits brought about by fluctuating moods. In addition, the longer people have lived with their personality traits the harder it is to accept them as something that is medically-defined rather than as existing within normal understandings of their personhood. As Inder et al. (2011) found, people who had lived with the condition for some time before achieving a diagnosis were quite likely to find acceptance of the new identity as a person with a bipolar disorder more difficult.

Resonating in Inder's findings, my participant, Jane, had to learn how to accept her 'illness' identity. This meant that emotional needs had to be met which could not be achieved by using medications. Emotional needs were met by engaging in psychotherapy, and also through family and other interpersonal support that offered comfort and reassurance. In addition, as Jane said, knowledge gained through acquiring information about the condition and how to manage it by controlling eating habits, for example, provided several ways to achieving self-management.

It may also be argued that all of these combinations of management are chosen by individuals to achieve self-efficacy, so important to the mastery of the self. In achieving self-efficacy people are engaged in negotiating with thoughts that are both 'self-aiding' and self-hindering' (Bandura 1989). There is advantage to be gained through being a self-determining person who is able to capture negative feelings about the self and transform them into something more positive, through for example, psychotherapy. For people with bipolar disorder, self-management and self-efficacy, practised to bring about stability to life, requires 'a major function of thought [ ... ] to enable [them] to predict the occurrence of events and to create the means for exercising control over those that affect their daily lives' (Bandura 1989, p. 1176). Reaching self-efficacy, through self-management, may be considered to require a 'tripod' of remedies, as finding the balance to life has been found to have been insufficient when using pharmaceutical treatments alone.

#### **7.5. Problematic treatments: Balancing life while maintaining personal identities**

As well as emotional problems experienced due to coming to terms with a bipolar identity, there are other problems often not overcome by medications. Being autonomous subjects,

living within a neoliberal society, meant that there were responsibilities about achieving and maintaining being a balanced person, in control of mood swings. Most participants were fully aware of the consequences of mania and depression and were prepared to meet personal obligations to restore normalcy. As discussed in chapter 6, they also became aware that medications did not always maintain efficacy. Sometimes, medication for bipolar disorder was experienced to be controlling mania while producing effects that tended to induce depression; or it may be that depression was controlled leaving symptoms of mania not so well controlled. Therefore, finding the right kind of balance through pharmaceutical treatment was difficult.

Fullagar (2009) found, when studying anti-depressant use that people used pharmaceutical treatments because they believed depression was caused by ‘chemical imbalances’.

Consequently, they felt the only way to restore ‘normality’ was to take chemicals that corrected the imbalance (Fullagar 2009). Most participants for this study, accepted that bipolar disorder was due to chemical imbalances within themselves and were willing to take the biomedical approach to treatment. However, due to the poor efficacy often experienced from pharmaceutical control, most participants sought CAMs as a way of detecting and controlling mood swings, and thereby achieving a balance to life.

Contrary to the findings of Lim et al. (2004), where bipolar patients preferred to take medications because they felt they could not ‘forecast’ their mood swings, participants in this study mostly believed that using complementary therapies enabled them to predict the onset of mood episodes. For example, avoiding the depressive side of bipolar disorder by ensuring

the continuation of a 'pro-active life-style' was seen to be an important part of therapy, particularly since feeling depressed could be seen to be the 'trigger' for a manic high, viz:-

Boredom and depression itself can be a trigger to a bipolar high, whereby the sufferer feels that they will be better off seeking that elusive high, and go on a lifestyle bender. This may include ceasing medication, drug abuse, promiscuity, dangerous behaviour and consequent mania. If the increasingly manic behaviours are not immediately addressed, the manic person becomes the kite, oblivious of the fact that it will ultimately crash back down to earth. Therefore, treating depression with a proactive lifestyle is just as important as the focus on the manic side of the illness.

#### Testimony 4

The above excerpt refers to the individual's problem with experiencing depression and what it does to his/her personal satisfaction in life. It clearly indicates that the feelings experienced with mania are more preferable due to the euphoria, even though the individual knows the consequences of embarking upon problematic behaviours.

For some participants, boredom and depression were experienced when using pharmaceutical treatments that tend to have the effect of 'dulling' the brain, a feature from medications already mentioned in Chapter 6. In fact, pharmaceutical-use has frequently been reported to contribute to a dulling of life experience that has been the result of people choosing not to continue with it (for example, Malpass et al. 2009, p. 163; Fullagar & O'Brien 2013; Fernandez, Breen & Simpson 2014). Participants' desire to lead a more challenging and exciting life than when under the effects of medication also reflects concerns about how they are able to identify themselves as an active person. That is, the act of being proactive was

associated with the person who was a proactive person. The 'proactive' lifestyle sought after was a 'natural' way of avoiding depression while protecting the identity of the individual as an active person who has a contribution to make within the society. When people are able to visualise what their future achievements might be through, for example, leading a 'proactive' lifestyle, they tend to refresh their goals and applaud their new identity through personal achievement (Charmaz 1995). For people with bipolar disorder, personal achievements gained through a proactive lifestyle may be seen as the way to wellbeing and stability associated with a desirable identity. Knowing the consequences of mania means choosing to control mania with pharmaceutical treatment as well as being self-aware, ensuring pro-activity, and thus avoiding depression. Balancing life, therefore, is achieved through a combination of self-management and pharmaceutical control.

However, contrary to those people who chose to take medication as well as monitoring themselves, others' experiences with medications have been too deleterious to continue treatment. In such cases, personal goals have been obstructed when using pharmaceutical treatments, making the 'natural' way to bipolar disorder management more preferable than taking medications. One of the most often reported disincentives for the adherence to medications with bipolar disorder has been related to cognitive impairment and its effects upon the transformation of personal identity, usually associated with abilities to retain personality traits, for example Johnson et al. (2007, p. 549) and Proudfoot et al. (2009, p. 124). As discussed in chapter 6, some participants preferred to regain cognitive function through taking medications, while others mourned the loss of desired personality traits due to the medications. These effects have brought about concerns regarding individual tolerances towards accepting a changed identity associated with personal abilities versus benefits gained from taking pharmaceutical treatments.

The excerpt below exemplifies personal experience with medications related to physical side-effects and the resultant effects upon feelings about personal identity. As Zoe explained, personal identity is related to how an individual perceives their looks and personality as well as their feelings about themselves. In fact, the preservation of a 'true' identity may become preferable to any risks associated with not taking medication:

I took the medication and had a very bad reaction to it. All my hair fell out, I got the shakes, and I put on 10 kilos...I didn't feel like I was myself. I felt like it changed me. It changed my personality. I didn't like that, because I don't think bipolar is a personality disorder. You know, you have your personality, and then you have these mood swings which impact on your personality, but it's not your personality. So, now I see a holistic doctor who specialises in mental health and she treats me naturally, checking my zinc levels, and I do lots of mindfulness, meditation; and with my diet, I am vegan, gluten-free. Interview, Zoe.

Fullagar & O'Brien (2013) found that there were negotiations to be made when acknowledging the self as a 'neurochemical-self' due to the effects medications had on transforming a personality from the 'true' original self to the 'neurochemical-self' (Fullagar & O'Brien 2013). Jenkins (2015, p. 25) argues for a wider understanding of the model of disease and the illness process that includes 'socioemotional' experiences, 'cultural meaning' and 'ecological constraint'. In any case, acknowledgment of the self as a chemically balanced person could only be sustained if the chemicals worked to enhance the self. If medications are to be accepted, then they must meet their promise to help the individual in self-management; if not, then the taking of the medication had a twofold deficit, that is,

experiencing the side-effects, and having the effects of leaving the person without a 'true' understanding of the self (Fullagar & O'Brien 2013).

As Zoe explained, her true self belonged to the bipolar condition, and the chemically-changed self became unacceptable because of the ways in which the medications had changed her identity into something she did not like. According to Fullagar & O'Brien (2013), the tendency to interpret the self as 'neurochemical' was found to have worked against being able to view the self-image as anything else but a medically-changed identity, thereby obscuring any recognition of the 'true' self (Fullagar & O'Brien 2013). This latter interpretation of the self was found to have decreased feelings about sense of worth – problematic for Zoe as she did not want to lose the personality and appearance that she liked (Fullagar & O'Brien 2013).

Therefore, Zoe's view is an example of a shift away from the tendency to regard the biochemical approach to management as a 'normal' approach. This highlights the decisions that are made when pharmaceutical promises have not fulfilled the individual's expectations of management and recovery. It also demonstrates that some individuals with bipolar disorder are able to put into question the use of medications in their self-management, a divergent from the explanations and claims about the cultural 'normalisation' of the use of pharmaceutical treatments where medications may be called 'meds' (Luhrmann 2010, p. 179) or an 'aid' to a natural biological function (Martin 2010, p. 188) or fulfilling a 'pathogenic space' (Ecks 2010).

In addition, the concept pertaining to the determination to adhere to the 'natural' personality is contrary to the considerations and beliefs of those individuals who feel the need to be

controlled. As for my sample of participants, others have found that people who have become committed to pharmaceutical treatments in the management of bipolar disorder have determined that medical control is what they have needed. In this case, the tendency is for people to substitute feelings about retaining a ‘natural’ personality for a chemically-transformed personality. For example, Fullagar & O’Brien (2013) found that participants’ opinions of themselves when using pharmaceutical treatments sometimes shifted away from an independent self to one of a biochemical subject with a ‘neurochemical deficit’ who is dependent upon medications (Fullagar & O’Brien 2013). One way of interpreting this relinquishing of the self to the control of the medications may be connected to a desire to adopt diminished responsibilities – a proposition more comfortable for some people than others. The following is an example of participants who felt the need to accept their deficit and submit to being clinically-controlled:

So for me, I put my brain on the doctor’s diet. I didn’t feed it drugs. I deprived it of alcohol. I drank water. I took my mood stabilisers. I went to sleep at the same time every night and made sure I got my seven to eight hours rest. If I’ve had a problem with sleeplessness since, for more than twenty-four hours, I’ve taken my anti-psychotics. This is all monitored by my doctor.      Testimony 3

The above excerpt is an example, similar to that as demonstrated in chapter 6, where participants were overcome by mania in such a way as to feel the need to submit to the control of the clinical professional. In such cases comfort may be gained through being the biomedical subject and where pharmaceutical treatments have been found to be beneficial.

Conversely, since chemically-induced side-effects present ways of changing a personal identity through visible signs, such as loss of hair and weight gain, as well as personality changes, side-effects have been found to change the ways in which people view continuing pharmaceutical treatments. Research has shown that anti-depressant side-effects are both physical and mental, and life-impairing due to sensory and emotional losses (Malpass et al. 2009, pp. 162-63; Grime & Pollock 2004; Haslam et al. 2004, p. 204; Brijnath & Antoniadis 2016). Participants often mentioned similar side-effects, although some were still prepared to tolerate them, depending upon personal attitudes about the need for medications to control mania:

Oh, I think I have to be on medication for the rest of my life, that's just my lot. If I had diabetes I'd have to take insulin and I'd just accept that this is what I am going to have to do. It took me a long time to realise that, but yeah, that's just what it is.

Interview, Helen

For some participants the only way to control their condition was to submit to the benefits of pharmaceutical treatments. In such cases, the benefits of pharmaceutical control outweighed any disadvantages caused by the side-effects. However, if side-effects were severe, then 'natural' therapies were engaged in more vigorously. Where retaining personal identity was important to people, then there was a move away from pharmaceutical treatments. Such choices were made due to participants being able to find alternative ways of managing mania that offer better ways of maintaining identity. It has been apparent that most important for participants was to be a balanced person, because being balanced facilitates knowing the self, dependent upon a predictable identity. Therefore, preventing mood swings is a very important part of treatment for people with bipolar disorder.

## 7.6. Using ‘natural therapies’ alone

I have been demonstrating within this thesis that people living with bipolar disorder, once diagnosed, recognise the ‘problematized’ condition within themselves. Participants have also demonstrated their abilities to choose to either fully medicate, supplement medications with ‘natural’ therapies or, as for a minority of people, to use ‘natural’ therapies alone. The following is an example of a minority who choose to use only ‘natural’ therapies:

...so, not taking medication, which is unusual, I know, for people who have been diagnosed with bipolar, because the general consensus is that you have to take medication. I have this wonderful doctor who has another perspective. So that’s what we are trying at the moment, knowing that if I get too ill I will need to go onto medication again...I am starting to bring these ideas into our support group because a lot of people take medication but they don’t do other things. They just do medication. They don’t have the – I do women’s circles and I do meditations and I do nature walks and all these really nice things to try to even my mind out to stop all the things that are coming in to my brain. So, I think that if you can do those things regularly and take good care of yourself, you can actually be well. And when those things hit you [manic and depressive episodes] – you will have to accept that these things will still happen; but if you have the tools and things to help yourself get out of it, and you’ve got people around you to help you, then you will be able to manage those episodes. They won’t send you down the path where I’ve been on before in my life – where I’ve been destructive towards myself and other people. But, I think that’s the challenge for people to believe that. A lot of people don’t think that it is possible to treat mental illness naturally. So, it’s something that I’m passionate about changing – this perception that you have to take medication. Interview, Zoe

Zoe's view here demonstrates a shift away from pharmaceutical treatments as prescribed when taking the biomedical approach in the management of bipolar disorder. Zoe has found the way out or around what is normally prescribed, engaging in a form of self-management that requires strict self-surveillance, and negotiations between her holistic clinic and people within her social setting.

Weiner (2011) argues that the notion of self-management for people with bipolar disorder is difficult to grasp considering that they must continually negotiate their way between knowing the difference between being rational and irrational (Weiner 2011). Nevertheless, maintaining a vigilance over personal thoughts and actions to prevent onset mania or depression has been notably an ongoing task for participants even when combining medication with 'natural' therapy. The tendency for medications to lose effectiveness has meant that participants have needed to note when it has been time to seek help and have the medications readjusted. Preventing onset mania has also been a task participants have been able to set for themselves through the use of complementary 'natural' therapies.

As Zoe has explained, living with the bipolar condition is considered to be ongoing, or as Weiner has argued (2011, p. 462) it is a 'disease' that is 'stable'. The ever-presence of the condition means that detecting when it is time to manage it involves the person who is attached to it in ways of 'calculating' by rational thought processes (Weiner 2011). As Zoe and other participants have explained, managing the episodes requires knowledge of moods, knowing that the condition is always present and likely to cause mood disturbances, and making choices about engaging with the means with which to control them when they do arise. Therefore, using 'strategic freedom' in self-management of bipolar disorder requires a

‘calculating subject’ who is at one with the condition but is able to objectify the condition as a part of the person that needs monitoring and controlling. However, as Zoe has accepted, there will always be the time when the self-governing agency is not enough and the condition will be likely to overtake the ability of its harbourer; therefore, the individual who chooses ‘natural’ methods engages in knowing the ‘tools’ needed to control the condition.

In contrast to other participants who felt the need to rely on medications (see also Weiner 2011), Zoe had found that she was able to cope with working on stabilising a calm mind, predicting that she would be able to sustain her ‘natural’ therapies. From this kind of engagement in self-management, the individual choice to control mood episodes ‘naturally’ may be reliant upon a process of internal self-motivation. Most of the participants also adopted self-motivation to monitor moods, even while using medications. Contrary to Barlow et al. (2002) explanations about the need for external motivation by ‘reward systems’, this attitude to self-regulation demonstrates that external means of motivation are not essential to personal strategies used to avoid mood episodes. Self-regulating negotiations, in this sense, are made within the scope of the individual upon the self and are not reliant upon any external techniques of monitoring. Nevertheless, Zoe and other participants also emphasise the importance of being connected socially, for example, through group support that may be viewed as an external influence; but the choice to engage this type of help also arises from internalised personal strategies.

Pound et al. (2005) and Kelleher (1988, p. 146-54) have also found that in practises of self-determination, disuse of medications amounts to what may be argued to be a form of ‘non-compliance’ that in itself may be used by people as a management strategy (see also Malpass

et al. 2009, p. 155). People felt that they were more in control if they made changes to medications, sometimes without clinical consultation, so long as they were able to continue life without disruption. Self-determination then means adopting personal strategies to monitor the self within certain boundaries, and readjusting medications and life to suit the individual (Kelleher 1988, pp. 146-152). Comparisons individuals make between experiencing side-effects and continuing with medications, supplementing medications or discontinuing with medications are forms of 'strategic freedom' that individuals use to negotiate their wellbeing. As participants for this study have revealed, being able to cope with outcomes that are the result of choices about which techniques of control are used, is the result of individual strategies, personal commitment and personal feelings about the ability to control their condition.

## **7.7. Conclusion**

As demonstrated in the previous chapter, enterprising individuals with bipolar disorder are most likely to take medications and visit their doctor to restore 'normality' from problematic behaviours. This has been due to life events being produced by episodes of mania and depression that have proved for the individual too difficult to control according to social practises required in the 'mastery of the self'.

However, due to limited efficacy of pharmaceutical treatments, participants continued to experience mood fluctuations that were unpredictable and extremely disturbing. In addition, individual reactions to some psychotropic medications resulted in hospitalisation where medications were readjusted, regaining control of mood balances. Therefore, the chronicity of the illness itself, the unpredictability of the disorder, and problems with finding the right

combination of medication for each individual meant that clinically-controlled pharmaceutical treatments were not always dependable.

Furthermore, there are side-effects that are problematic when choosing to adopt practices of the pharmaceutical self. These side-effects are related to individual identity experienced through mood fluctuations as a result of medications, changing personal characteristics associated with performing abilities, including the ability to live a 'proactive lifestyle', and being able to reach personal efficacy.

Therefore, the inability of pharmaceutical treatments to reach efficacy has brought about concerns for the participants about being able to sustain a more predictable life. Balancing life was noted to be a key concept, used by participants, when referring to the management of mood swings associated with bipolar disorder. Participants expressed the importance of learning how and when to use techniques to balance moods and maintain stability in their lives. Moreover, finding the balance to life entailed keeping strict self-determined practices of self-surveillance, as well as adhering to the use of complementary and alternative medications and therapies. Such self-management practises were an important part of daily life for participants in the avoidance of a 'life-style bender' or a 'crash back down to earth'. In fact, for participants, achieving the mastery of the self by controlling the symptoms of bipolar disorder required much self-commitment.

The personal commitment to a balanced life was often initially practised through using a set of 'signs' as a method of self-surveillance. Visiting a 'holistic' clinic where complementary and alternative medicines were being used, together with doing certain meditative and

physical exercise were ways of balancing the self in a 'natural' way. Where more severe side-effects had been experienced, the tendency was to discontinue using traditional pharmaceutical treatments in lieu of 'natural' treatments. The more a participant engaged in 'natural' therapies, the more likely they appeared to be concerned with maintaining their 'true' identity. Maintaining identity, therefore, may be linked with the ability to master the self because it required knowing the self, through recognising the bipolar part of 'me', watching for 'signs', and taking on strict responsibilities of self-governance.

In contemporary society individuals exercise autonomy and make choices about whether to accept medical treatment. As has been demonstrated within this chapter, this has meant that some difficult choices have had to be made. The difficulty of choice has meant that participants have had to depend upon personal rationalisations made through practising much self-discipline. In fact, it may be argued that, through the lens on the experiences of my participants, the personal effort and self-discipline needed to control bipolar disorder has been made more difficult due to perceived social expectations about being an 'enterprising' and achieving person.

## Chapter 8 Searching the internet with bipolar disorder

### 8.1. Introduction

‘What did you do before Google?’ is the first line written by Hillis, Petit and Jarrett (2012, p. 1) in *Google and the culture of search*. When considering the time it used to take to obtain information from a library, the lack of opportunity to come across government disseminated information and the questions that remained unanswered, it comes as little surprise that the internet search engine has become an attraction to the broader population (Hillis, Petit & Jarrett 2012, pp. 1-3). According to the Australian Bureau of Statistics (2014-15), 1.3 million households had internet access, being 14% of the population; and the number of hours spent using the internet in a typical week has been estimated to be between 6.4 and 18, with the largest number of hours’ use being by people aged between 16 and 17 years. Hillis, Petit and Jarrett (2012, p. 5) argue that search is ‘easy, efficient and rapid’ and ‘the searcher’ performs a ‘moral duty’ to contribute to a ‘retrieval’ and ‘search history’ of ‘truth’ within the Google ‘culture of search’. Considering the economical expediency in terms of time saved in searching information, the availability of internet to households and the obligation to seek and contribute to information it seems inevitable that people would turn to using their home computer as a quick and easy means to search for health or, indeed, mental health related information.

Surveys, conducted in both the US and UK, have found that the majority of people who use the internet for medical information search for information about a specific condition (McMullan, 2006). Although there is a dearth of statistical publications about internet use for health-seeking information in Australia, the Better Evaluation and Care of Health (BEACH) survey assessed that just over one quarter of Australian patients sought online health

information (Wong et al. 2014, p. 876). In addition, 17.1% patients sought information online about a condition being managed by their GP (Wong et al. 2014, p. 876). In any case, there has been a significant amount of government-sponsored and not-for-profit organisation websites set up for the purpose of attracting people to seek health related information.

Consistent with Australian government policy to promote individual autonomy in health care practises (for example, Australian Government Department of Health, 2013), internet health sites have been promoting individual health care. For example, the World Health Organization, *beyondblue* and Grow were promoting general health and wellbeing, and mental health, using the slogan ‘empowering people to help themselves’. More recently, none of these organisations have been using the slogan, but *beyondblue* and Grow (for example) have replaced it with text that carries messages about group support. One of the reasons for making changes in the way in which health care has been promoted may be due to inconsistencies within individuals’ abilities to enact ‘empowerment’ for resolving their health problems. In addition, personal responsibilities associated with ‘empowerment’ may be somewhat overwhelming for individuals, and may also lead to them gaining misleading information or misinterpreting information. Resolving health problems usually requires some level of ‘expertise’ as provided by a professional by way of consultation. Accordingly, Lemire, Sicotte and Pare (2008) and Adams & de Bont (2007) have argued that the word ‘empowering’ has become ambiguous because of its coexistence with ‘expert’ advice’ and the ways in which health consumers have been constructed to be the autonomous agents who seek health information. Lemire, Sicotte and Pare (2008, p. 134) explained that ‘empowerment’ was, in fact, a combination of ‘professional, consumer and community logics’. For the consumer, being ‘empowered’ through using the internet means using one’s own ‘logic’ to make choices, based on personal judgments, with the assistance of a ‘virtual’ community (Lemire, Sicotte & Pare 2008).

The ubiquitous supply of health information and neoliberal ideas about ‘empowering’ people with the responsibility for health-seeking and self-managing accordingly have raised concerns about the quality of information and individual abilities for assessing the accuracy of information (Sundar et al. 2011, p. 195; Zermatten et al. 2010, p. 853). How does an individual sieve out the right information? How do they use that information? And what happens when the process of searching and sorting is modulated by severe mental illness such as bipolar disorder?

This chapter explicates the ‘logics’ underlying the reasons for and the ways in which people with a bipolar disorder have engaged with the internet. Foucault’s model of *parrhesia*, provides the necessary guidance for analysis of knowledge exchanges being performed between the internet community, the medical expert and the person with a bipolar disorder. *Parrhesia*, translated from the ancient Greek means ‘fearless speech’ (see Foucault 2001). In the use of *parrhesia*, there are certain assumptions about trust and telling the truth. Performing *parrhesia*, in ancient Greece meant that an individual must be able to impart certain truths and understandings about the self to an audience who must adopt similar commitment to asking, in trust, of the speaker. Within the practice of *parrhesia* there is a required moral obligation to tell the truth and also a pedagogical feature that teaches the skill required to make a judgment about the truths being told (Foucault 2001, pp. 91-9; see also Luxon 2004). Such practices are meant to educate the individual rather than ‘produce’ a desired individual and are applicable to a neoliberal society within which personal responsibility and informed individual choice are the dominant practice (see Luxon 2004).

When using the concept of *parrhesia* for analysing the use of the internet there are three main ideas that should be understood. These ideas are about the courage and risk needed to engage in the act of self-disclosure, the pedagogical effect of the practice of *parrhesia* through engaging in the discourse of the internet, and the act of ‘navigation’ towards a truthful answer (Foucault 2001, pp. 111; 15-16). First, ‘navigation’ and ‘truth’ pose an interesting problem as Foucault explains *parrhesia* does not seek to find the final answer to the truth spoken, but is an instrument of education because it compels people to engage in a process of reflexivity, producing free and fearless speech, and the kind of thinking beneficial to the ‘care of the self’ (Foucault 2001, p. 92). The link here is that people with bipolar disorder engage in the care of the self through seeking a kind of personalised truth through a process of reflexivity combined with engaging in knowledge-seeking online. The pedagogical effect from the navigation of the internet by the person with bipolar disorder may be gained from finding the most appropriate personal identity rather than trying to argue truth matters with their clinician. This kind of engagement with the internet, therefore, would permit the individual the opportunity to reflect, test and choose, rather than simply accept a dominant body of knowledge. In other words navigation of the internet may be considered to be a supplement to clinical resources and may be used as a technique for combining practical, theoretical and experiential knowledge for the greater benefit of the self, and, hence, the community (see Foucault 2001, pp. 108-9;110-11).

Nevertheless, the question may still arise about how people assess and choose their sites of trust on the internet. Foucault (2001, pp. 93-4) notes that practising *Parrhesia* also does not rely on education in order to be able to assess ‘a competent teacher’, because people demonstrate their competence by both academic and practical means. Therefore, recognising

a good teacher who tells the truth can be done by using individual experience as easily as it can by using academic knowledge. The use of such personal assessment criteria may best be explained by way of the analogy Foucault uses of the 'touchstone' that was a technique for measuring the speaker's 'intelligibility' (*logos*) to decide on the credibility of the given information (Foucault 2001, p. 97). Foucault (2001, p. 97) explains the ancient Greek method of testing for gold which used a black stone, called a 'touchstone', upon which a piece of gold, if genuine, would leave a trace of itself when stroked upon the stone. Metaphorically speaking, this 'intelligibility' is a two-way process in which the stone accepts the gold and the gold recognises itself upon the stone. Within the concept of *Parrhesia*, therefore, it may be quite credible that people with bipolar disorder use their individual experiences as the 'touchstone' to assess the kind of information necessary to perform certain techniques of the self, through identifying with the information itself.

I argue that people using the internet for health-seeking information do so because they are seeking as much information as possible in order to produce a measurement of trust. In fact, the practice of *parrhesia* through the use of the internet may be thought of in terms of a contribution to breaking-down risk associated with relying on one 'expert' form of knowledge. However, as Derrida (1996, pp. 2-5) has explained, there is much to be considered when extracting information from any archive due to the way in which knowledge has been stored as memory and retrieved through a system of recovery and interpretation. Information extracted from the 'archive' can only be said to be the 'truth' in so far as one stored form is not contested at some other time, and to the extent that all information can be supported by the 'archons', that is, the people who guard, retrieve and interpret the information.

For people with bipolar disorder trust may be formed from retrieval of information that may be used and subsequently found to have an effect of helping to maximise their life opportunities. The kind of information used in the resolution of any discrepancies existing between the way participants perceived themselves and self-management outcomes may be partially dependent upon attitudes of trust formed through internet use. In the following, I will demonstrate how knowledge has been assessed by my participants, and trust measured when exploring online lay forums, consumer sites for mental illness, as well as engaging in professional relationships.

## **8.2. Surfing the information highway with a bipolar disorder**

Across my interview data it was evident that people navigated the internet widely, searching both within Australia and internationally to try to identify the type of information and services they needed. For example, Jim searched 'Facebook', 'medical journals', and NGOs, 'I've probably looked at all of them' (interview, Jim). Graham was 'comfortable' with using the internet as he used it regularly, also contributing to forums such as 'Reddit' which he described as having a 'world-wide audience' and much more 'traffic' than any Australian site (interview, Graham). Helen used Wikipedia for information and also because of its links to other resources such as YouTube and e-newsletters, searching globally as well as within Australia.

The people I interviewed all had used the internet, younger people being inclined to spend time to navigate broadly. I found that searching on the internet often began with a quest for personal identity, keying-in the word 'bipolar' or 'depression'. Such a search resulted in the discovery of a set of online textual symptoms that matched an individual's own which

confirmed their identity as a person with bipolar disorder. People I interviewed also sought information about bipolar disorder and treatments, either finding text bearing scientific claims or by finding textual exchanges of information by people with a bipolar disorder.

Participants made choices about whether they preferred to engage with ‘apps’ or ‘blogs’ through their own personal chat settings, NGO-sponsored chat sites, or to seek for more scientifically-based information. I found that people who were contributing to the SANE Australia chat site talked about personal feelings with each other to confirm their identity as a person with bipolar disorder. There was some discussion about management of their condition and they often expressed compassion towards each other, giving support. The conversation threads were also about causes of bipolar disorder with some political overtones relating to possible government policy. I also found that they posted academic writings they had selected, searching for a deeper understanding of what they had experienced due to their condition. However, my sample of chat threads, as for the testimonies, revealed little about interrelationships between the internet and the clinical experience, although occasionally there were references to a psychiatrist, psychologist, or hospital. Some interview participants mentioned their difficulty in finding the kind of information that was more specifically tailored to their particular personal bipolar identity. Nearly all interview participants expressed the need to seek out reliable information. Searching widely to find the right type of information could be challenging, and even overwhelming:

Sometimes the internet overwhelms me and I’m sitting here and I’ve got eight different tabs open, but how effective am I actually being, you know, what am I actually getting done here? And it feels like not a lot, so if you could just narrow that, if you could just have your own little burrow within the internet. Interview, Elyse

Importantly, participants searched the internet to find out whether their feelings could be related to a medicalised problem and to identify a particular category. In this regard, participants were identity-seeking for the purposes of wanting to learn what kind of help was available and how to access the most appropriate type of help. Identity searching through the internet included selecting internet sites through self-imposed criteria such as age, gender and personal interest:

I mean Headspace is probably a bit more for a younger demography so I don't identify with that quite as much. I found *beyondblue* was really focusing on men's health when I was searching, but it still had all the stuff that I needed, the facts sheets and that kind of thing. But I focussed more on an American site I found with the test that you do, when I was in my 'it might be bipolar' phase – you do the test and get the score: 'Yes, you're off the charts, you have bipolar, go see a doctor'. Interview, Helen

An important feature to be noted from the above excerpts is that searching the internet was a task that took some considerable commitment on the part of participants, is demographically scripted, and people must find their own 'comfort zones' within it. However, establishing the 'comfort zone' and pursuing the 'truth' is assisted by background machine analyses and processes; the more an individual uses the internet for a specific reason, using precise key words, while remaining in, for example, Australia, the more the internet 'filters' out information. From 2009, Google, the largest-used search engine in the world set in place its algorithm to 'personalise' searches. The significance of this is that computers will not return the same search results for everyone, everywhere. Instead, the search engine 'filters' everything that it decides a particular user does not want and returns a customised list of results according to the habitual usage of the user and from where they are logging-in (Pariser

2011:1). As Pariser (2011, p. 3) argues, 'More and more, your computer monitor is a kind of one-way mirror, reflecting your own interests while algorithmic observers watch what you click'. Therefore, it should be considered that, while people do, in fact, request a specific type of information, they are also being excluded from extra information that could be more accurate or beneficial to them. For people with bipolar disorder, for example, who are searching for resources to fit their identity and specific needs, 'filtering' could be advantageous by narrowing down certain information to their specific locality and cultural context; on the other hand, this filtering could be highly circumscribed reflecting an image about themselves more limiting than they would anticipate.

I found that participants used the internet widely, looking for resources that would enable them to recognise their own identity and provide enough useful information. The amount of engagement with the internet, by some participants, indicated a determined search for truth that required frankness with the self, for example, when engaging with online self-tests for mental health. Online health-testing was used, using present knowledge about the self in order to fit the self into a medicalised category, such as bipolar disorder. This action has enabled participants to reveal certain truths about the self, recognised through a set of symptoms used to identify personal feelings being regarded as problematic. It is the sorting out of truths about the self that are the 'touchstone' that qualify the online information. If the person recognises themselves in the text, then the text must be right; one component reflects and confirms the other.

### **8.3. Finding the right comfort zone**

Finding a comfort zone for participants as they used the internet meant navigating through previously personally unexplored sites. Finding the right internet site took some time as each person searched for their particular identity. Finding that identity then allowed people to engage in a space that felt comfortable to them, making it possible to select information or interact with others.

I accessed the SANE Australia bipolar chat site through the link provided. Observing the threads of conversation, I realised that people discussed their condition freely with each other, and that there was an established group who were used to talking to each other. One or more of the group appeared to be a 'moderator' and would come into the conversation with a commitment to servicing the mode of talk in terms of subject matter and continuing the flow. I detected about six consistent voices with a few dominant ones at a time, and the occasional interruption by a new or prospective 'member'. For those engaged in the chat, there was a friendly and supportive approach to the communication and all members appeared to be comfortable with the 'virtual' experience.

Only four interview participants had contributed to a chat forum at any time. Mostly, interview participants engaged with the sort of internet action often referred to as 'lurking'. 'Lurking' is used in lieu of taking part in internet discourse essentially because it allows people to observe and collect information. However, 'lurking' is not used where interrelationships are intended or other forms of engagement with internet discourse is considered (Aycock 1995; Blumenthal 2002). Taking internet ethnography as an example, it has been found that the internet only permits observation of what people say rather than what they do (Aycock 1995). Therefore, actually engaging with the internet chat threads or

posting may be generally considered to be an act of standing back from the setting rather than being in it. I found that the participants I interviewed preferred to belong to face-to-face bipolar-specific groups where they were given the opportunity to talk about their condition:

Well, if you are in a thing where you are chatting to a person [online] as opposed to just writing on a message board [online] it might be a bit different. I have got onto a girl in Texas who I started writing to who has got bipolar...that could be really good, really useful. I do attend one group [face-to-face] who are people with bipolar and there are a few support groups available that I would be interested in attending. I have found that in the past just talking face-to-face over coffee for a few hours with people is better. It is a very specific experience in a way...you find that you experience such a similar thing. I know a lot of people from other [face-to-face] groups with, more broadly, depression and anxiety but there is nothing remotely common in the way that there is with talking with other people who have bipolar, I find. Interview, Graham

Graham's analogy of chat forums with message boards is interesting in that it indicates a kind of personal distance between the person who posts a piece of conversation and the viewer. In addition, as Graham's experience would suggest, individualised relationships that are made through the internet are formed at a physical distance. The virtual experience, as Graham's opinion would suggest, is not a 'specific experience' unless it enables the formation of a more personalised relationship with someone. It may be seen from this that trust needs personal interaction that is gained through recognising someone with a specific identity and is shared only by those people who recognise the same things as being true. In the practice of *parrhesia*, it is the coming to know the self through the experience of the person who tells the recognisable story of truth about the bipolar symptoms. It would appear, therefore, that the

face-to-face experience has been easier to find and share the type of personalised forms of trust through relationships formed, than through the internet.

Further to finding one's own comfort zone by being able to select the right kind of identity to communicate with, understanding the bipolar identity for the individual is closely associated with the type of support people expect to attain:

It would be good if there were particular forums that specialise in people with particular conditions, so not just everyone's in together, because it's very difficult to talk to someone with bipolar II whose had a couple of bouts of depression and one manic episode as opposed to me. I don't even know how many manic episodes I have had and how many cycles. People say that it's more than four a year and sometimes I've had four a month. I've sometimes had it within a ten minute cycle when it's really bad so it's like, it's mixed, so I need to speak to people that are mixed and rapid cycling to be able to get that. Interview, Catherine

The above two examples demonstrate that participants were seeking to clarify or build on their personal identity through sharing their lived experiences. Fitting the perceived self with personal identities that are found within the online experience is difficult due to navigation that does not lead to the exact criteria. Also demonstrated here, is the extent to which participants have engaged in the technologies of the self, using self-reflecting techniques to seek out and match a true or recognisable identity.

Therefore, it may be argued that expectations about sharing feelings that form trust are based on being able to recognise truths in someone else's story that conform to one's own very

precise feelings about the self. Referring to the concept of *parrhesia*, there are two sides to recognising the truth in someone else. The first requirement is that the person trying to recognise the truth in another person must give up their own *philautia* (self-love) to the extent that they recognise their own short-comings. The second is that there is a ‘conformity’ that must be able to be recognised between what someone says about themselves and what they actually do (Foucault 2001, pp. 134-36). If the virtual is to be considered to contain discourse that only ‘says’, then it may be seen that there would be some difficulty in coming to know who conforms because it cannot be measured with the actual ‘doing’. As Graham’s interview would suggest, the ‘doing’ while sharing a cup of coffee seems to have enabled the recognition of identity sought. Searching the World Wide Web, for both Graham and Catherine had not brought the personal support they really desired, through shared information, because there was no sign that had led them to feel that they were engaged with someone who could conform to their own measure; thus the element of trust was missing. In addition, entering into the act of ‘doing’ for Catherine was possibly made more difficult because she still did not appear to be certain about her own personality traits, relying upon other people to inform her. In the act of ‘doing’ face-to-face encounters, interview participants were able to produce a *parrhesia* that confirmed and supported identities by recognising commonalities more easily than through the internet:

Well, from my point of view, in our group it’s all disclosed and our face-to-face discussions are more supporting each other and talking as friends as is far more meaningful and productive. Interview, Maria

#### **8.4. Trust in lay forums**

For the people who do engage in online chat, as observed through the SANE Australia forum, there appeared to be an embodiment of trust, possibly engendered and held together by the

auspices of SANE Australia. First of all, contributors to the forum enter the conversations by announcing themselves, inquiring about the site or outlining a particular problem they have. They are soon met with a reply from another contributor and an interruption to the conversation by a person who introduces themselves as a moderator and welcomes the newcomer to the chat. Other thread contributions may be accompanied by the title 'senior contributor' or 'contributor'. The moderator, who is easily recognised by the title 'moderator' may be observed to be contributing and guiding the conversations at any time, occasionally alluding to the organisation's policy on a matter raised. For example, a contribution by a 'moderator', in answer to a contributor query about the use of potentially stigmatising descriptive terms for bipolar disorder, outlines how the speaker-representative engenders trust and morality, as conceptualised in the practice of *parrhesia*:

Just to clarify where things stand from SANE's point of view, the new website was developed without any funding or input from pharmaceutical companies. The process of choosing the layout, wording and images included quite an extensive consultation process with people with lived experience. 'Moderator', SANE forum contributor

Thus, although virtual, the chat thread experience has the effect of simulating the act of 'doing' by way of textual response, and in so doing creates a discourse that carries the message of an ideology of trust and confidence to its contributors. This trust is significantly reinforced by the organisation through using information about the site's integrity. In this way, all contributors to the conversation are essentially enclosed within the auspices of the institution. The controlled environment of this virtual conversation is accomplished in such a way as to allow the digital chat of the participants to run as if they were face-to-face, producing feelings of trust due to the knowledge that any unwanted discourse is being controlled.

United Kingdom and Swedish studies have found that people use chat forums for information, identity recognition, and support (see Widemalm & Hjarthag 2015; Moore & Ayres 2016). These reasons were, in fact, the same reasons for navigating internet sites given to me by my participants who tended to use sites from a 'lurking' perspective. However, for those people who do contribute within chat forums, there may be certain benefits to be gained, through the practice of *parrhesia*, that are recognisable to those who share experiences through joining in the conversational interactions. These benefits could be argued to be pedagogical because of the ways in which the participants interrelate to each other in the belief, assessed by textual messages, that each possesses the same problems.

In addition, the use of a forum not only provides a space for trusted exchanges of information, but has been found to offer refuge for people because the online experience is anonymous and, therefore, offers what a face-to-face experience cannot. For these people, the fact that they are not facing someone in person but are engaging with other people online provides a comfort zone away from the fear of stigma generated from community responses to mental illness. In fact, according to Moore & Ayres (2016) people actively look for a forum with a moderator to ensure a safe place against judgmental behaviour. In addition, Widemalm & Hjarthag (2015) found that children of mentally ill parents engaged with chat sites because it was a way of talking with people in the 'world outside' through a virtual space that sheltered them from fears of reprisals due to social taboos about mental illness.

Consistent with Widemalm & Hjarthag (2015) findings, I found that contributors of the SANE Australia forum discussed symptoms and feelings of being bipolar and offered support to each other. Within the comfort of a controlled internet environment contributors were able

to offer personal information, becoming familiar enough with each other that they were able to recognise the possibility of sharing a broad collection of information. Such information included scientific publications they had found. The following excerpt is an example of conversation about the sharing of academic information:

That's excellent. Thanks! Well done. I am wondering if you could post the links for the research you've quoted. I am interested to read more. I've been trying to find an open copy of the Teicher 2002 paper, maybe I haven't dug far enough through the Google search list yet. Found other interesting related stuff though. Dale, SANE forum contributor

In addition to the support given by way of congratulations, thanks, and information-sharing, the above excerpt is indicative of the amount and type of information-searching that is being carried out by some people with bipolar disorder. In collaboration with each other, these participants have been searching for scientific information within academic writing. They are talking about an academic text, *Teicher 2002*, which signifies their desire to learn from complex material about their condition; in other words, they are not seeking out small amounts of information necessarily at lay reading level, but are engaging with learning about their condition at an in-depth level of inquiry. In addition, these forum contributors demonstrate their trust in academic information as a scientific authority and use the forum to share it.

Nevertheless, for others, internet navigation experiences not only found matching identity difficult but found internet forums unhelpful. Participants who preferred to remain outside of any chat forum had formed different ideas about chat site content and what was on offer:

The discussions seem to be very cyclic. It could be someone just winging and when you are in a bad mood that is not what you want to see. Or it could be someone who is being really manic and if you are the same it is not really very helpful to be doing that either. I am looking for something that I can get my hands on and help me resolve my problems. I'm a problem solver. The forums tend to be a bit too touchy-feely. Interview, Catherine

And in support of Catherine's argument, the following chat thread indicates how contributors can use emotive language to express their feelings:

I am sure I did not say it was hypocritical to hide your mental illness. I was sure it was to do with not employing someone with mental illness and being a mental illness sufferer yourself. I would never say that someone is being a hypocrite for hiding their problem. It is theirs and no one else's. I always try to tread softly as when you are a sufferer you do not want someone shoving their ideas down your throat or demeaning their thoughts. In answer to your last comment, rest assured, I would let you know if you overstepped but then again I really don't worry about things like that. Robin, SANE forum contributor

The above example of chat was taken from a thread of conversation about stigma and the workplace, and whether or not to disclose one's own mental illness or anyone else's. The initial inquiry had led to some expressions of misapprehension that reoccurred within the ensuing threads, due to at least one participant's misunderstanding of another's comments. In such a case, the participants' abilities to express themselves in writing and to interpret text written by others is the likely problem, and the distance in time between thinking about the subject and sending the message. In any case, it may be seen that written text can carry

disputable content that may induce an emotive flow of conversation that, as Catherine has described, could be ‘unhelpful’ to someone who is trying to control their mood swings. Vayreda & Antaki (2009) also found that people’s use of emotive language in conversation threads, had led to overemphasising a problem in a negative way. Disputing the use of the word ‘hypocritical’, talking about ‘shoving’ ideas and ‘demeaning’ people’s thoughts demonstrates the type of emotive conversations that could serve as a deterrent to some people’s contribution within chat sites.

In the practice of *parrhesia*, however, forum speakers have presented themselves as the open-minded contributors to a series of self-disclosures that have, in due course, been met with the expected challenges. Frankness, sincerity, the kind of truth that needs qualification, criticism and risk are all part of what constitutes the practise of *parrhesia* (Foucault 2001, pp. 12-17). Therefore, the pedagogical effect of telling the truth as marked by the risk taken and the criticism encountered has produced the kind of social discourse that has increased the knowledge of those who engaged in the online chat thread debate. At least one speaker has felt the need to adapt his behaviour in a manner of self-reflection, also demonstrating the relationship between *parrhesia* and the technologies of the self. This is not to say that those who prefer to ‘lurk’ cannot gain from the enactments of *parrhesia* by being part of the audience, rather than being a contributor. There does, however, appear to be a divide between those who see the advantages of using chat forums and those who do not. In this case, it could be considered that there is some risk to be taken by participating in an online chat thread, and that some people find benefits in participating while other people are not prepared to take the risk.

## 8.5 Trust in consumer sites

The data examined for content about internet consumer sites came from the interviews.

Participants revealed that they were not always sure of the names of the sites they had visited but most were able to name one or two they remembered. Of the consumer sites discovered, interview participants mentioned having visited the SANE Australia site, Reddit online mental health, the Black Dog Institute site, the DSM (Diagnostic and Statistical Manual online), the Mayo Clinic online, MIMS Australia online (Monthly Index of Medical Specialties) and *beyondblue*. Participants also mentioned using key words such as ‘depression’, which then might mean they transgressed towards a bipolar disorder link when the description for depressive illness did not fit their personal experiences. People were mainly looking for information around diagnosis and treatment of bipolar disorder. Two participants said they just went looking on the internet to check information they had been given by their clinic about their medications, or to find out about any updates relating to their medications.

All the participants used their personal abilities to assess the quality and reliability of information within online mental health consumer sites. Some participants knew exactly where to go to find what they already knew they wanted, and others spent some time divining for the type of information that they wanted. I found that people did not merely accept information accessed through internet sites because it was there. In fact, people used some measure of choice to take away the type of information they felt they could rely upon and use.

Research carried out in Australia on purchasing consumer items from Australian government-sponsored health websites found that trust was ‘strongly linked to usability’, that is, ‘ease of

use' (Fisher et al. 2008, p. 483). Discontent with 'ease of use' usually meant that people who did not trust the health websites complained of 'serious design problems' (Fisher et al. 2008, p. 493). The following excerpts are some examples I use to explain how my participants were able to assess the site content and in what ways they were able to make their decisions about the quality and kind of information they needed.

At the time of interview, Deryn was 68 years of age, so she was able to describe her experiences with bipolar disorder before the internet as well as following access to the internet:

Things like the Mayo Clinic or beyondblue, so that it's accessible to ordinary people. And then you can always click on the links if you want something more. When I was first in hospital we had trouble finding the combination of drugs that was right for me. It was before the Internet. This went on and on, and on. And, so, later, when we [herself and her clinic] were going to tweak it [the medications] slightly, I just looked it up to see what had changed from one drug to the next, and, like in the old days, I would go to the chemist and he would get out that great big fat MIMS book and show you things in that. Well, I didn't need to look in a big, fat MIMS book because it was online. Interview, Deryn

This interview excerpt shows that the value of the internet to the consumer is in that it is easy to use, and is capable of carrying familiar content that the consumer is able to easily interpret, and put into practice. In addition, it is possible that quick, easy access to content that is readily understood by the consumer most likely enables efficacious treatment for bipolar disorder. Personal experiences of pharmaceutical use may well assist the individual to assess whether specified pharmaceutical products will improve the management of their condition.

It would appear that trust in internet sites may be gained from knowledge of, or experience with pre-existing trustworthy resources, such as pharmacists or libraries, the identical information of which has become available online. This type of information, combined with personal experiences, could then be carried to the clinical setting, providing a more efficient management outcome.

Deryn's interview has, therefore, outlined an interesting development concerning interrelationships between the clinic and the individual. For Deryn, the internet has provided a more immediate way of checking her medications. There is a strong sense, from this narrative, that Deryn feels she is able to understand what is being used in her medication regimen and that she is taking some personal responsibility for its potential efficacy.

According to Blumenthal (2002), patient use of the internet has become so profuse that it is possible that they can know as much as their doctor and, even, specialist. However, even with the acquisition of knowledge about pharmaceutical products, in particular, patients will still need to use their clinicians as 'trusted advisers' because they are the ones who have the knowledge to assess the correct dose of medications. This view is argued by Blumenthal (2002) on the premises that internet information is designed to meet the needs of 'all' and does not always meet the needs of every individual case where medication requirements may differ. Using the above excerpt as an example of this clinical and informed patient interaction, it may be noted that Deryn feels that she is engaged in assisting her clinicians in decisions about her medication use. Concerning her treatment, Deryn does not refer to her doctor or her clinic, or indeed herself, in the first person singular, she uses the word 'we': In other words, Deryn feels that she is co-producer in the management of her medication.

Deryn's 'touchstone' for measuring the truth about her treatment has been created through her previous knowledge about how she has experienced her condition, and her faith in the

MIMS book that her pharmacist had produced: Deryn has used this knowledge to make a choice about the internet sites she would use in order to join in on medical decisions concerning the management of bipolar disorder.

Where information was not already well-known, interview participants expressed their awareness of pitfalls associated with internet use, including the trustworthiness of internet site content regarding its accuracy. In such cases, further personal assessments about site content needed to be employed. The following interview excerpt shows how visual content may be important to people in being able to assess the internet sites that they decide to rely on for information:

I think Black Dog is amazing. It think it's really well put together. I mean just visually it's really beautiful and well put together and the information is clear and it's quite intuitive and easy to follow. SANE as well. I mean I know I've used it but I don't have so much of a memory of what it looks like and how it's arranged. Other stuff – I think it's all easy to find but whether, or not, it's quality information, whether you can trust it, whether or not it's safe, I mean the danger you run with the internet nearly all the time. Interview, Elyse

The main point of interest, from the above extract, is that Elyse is attracted to the site she found visually attractive; it led her to the right kind of information: Furthermore, the idea of a well-organised, clear and visually beautiful website appears to be linked to trust in its content because the information is easy to follow; therefore, it is transparent to the observer. Other sites, not mentioned, or only vaguely remembered, may mean that the individual was not able to find a necessary transparency within the site content. Therefore, trust did not develop through engagement with such sites. In addition, the distrust of sites encountered, it

would appear, is associated with safety, assessed by a lack of quality of information, and feelings about encountering online danger.

In another interview with Jim it appeared that visual cues could be linked to trust:

I suppose, when you do things like write a story, if it is just a piece of black and white information on a page, it might not have credibility. That's when you start I guess having things like the picture of the person down in the bottom corner and all sorts of things like that. Something that gives it some kind of human sort of element to make it a bit more substantial. That may be the difference – I don't know. Interview, Jim

Visual design, social cue design and content design were the main areas of investigation for Karimov, Brengman and Van Hove (2011) who found very few studies that were able to validate any theory about how these factors influence first-time visitors of internet sites. Through my analysis, I would suggest that the trustworthiness of internet sites for people with a bipolar disorder is derived from initially two attributes: The first comes from a person's ability to navigate the internet, and the second comes from knowledge through prior education that enables an attraction for scientifically-supported information that is acquired from an academically-accredited source such as the Black Dog Institute and MIMS. In fact, as a further consideration of trust by scientific association, I found that a younger participant referred to the use of apps that were known to her psychologist, and were, therefore, considered by her to be a worthwhile application for her management. Using a clinically recommended internet site meant that the possibilities of 'danger' could be eliminated through direction from a trusted source such as the clinic.

An interview with Graham is a further example of how people with bipolar disorder were attracted to online sites that display content pertaining to scientific literature:

Well it's easy – I mean I am using the internet all the time so I am very comfortable with it. I guess originally I looked on internet sites, looking for things like the DSM, just basically trying to pick up useful information. It was difficult to find anything, partly because I didn't know what was going on, I was trying to figure it out. And it's very easy to find a two-page fact sheet explaining what depression is, right? Well it's helpful to read the first time but if that's all there is, that's not very helpful... There would have been quite a number of things I went through. One thing that was very helpful was the Black Dog Institute. I like Gordon Parker's [Professor of Psychiatry at the University New South Wales] work on bipolar II; it fits with what I have very closely. And even at that stage, I remember looking through there and finding his distinction between melancholic and non-melancholic depression was very helpful and pretty much explained the bottom line of what was happening. So that was very helpful. Interview, Graham

Often, participants were searching to find out 'what was going on', indicating that finding something to identify with was the key to trust. As previously mentioned, recognition of the self, and the confirmation of a set of facts that are able to be tested with the self-identity, produce trust. Recognition of the self through a set of online facts may help reinforce a relationship of trust between the individual and the clinical experience.

I found that there was a tendency for participants to search for and finally rely upon a site they recognised as being linked to medical authority. Typically, I found participants were more interested in reading online scientific information. This may be due to, first, what

Blumenthal (2002, pp. 527-30) has nominated as being the ‘asymmetric competence of the [medical] profession and its underlying cognitive, moral and collegial supports’, as understood within deep cultural beliefs about healing and who should be the healer; and, second, the existence of scientific literature and social beliefs about scientific credibility. Scientific credibility is largely due to education and personal beliefs about who is the ‘expert’ (Thomm & Broome 2012). The ability to be able to discern who holds the most credible knowledge, within a discipline, including ‘clustering’ that knowledge into disciplines, has been found to exist within children as young as pre-school age (Thomm & Broome 2012; see also Keil et al. 2008, pp. 272-82). Using text extracted from the internet about two scientific subjects, Thomm & Broome (2012) found that participants were able to distinguish between general social discourse on science, or ‘official science’, and their own personal judgments of texts claiming to have scientific credibility. Thomm & Broome (2012) concluded that, while using their own personal views about science, lay people may not necessarily be susceptible to suggestions made by scientific experts; however, lay people do rely on their prior knowledge and may be reluctant to accept unfamiliar scientific information within text due to their limited understanding of how science ‘guarantees truth’. Therefore, it would appear that any new scientifically-based information encountered by people with a bipolar disorder would need to be discussed with an ‘expert’, within the frame of personal knowledge and views about science. How they make their personal judgments about whether the internet or the clinician is the most ‘expert’ may be better understood through the explication of the next segment in this chapter.

## **8.6 Trust in the professional (professional discussions)**

People with bipolar disorder often mentioned their general practitioner, psychologist or psychiatrist in terms of an anchor to depend upon where a final solution was in consideration

for their problem. The internet was a source of information that could be used to challenge clinical information where implicit trust in the clinical solution to a problem may be seen to have become equivocal. Individual misgivings about the clinical setting arose where not enough information had been given, or where a more explicit guide to what kind of medical assistance was required; for example, the lack of bipolar disorder management and support.

Historically, knowledge about a condition or illness was once entirely derived from a trusted person who was elected by society to perform remedies, usually as a result of lay beliefs about curative events. According to Blumenthal (2002) individual reliance upon the skills of the medical professional has been due to three attributes; (i) their cognitive performance based on scientific knowledge, (ii) professional morals, based on commitment to patient benefit; and (iii) collegial checking on members' competence. However, the internet is seen as a challenge to previous medical professional beliefs about the patient's lack of ability to judge their performance (Blumenthal 2002).

First, as a way of outlining problems concerning individual imperatives to be able to assess correct clinical help and possible short-falls experienced within the clinical encounter, I quote a person who was hospitalised in 1985. The text (below) is taken from a testimony about their life experiences with bipolar disorder including their clinical experiences. In the context of the written testimony, a personal conclusion has been reached about the abilities of professionals based on past experiences and personal knowledge gained:

The psychiatric help I have received has been patchy, but sometimes good. As I have gotten older I have become more assertive about seeking and maintaining good GP

and psychiatric support. I value a good sounding-board in times of crisis, but more importantly, in negotiating personal growth. Testimony 2

The above testimony suggests that experience is what is required to make personal judgments about professionals. Using the Foucauldian concept of the ‘touchstone’ it may be observed here that the individual has accumulated enough knowledge through experience with professionals, over time, in order to test professional performances in relation to the individual *logos* or ‘intelligibility’ (see Foucault 2001, p. 97). It is a mode of measuring professionals against other professionals. The resultant feeling for the individual has been one of assertiveness so that trust is engendered through personal enlightenment and associated abilities gained for making judgments about professional help. Also, it may be considered that the knowledge gained from consultation with a number of different professionals has caused the individual to engage in self-reflecting technologies.

The message to the reader of the online testimony is that the technologies of the self needed to forge pathways to truths engender trusts that enable the self-adjudication of ‘personal growth’. The trust, gained through experience, has meant that the individual has gained autonomy and, hence, only needs to use the clinician as a ‘sounding-board’, a further example of how it may be learned, through the internet that people are moving towards clinical relationships that produce efficacious management by a form of mutual agreement.

The following interview excerpt indicates that measuring the knowledge of the professional also occurs when people engage with online information:

I think because it’s [the Black Dog Institute] the parallel with what my doctor and psychiatrist are saying. But I have read some scientific journals as well, because I am

interested in different ways of treating it; what might be new, new research and studies. I am interested in the shock therapy thing, oh, my gosh, there's different approaches, different ways. All I know is I tried the holistic approach once and it didn't work. I really just have to lie in the sand. I've got to listen to the psychiatrist. If I saw online something that kind of flew in the face of my psychiatrist, I'd bring it up with him. I'd say, 'I'd read this online', and I would want to know what he thought about it. He has even said to me 'You've gone and Googled everything'. You know, he pre-empted the fact that I spend hours and hours on the internet researching, I was like 'Yep'. Interview, Helen

The more knowledge that can be accumulated through making use of as many resources as possible, including the internet, the more trust can be attuned to the professional. The excerpt suggests that relying upon a professional person for information alone is limiting the choices for the individual and thus the trust endowed. In a society where choice has become the norm, it is possible that people feel the need to search widely for as much comparative information as possible. Many sources of information, as offered from reading print and online, enable the individual to pursue a collection of truths or evidences that help propagate ideas that form trust. It is a way of cross-checking, between the clinic and the internet, in order to confirm that the scientifically-based knowledge within both resources is accurate. It may also be true that individual use of internet sites such as the Black Dog Institute as a 'touchstone' for cross-checking scientific information, is a way of ensuring that clinical responsibility is met. In other words, the internet has become a resource for external 'collegial checking' as carried out by patients. I refer here to Foucault's study of Socrates' practises of cross-examination that he performed in his 'role of the touchstone' which was for

the purpose of confirming the truth of the existence of the object in question (Foucault 2001, p. 102).

Another reason for searching online for information about bipolar disorder was found to be due to the lack of sufficient information given out at the clinic. Because of the differences between individual experiences with bipolar disorder, individuals tended to seek more information to fulfil their personal needs. The information required involved gathering symptomatic information, selecting out components important to the individual, as well as searching for the many different regimens of management available. Perusing different internet sites of information also helped participants to make assessments about trustworthiness, based on comparisons of the sites as well as the professional clinic:

The lack of knowing where to go to get information. Without the internet, I just didn't know. Even when I got diagnosed they didn't give me any information about bipolar. They just said 'You have bipolar; these are some of the symptoms of bipolar, and these are the symptoms that match your experiences'. They didn't give me anything to actually help me with dealing with bipolar. And the thing that I discovered is that even the information on the internet is inaccurate at times...So, when I went to the Black Dog Institute website, I would find all these random things that had been happening to me and I realised that it was bipolar disorder. It's all connected to that. So it made me understand the illness much more. Interview, Zoe

It may be seen from the above that the internet has become a door to information previously harder to access by the lay person. Thus, the internet has become an important resource, particularly where augmenting existing information has been necessary. Importantly, tailored information, as alluded to above, has helped to verify the condition, bipolar disorder, and

provide relief to the consumer through better understandings, not addressed within the clinical experience.

The above also provides an example of the ways in which participants have been able to assess whether an internet site has provided trustworthy content. The recognition of the self from the described symptoms found within the site content of the Black Dog Institute demonstrates that participants were able to connect fact to personal experience. The knowledge already gained from the clinical diagnosis of bipolar disorder has helped participants to assess the credibility of certain internet resources. Zoe's internet exploration which led her to connect to the Black Dog Institute site is an example of how participants used their beliefs about scientific credibility in order to find trustworthy information.

## **8.7 Conclusion**

Through an examination of the engagement of participants with the internet I have been able to explain the importance of identity-seeking action and how identities have been found. Establishing the bipolar identity was crucial to the ways in which participants were then able to educate themselves about their condition. Using the Foucauldian concept of *parrhesia* I have discussed how participants engaged in the technologies of the self through internet use. Participants were able to, in effect, practise the ancient Greek concept of *parrhesia* through techniques of reflection, truth-seeking identification techniques, and seeking online information helpful in the understanding and management of their condition. Through self-reflection participants were able to successfully sieve through internet content using their personal experiences and knowledges gained from clinical interaction as their 'touchstone' for assessing the truth within internet site content.

In a system of community 'logics' that combine the interactions between the individual with a diagnosed bipolar disorder, the professional 'expert' and the internet, I have demonstrated that there is a possible benefit in improving the efficacy of self-management. Initially, such logics have been able to be integrated due to easy internet access and trust engendered through certain exploratory findings that have been able to conform to personal experiences.

Although navigating the internet proved to lead participants to a wide choice of internet sites, there was found to be a lack of internet machinery that easily facilitated the navigation towards a tailored content. Tailored internet site content that meets specific individual needs, plus visual cues that lead to easy interpretation of site content, plus easy site content access, may help form ideas about trust.

Using the Foucauldian concept of *parrhesia*, engendering trust could be achieved by finding an exact identity, as identity is authenticated through conformity. However, I found that there were difficulties in finding the 'touchstone' through internet use as participants could not find a resource that offered a tailoring suitable for their exact symptomatic condition. In the absence of an easy pathway to a tailored internet experience, participants often preferred an off-line face-to-face venue for engendering trust. Participants showed a high regard for scientific truth, tending to choose internet sites they could trust through recognising scientific information that was easily-understood. Trust engendered through support groups depended largely upon personal habit, the virtual being accepted by those already engaged in it and used to it, and face-to-face preferred by those who needed the 'doing' experience.

The online experience was helpful for engendering and enhancing trust between the participant and the clinic. This was apparent when participants explained how the online experience helped to test and confirm diagnosis and the clinical management of medications. However, consulting an array of different professional clinicians was found to be valuable to individuals and clinical consultations remain an important source for gaining 'expert' advice and treatment.

Therefore, the findings were that the online experience brought much to the participants concerning diagnosis, assessed through identifying familiar personality characteristics and establishing self-identity. Participant use of the internet assisted practices of autonomy that helped with making choices about management of bipolar disorder, particularly with regard to pharmaceutical treatments. It is concluded that using the internet may be useful in procuring an efficacious self-management outcome for people with bipolar disorder, where personal experiences are used to assess trustworthiness associated with clinical advice, and where scientific information is easily accessed, reliable and easy to understand.

## **Chapter 9    The researcher reflections and limitations on studying bipolar disorder**

### **9.1.    Confining the study to bipolar disorder**

In the beginning, my desire to do research in the mental health area of bipolar disorder brought all sorts of self-doubts to the forefront of my mind concerning whether I could respectfully do justice to the lived experience of such people. As Denzin & Lincoln (2008, p. 1) remind the researcher in their introductory chapter to *Landscape of Qualitative Research*, qualitative research ‘serves as a metaphor’ for past colonial research that has been claimed by some to have been privileged, powerful and exploitative of ‘the other’. However, my own experience, with post traumatic distress disorder and depressive/anxiety disorder, was instrumental to my thinking that I could help expose, in a sensitive way, the problems faced by people with bipolar disorder. Nevertheless, there are some issues to be noted pertaining to researcher bias when being involved with collecting knowledge that is to some extent already familiar. I begin by reminding the reader of the type of limitations already intrinsic to a qualitative paradigm. I then discuss some of the limitations and problems associated within the three sets of data used in the analysis, and I conclude by reflecting on some of the decisions and awareness needed when being a researcher closely related to, but not quite an insider, to the group under investigation.

The study has been conducted taking a typical qualitative design approach that has focused on a narrow field of investigation (Corbetta 2003, p. 283). Narrowing the field for an in-depth investigation has its advantages because the small-scale investigation allows the researcher to extract more detailed information. However, there are always inherent disadvantages to doing such a study because of its focus upon a particular subject under investigation. Because bipolar disorder has its own set of characteristics, the study could not be generalised to any

other type of mental illness category. Therefore, the results of this study are only meant to be understood within the confines of social experiences of participants selected from the sampling.

In addition, the study has been carried out from Melbourne, Australia and the data sets have been selected from Australian internet sites and by conducting local face-to-face interviews in Melbourne. Although Australia has its particular cultural practices and attitudes towards mental illness, it does belong, in the broader sense, to the Western countries of the world. Therefore, while there may be some differences to be expected within the colloquial context of Australia, many characteristics of the study's findings could be attributed to some English-speaking countries of the Western world, but not necessarily other contexts.

The study has used a small purposive sampling method in order to explore the life experiences and health management practices of people with a bipolar disorder. Therefore, the perspective within the analytical lens was concerned with those people who have been diagnosed and live with the disorder. The study does not include the experiences and opinions of people who live with bipolar-like symptoms, but either reject diagnosis or were not diagnosed. At no time was the investigation meant to analyse and understand the medical practitioner's point of view. I was careful not to engage with any practitioner perspectives that may have arisen when analysing the data as I wanted to explain life experiences of people with bipolar disorder from their own perspective. However, I could not eliminate any feelings conveyed within online text or interview that participants may have imparted about their negative experiences within their clinical settings. In this respect, I have also been careful not to include clinical judgements about the quality of care, as I am not qualified to do

so. The investigation was not designed to understand public opinion based on public understandings of bipolar disorder. Although I recognise that there are some further problems for people with bipolar disorder associated with stigma, I have limited such concerns within this thesis.

## **9.2. Online encounters**

The narrow focus and time frame used for the sampling of the online chat gave opportunity for specific topics to be analysed in some depth, but did not allow for a study of broader chat site content. While the additional online testimonies were informative in the narrative sense, providing some detail for analytical purposes, they lacked spontaneity of the moment, more privileged through interview or chat. However, when analysing internet chat sites, there are other considerations that should be noted. For example, I found that there could be some affects upon users of chat sites due to the ways in which they may be organised, such as the presence of a moderator, used by SANE Australia. When viewing content at the chat sites it became evident to me that some people related the presence of a moderator to a type of policing that made them feel inhibited about expressing their feelings in a more open way; for example, being able to vent their concerns about their experiences with medical practices. This was evident where one new-comer to the chat site wrote that they would not tolerate the interference by a moderator and would, therefore, not continue contributing to the chat. In addition, some conversations would be vetoed by a moderator thereby being made invisible to the other contributors and the public. This action may lose data that could carry important messages; therefore, any material for research purposes that is downloaded from an internet site can only be viewed in relation to the content visible at the time of the investigation. People and the internet sites they interact with to produce visible content make agreements

about how they should be presented and viewed, and what kind of things they talk about (Murthy 2008). Moreover, usual visual and verbal cues that are given when conversing face-to-face are obscured within online text; the researcher can only observe what there is in relation to the talk being presented (Roller & Lavrakas 2015, p. 190). Therefore, the researcher who uses the internet as a tool for research investigative purposes is limited by the governance of the site and the content available for public access.

The two websites selected for analysis were influenced by government and scientific sponsors, orienting the sites more specifically to the biomedical model of mental illness (also the premises for this study). The study of these sites has been successful in relation to inquiry about how participants have been able to self-assess their behaviours and feelings, and form their ideas around obtaining a label/diagnosis. However, it is recognised that there are other voices within the community who do not espouse medicalisation with regard to psychiatry and mental illness, who have not been represented through the two sites selected.

Overall, the scope of the study did not allow for alternative views about medicalisation that reject the reductionist pathological approach (Dos Santos & Beavan 2015). In such studies, living with voices, for example, is not regarded to be a problem, but treated as a way of living that actually enhances ways and means of achieving a full and meaningful life (Dos Santos & Beavan 2015). Although the scope of this study has provided some critique about the performance of pharmaceutical treatments, it has not entered into arguments that support the anti-medicalisation critique. For example, author and journalist, Robert Whitaker, in his book titled *Mad in America: Bad science, bad medicine, and the enduring mistreatment of the mentally ill*, has been highly critical of the medicalisation of mental illness, advocating

different solutions (Book Review, JAMA 2002). These arguments are based on such things as past scientific beliefs that brought about ‘mistreatments’ of the mentally ill, such as electroconvulsive treatment and lobotomy, the aggrandisement of psychiatry, and the commitment by Western societies to meet economic constraints. Such critique has left much to be explained about social inequities and the mentally ill as an underclass (Book Review, JAMA 2002).

The biomedical approach undertaken for this study has also meant that there have been limitations to some ways in which the researcher has been able to construct the lives of participants through the internet. Choosing internet sites that did not encourage anti-medicalisation viewpoints, meant that the researcher power/knowledge stance tended to lean towards the production of knowledge from subjects living with a diagnosed condition. It is, therefore, acknowledged that the limited discussion around views about living outside of the biomedical construction of bipolar disorder, has oriented the research outcome with a bias towards those who were living within the boundaries of medicine.

While this study has noted some difficulties around becoming medicalised, using medications, and feeling the need to conform to social economies within Australia, its scope has not been large enough to enter into in-depth analysis of alternative ways of dealing with feelings associated with mania or depression. Therefore, the more conventional approach to selecting internet sites that supported the biomedical model of mental illness was taken.

### **9.3. The Demographics**

In order to produce unbiased results, it is desirable within a qualitative study, using a purposive sampling technique, to ensure, as far as possible, even distribution of age, socio-economic status, type of work and gender (Barratt, Ferris & Lenton 2014). However, controlling such criteria was difficult where online content was obscured and interviews depended upon gatekeepers to channel participants from their particular organisations into the interests of the study.

When analysing written content within the internet sites I found that personal identities such as gender, age, and education levels and socio-economic status were obscured due to the anonymity of the contributors. I found that gender, particularly, was difficult to assess when reading the testimonies, and that age and gender were both hard to assess from chat site content. Therefore, it was difficult to assess what difference age or gender would have upon the experiences of the participants found within the internet sites. Differences in social attitudes, detected between the conversations of older people and younger people may not be recognised within such content either. Furthermore, I could not account for any cultural differences as they were lacking among interview participants, and online conversations did not appear to embrace any noticeable differences in experiences and attitudes that would indicate the cultural diversity within Australia.

In addition, where interviewing was concerned, with a small number of interview recruitments, adhering to such requirements was difficult. I found that there were limited opportunities for recruitment because of the cautious approaches needed due to sensitivities associated with the topic. I found that the many places, such as libraries or community

centres, where I was able to post my flyer publicly, failed to attract any responses. I therefore turned to my NGO gatekeepers in order to gain recruitment success. My interview participants were mainly women, only two being male. The ages of my participants, however, varied, ranging from around 30 to 68 years of age.

Education levels were easier to assess from my observations of online content and from getting to know the participants who took part in the face-to-face interviews. The written testimonies were collected from a writing competition that was being conducted by the Black Dog Institute, comprising selected yearly topics including one year in relation to experiences with bipolar disorder. In the first place, the testimonies had been chosen because of their content and their ability to convey the kind of message sought by the Institute. The testimonies were well-written suggesting a high secondary or tertiary level of education. I assessed the linguistic abilities to be, generally, lower for the chat sites than the abilities of the participants I interviewed or found within the written testimonies from the Black Dog Institute. However, my analysis of the chat sites was based on content that was internet-specific, conversational, local, being within Australia, and, therefore, somewhat colloquial. It is quite likely that colloquial language is normally the preferred mode of speech when people are talking informally and when higher education levels are not necessarily a requirement. In a de-contextualised virtual setting, where people are in an electronic space, language changes due to the development of 'codes' that are being related to online communication (Isabella 2007). Therefore, the researcher observation in this regard may be skewed if relying upon stereotyping people, based on a particular type of conversation that takes place between people who are engaged in internet chat.

All people interviewed had attained at least final year of secondary school, with most having tertiary education. Some interview participants were well-known within their area of work expertise, suggesting that there may be a 'high-flying' personality trait connected to bipolar disorder which may not, in fact, prove to be the case from a broader social investigation.

The high level of education articulated by my participants, and noted from my interview notes, could not be compared with the broader population of people with bipolar disorder. For example, I have previously noted that general health literacy skills for the Australian population are competent, favouring younger people, but are lower for older people (Australian Bureau of Statistics 2006). This comparison would indicate that my sampling did not provide an exemplar, and therefore, could not be generalised to the health literacy skills of the broader population of people with bipolar disorder.

#### **9.4. The researcher**

I was constantly aware of having to check the rigor of my interpretation of the data collected. I felt that, on reflection, it was easier to adopt a neutral researcher position when analysing the internet data than data collected by interview. Analysing data from the internet always felt as if I was standing some distance away and observing what I could see from the text. I found there was some impartiality to the impersonal, anonymity of the internet content. Through the internet, I felt I was able to disengage from more empathetic feelings towards the participants, approach the analysis of the data in an objective way, and interpret the subject matter through time and space. The creation of empathy has been noted to be the result of having a shared experience and a sense of belonging, something not available to the voyeuristic researcher (Smith 2012; Bheenuck 2010, p. 81). By contrast, the written word is

fixed within its site of discovery only waiting to be interpreted by whomever discovers it. Once written it cannot be changed and therefore can only be revisited – and revisit it I did, checking over the content to make sure that I had done it justice and had not been guilty of imputing my experience upon the experiences of the writers. Therefore, although I was vaguely familiar with the subject under investigation I felt that as a researcher I was able to look more objectively upon the internet content than, perhaps, the transcripts I analysed from interview.

While participants I chose from the websites wrote, in their own time, what they wanted to say, my interview participants were confined to answering my semi-structured questions within the nominated time-frame of approximately one hour interview duration. My selected framework for the interviews meant that I could focus on what I wanted to know rather than relying entirely on what the participant wanted to tell me. To some extent this type of inquiry tends to inhibit the narrative given because it asks the participant to recall only certain particulars within their experiences. However, I was conscious at the time of interview to locate myself outside of the narrative being given, while expressing my concern and interest to the participant.

Conducting myself in this way, I was able to elicit some extensive monologue. I found that guiding my participants' thoughts with the use of a set of open-ended guided questions was helpful for keeping the topic on track: However, I tried to adhere to Riessman's (2008, p. 24) instructions, generating the narrative by using longer turns in talk between the participant and the interviewer. At the same time, I allowed the participants to take considerable freedom to relate their experiences through events of their life, as they came to mind. I found that by

assuming the listener/researcher role and allowing such freedoms, participants often talked for some considerable time. I then only had to remember what they had said so that I may return to further probe and clarify something or merely interrupt to keep the narrative on topic (Riessman 2008, pp. 23-4; Corbetta 2003, p. 278).

Qualitative interviewing takes considerable practice, and as a doctoral student I can only claim a novice approach to my interviewing abilities (Chenail 2011). However, I have relied upon my knowledge from my readings to guide me in my thoughts during the interview process, beginning with the way in which I introduced myself, to running my interview, and my concluding conduct and farewells. As I was aware of my own nervousness, I also assumed that my participants may be feeling a little uneasy as well. Abiding by concerns raised in Chenail (2011) about the researcher as the instrument through which data is generated, I tried to establish a relaxed interview setting by making some informal chat with my participants before we began. As Chenail (2011) has noted, trustworthiness pertaining to the data obtained, and the information arising from the analyses, is related to the researcher's own mental state. Keeping an even temperament myself was particularly important to the collection of data from interview, and creating a comfortable setting for my participants and myself was important to gaining trust, thereby ensuring rigor through the 'truth' established within the data I was privileged to obtain.

Remembering that the researcher is the instrument in the investigation, I also was aware of the way in which social scientists have regarded the researcher as holder of power in the researcher/participant relationship; a perspective historically held responsible for much subject misrepresentation (see Marx 2001; Bishop 2008, p. 147). The hierarchical position of

the researcher in relationship to their participant is related to researcher involvement with the project which unavoidably amounts to their 'ownership' of it, and their implied control over it (Smith 2012). When equality has not been reached between the researcher and their participant, the way in which data is collected has been argued to have been compromised (Marx 2001; Bishop 2008, p. 147; Riessman 2008, p. 24). I found, however, that meeting on mutually agreed ground was the beginning of forming a fleeting friendship between my participants and myself. Further developments of any friendship could not be entered upon as I had only one opportunity to interview each participant. Generally speaking where a participant chose a coffee shop the atmosphere lent itself for a more informal meeting than, say, where a participant wished to meet me on my university grounds. However, I always sensed that participants regarded me as the professional to whom they had come to give their narrative, and felt they were doing good or gaining benefit from taking part in a research project that was about their particular problem (see Mooney 2014; Birch & Miller 2000). As inevitably the researcher and the participant are engaged in the co-construction of the narrative, rigor can only be assured when the partnership has assumed an equal 'dialectical relationship' (Smith 2012).

One problem pertaining to bias in qualitative research that has often been cited and commented upon is the problem of at what stage, if any, should the researcher share 'insider' information Taylor (2011); Bennett (2002); Beoku-Betts (1994). This was a problem that I often thought about, particularly when interviewing. There have been some thoughts expressed in studies by, for example, Taylor (2011) and Earle (2014) on the researcher sharing 'insider' information, that is mostly inclined to agree to its usefulness. However, the positive effects of belonging to the in-group have been counteracted by the argument that such a stance does not necessarily provide a more 'correct' or 'absolute' way of explaining

‘cultures’ or groups with similar experiences (Taylor 2011). In addition, in representing participants for this study, I chose to use people with a diagnosed bipolar disorder, making analysis difficult to interpret outside of the biomedical lens. My own belief in the need for a diagnosis for my depression had possibly meant that it has been difficult to interpret the ways in which bipolar disorder may also be understood outside of the atomistic individual. In any case, referring to Rose (2007) the choices people make about their bodies and minds are based on advanced liberal discourses about being ‘active’ in acquiring scientific knowledges.

As the researcher of a project on bipolar disorder, I could only partially ‘share’ knowledge with the in-group as I was diagnosed with depression, which is only associated with one side of the bipolar ‘pole’ – clinically known as ‘unipolar’ depression. Therefore, I could not claim to have any ‘deeper levels of understanding afforded to prior knowledge’ as an advantage, nor any disadvantages with regard to the collection of my data or the analysis (Taylor 2011; also see Smith 2012). However, where I felt my ‘insider’ knowledge might be useful was when I was able to use my experience as a way of breaking the ice between myself and a participant. I found, especially when I began interviewing one participant who was young, it was helpful to divulge my own problem as a means of explaining empathy, which actually had the effect of relaxing the participant. Instead of faltering as she tried to recall information to answer my questions, the participant was able to contemplate and bring to light her experiences more effectively. I found that there were other times when divulging my own problem during interview helped the participant to allow their narrative to flow more readily, although mostly, I withheld my experience to ensure the participant had full command of the speaker’s platform. In accordance with Smith’s (2012) experience, I also found that discussing a little about myself after the interview ended in a ‘reciprocal relationship’ and I was able to take away some further information off-tape.

However, it has been noted that having 'insider' information may also affect researcher bias (Taylor 2011). As long as the researcher is free to be accountable for presenting an unbiased view, not usually formed by taking sides with the participant, then shared experience may be alright. However, when empathy sought and given between participant and researcher affects the accountability of the data then the rigor of the analysis will be in jeopardy (Taylor 2011). In addition, as Taylor (2011) explains, there are obstructions to the objectivity in analysis where differences of opinion, as presented by the participants, have been allowed to merge into the researcher's own construction of what is actually being said. I believe that by incorporating triangulation into my research design, I was able to achieve, through the three kinds of data sets, a backstop from otherwise becoming too personally involved or adopting any favoured position. For example, by examining all data, I was able to contrast those participants who wanted to take prescribed medications with those who wanted to express all the problems associated with taking medications.

It is difficult for a researcher to undertake the representation of people with a mental condition such as bipolar disorder. In fact, I found that choosing participants who had been diagnosed with the disorder an advantage to knowing who I was researching, because of the otherwise socio/cultural vagaries around the semiotics of what culturally determines irrationality. Weiner (2011) describes the ways in which rationality/irrationality associated with bipolar disorder is difficult to determine, and hence self-manage. Sometimes, individuals with bipolar disorder feel signs, through acts of self-surveillance, that tell them that they are becoming irrational, while their close friends, as observers, may not be aware of these signs. On the other hand, there are times when others are able to assist in making

decisions about seeking help or going to hospital. Adopting a neutral ground, I did not seek to view my participants as irrational people. In fact, I found them to be highly articulate and rational. I, therefore, sought to inquire from my participants' own experiences, what their relationship was with their society, and why they had chosen to self-manage their condition.

With a purposive sampling method that narrowed the field of participants, it would be expected that the research would be limited. The selection of content from the internet chat sites and testimonies was used to help establish a broader demographic sampling, not achieved by interviews carried out in Melbourne alone. In addition, the interviews, the chat site content, and the testimonies brought into the field of inquiry three different perspectives through which to analyse the data. Limits withstanding, the three data sets and the depth of the study, which has used a qualitative grounded paradigm, provided sufficient analysis for building upon concepts for a worthy contribution to the field of study.

## Chapter 10 Conclusion: Bipolar disorder and individual autonomy

So imagine, if you will, the perceptions and reactions of a child's permanently damaged neural architecture in the body and mind of an adult. Here we have a person who through no fault of their own or genetic predisposition has mental health issues that are difficult to diagnose and seemingly impossible to treat. So this person must then manage a condition which pervades so much of the life they are trying to live – often desperately. Vivian, SANE forum contributor

The above excerpt encapsulates the problem with living with bipolar disorder. Whether the condition is said to be genetic or socially-formed, it has chronicity that often entails repetitive relapses of manic and depressive episodes and is difficult to diagnose (Parikh et al. 2015, p. 87; Phillips & Kupfer 2013). Whether or not participants for this study accepted the problematisation of bipolar disorder as a biomedical condition, they eventually, at some point in their life, recognised the need for constant management of mood swings throughout their life. For participants, problematising personal feelings and conduct in the first instance was found to be difficult, seeking out help and reaching diagnosis presented more problems, and managing mood swings, even when medicated, was found to have been an ongoing problem. In addition to all of this, this study has indicated that individuals living within a contemporary Western society such as Australia, are likely to find themselves trying to manage bipolar disorder according to social understandings and practices that embrace individual autonomy. As autonomous beings, participants have taken on responsibilities associated with the self-management of bipolar as a disorder that requires daily and life-long monitoring of mood swings. Without sufficient knowledge about the management of bipolar disorder, it would be

quite understandable why some people within the society would tend to feel ‘desperate’ to meet perceived social expectations and personal goals.

In the following I summarise the main findings from the investigation and provide some explanation. I begin by recalling some of the life problems participants encountered before diagnosis that pointed to the need to find out what was ‘normal’. The discussion continues around the ways in which participants engaged with the internet to discuss rationalities and social reality as they tried to grasp ‘normality’. I then move on to a summary of the findings regarding seeking for and reaching diagnosis, and the problems encountered. I finish the diagnostic discussions with a note about how the internet assisted participants to reach their diagnosis. I move on then to recount the use of pharmaceutical treatments and the concepts of control, and the ways in which the internet has helped to mitigate personal feelings about clinical control. Following this discussion, I then summarise the difficulties participants experienced when trying to ‘balance’ their lives. As will be noted, from this discussion, choices about management depended upon conventional clinical advice, and advice about alternative medicines/therapies. Finally, I draw upon the issue of identity and discuss what this entailed for participants when using prescribed pharmaceutical treatments and CAMs.

### **10.1. What is ‘normal’?**

The opening of the analytical chapters to the thesis was directed at discourse found within the SANE Australia online chat site. This was regarding some conversational description about ‘hearing voices’ from which concepts arose that were pertaining to how being socially ‘normal’ and living a ‘reality’ are connected. It became evident that participants judged their normality according to the ways in which they experienced and felt their ‘reality’ within a

particular social context. If this context was a community setting, then they assumed they were participating within that community like anyone else, and thinking similarly. Within a group setting where individuals were peculiar to one type of knowledge, such as a bipolar disorder online chat group, then 'normal' was an illness experience, and manic behaviour was felt to be acceptable. Therefore, recognising being 'normal' within the sense of a usual social construct, was difficult to assess, either through an online experience or within an individual's usual social/community setting. The outcome from this evidence would suggest that, at least initially, being the responsible, autonomous individual is difficult for people with bipolar disorder due to different understandings of what is 'normal'.

In any case, acknowledging 'normal' in relation to social reality where mania is concerned, usually meant that participants had to give up certain personal characteristics that were important to them. Often these characteristics were experienced as enjoyable and a way of maximising personal abilities. Due to the enjoyable and senses-fulfilling characteristics of mania, the temptation to accept the manic high and 'dance with the devil' was strong, and only experienced to be 'delusional' after the event. This was evident through the episodes described, such as running red traffic lights, driving cars at high speed, and making financial indiscretions. When experiencing mania, the internet could not be seen to be a useful apparatus for the technologies of the self, as usually someone else had to intervene and encourage participants to seek help.

## **10.2. Games of truth – seeking diagnosis and gaining knowledge**

However, once participants were able to come to know themselves and their condition, through experiential knowledge of the consequences of their actions, they were more in

control of their own behaviours. Realising the disruption of mania to their lives, participants were then able to take rational action to control their condition, firstly, by seeking a diagnosis. Reaching diagnosis was a moment in time that was largely welcomed because it offered a way forward to planning life. Only a few participants revealed that there was a down side to acquiring a diagnosis of bipolar disorder because they felt the condition was something that they did not want.

In agreement with Philips & Kupfer (2013), clinical diagnosis for bipolar disorder was a problem, and, according to the participants for this study, usually took some time to reach. For some participants, reaching diagnosis meant having to visit several doctors and psychiatrists over some years before a correct diagnosis was achieved. Factors associated with delayed diagnosis included misdiagnosing bipolar disorder for depression, a common mental disorder with which bipolar disorder has overlapping symptoms (see Phillips & Kupfer 2013), and the subsequent prescribing of antidepressants whose iatrogenic effects became a way of reaching correct diagnosis. This was a troublesome method for participants, described as a swing to mania from an antidepressant.

However, participants were also inclined to ignore living with their manic symptoms due to experiences of euphoria, and high energy levels – in other words, a general sense of having fun and even accomplishing worthy tasks very quickly. Depressive episodes were related to being difficult to live with due to an inability to ‘get out of bed’ and get on with their day, at home or at work. To date, the readiness of the patient to accept a diagnosis of depression has not been found to have arisen from lesser stigmatising affects associated with depression (Martin et al. 2007; Pescosolido 2007; Moses 2014; Jorm & Reavley 2013; Callear, Griffiths

& Christensen 2011). This study found that the tendency for participants to accept a diagnosis of depression more likely to be associated with individual preference for living with mania rather than the experiences associated with depression. For example, Maria did not tell her doctor about her experiences that were associated with manic highs and Helen thought the ‘world’s made for [her]’ when experiencing mania. Participants who mentioned their mood swings referred to depression as the side of themselves to be avoided.

Trying to identify the problem and obtain a diagnosis were the main reasons why people tended to lose faith in clinical ‘expertise’. Problems in reaching diagnosis, therefore, gave the impetus for participants to take more control over gaining sufficient knowledge and subsequent diagnosis for bipolar disorder. Much of this knowledge was gained through the internet. In fact, internet searching proved to be very important to helping participants decide for themselves whether they had bipolar disorder. Participants’ narratives revealed that information from the internet had pre-empted the clinical diagnosis, giving the individual opportunity to find answers to life problems that were otherwise taking too long to resolve.

Thus, participants were ‘enterprising’ (see Rose 2016 in interview) as they engaged with the internet as a way of finding sufficient information so that clinical decisions could be negotiated, if not, in fact, actually resolved. The internet proved to be a valuable source of information for participants, who, by using their knowledge of their own feelings and behaviours, were able to discern trustworthy sites and take away diagnostic criteria. In acts of *parrhesia* participants were able to use reflexive practices upon themselves to ask questions of themselves that helped them reach decisions about their condition based on, for example, internet ‘take the test’ questions. Participants were able to negotiate diagnostic possibilities

with their doctor and to confirm in their own minds when their professional clinician had reached the correct diagnosis. In other words, this study has found that the internet has been valuable for bringing information to the clinic and in confirming the 'expert' diagnosis. In addition, the internet helped participants to make confident self-diagnosis.

### **10.3. Negotiating the clinic and the internet**

This study found that there were clinical difficulties associated with, not only the diagnosis of bipolar disorder, but also the management of the disorder. In addition, there were ongoing difficulties concerning agency and the need to recognise the onset of mood swings associated with both the depressive side of the disorder as well as the mania. In some cases participants preferred to become the subject of clinical control, accepting the relief that pharmaceutical treatments brought to them, while other participants felt more comfortable with engaging in complementary and alternative treatments.

The differences in individual attitudes towards the acceptance or rejection of pharmaceutical treatment, is consistent with Fernandez, Breen & Simpson (2014), where it was found that there was a paradox which had been produced concerning patient autonomy. The question was whether, in fact, the patient who chooses to submit to pharmaceutical control is as self-determining as the person who chooses to use CAMs as a practise of self-monitoring mood swings. Participants for this study demonstrated how autonomous practises of 'strategic freedom' could mean making decisions about how they were to be treated, including choosing to be clinically controlled. I found that participants embraced such concepts as the need to manage their lives, reach self-efficacy and contribute to society. The tendency to seek clinical advice for the management of bipolar disorder and to, at least initially, depend upon

clinically prescribed treatments showed that individuals had an understanding about becoming the ‘pharmaceutical self’ where social requirements needed to be met (see Jenkins 2010). Consistent with the studies by Fernandez, Breen & Simpson (2014), Proudfoot et al. (2009) and Martin (2007), I found that participants tended to choose to rely on pharmaceutical treatments because of feelings of being out of control and concerns of being in a ‘living hell’ (Catherine), losing cognitive function (Jane), or what might happen in the future (Mayra). For some participants the knowledge of the after-effects of mania, such as depression, or, as Deryn put it being sent ‘right down’, was enough to inhibit negotiations, within the self, that may have otherwise permitted perceived benefits from mania.

Despite submitting the self to the control of the clinic, participants were able to maintain an aspect of individual autonomy through their use of the internet in the management of bipolar disorder. This study found some ‘democratising’ effect of the internet, in accordance with other studies that discussed some benefit to be gained from patient use of the internet, for example, where symptoms could be cross-checked (Ziebland 2004), or where patient-centredness could promote health professional and patient collaboration (McMullan 2006). I found that there was a tendency for increased rapport and collaboration between my participants and their clinic. Participants were at least able to test what they were being told, and their autonomous attitudes and practices were accepted by their clinicians. For example, Helen’s doctor’s comment ‘You’ve gone and Googled everything’, and her reply ‘Yep’, was indicative of the more collaborative relationship she had developed with her doctor and also his knowledge of her activities. In addition, as Deryn noted, the internet has taken the place of the original Pharmaceutical Society of Australia publication *Monthly Index of Medicine Specialties*, now MIMS or eMIMS, and was used by patients to check on their doctors’ prescriptions. In fact, participants often used the internet as the ‘touchstone’ for cross-

checking scientific information with the clinic – a sort of ‘collegial checking’ of professionals (see Blumenthal 2002). The ‘empowerment’ of the internet, therefore, could be a valuable tool in the management of bipolar disorder, especially where people have been found to be able to assess the reliability of information, as most participants for this study demonstrated. In addition, the ‘democratising’ effect of the internet has the potential of being a tool for developing more beneficial rapport between the doctor and the patient as more knowledge brought to the clinic is shared and considered.

The internet was engaged with to some extent by participants when trying to find contacts who could share the same or similar experiences. The use of the Foucauldian concept of *parrhesia* provided, for this thesis, a way of understanding how participants might gain ‘trust’ towards the ways in which they were able to engage with the internet. However, where experiential information was sought through forming individual interrelationships, finding the exact same ‘touchstone’ was difficult for participants. Searching the World Wide Web could be daunting when trying to identify someone with very similar bipolar disorder characteristics, due to the amount of variations experienced within the disorder itself. Unless participants could find their exact match they felt that it was impossible to form any interrelationship that would be beneficial. For this reason, it became apparent that participants felt they could form better relationships in a bipolar disorder face-to-face group encounter, where the ‘touchstone’ was closer at hand, that is, real rather than virtual, and where they could come to enact their experiences together.

Thus, the internet was most advantageous to participants for establishing the existence of the disorder and its diagnosis. Further knowledge gained through the internet by the participants

helped to form rapport with the doctor. At least it could be considered that there was advantage to be gained because internet knowledge brought to the clinic meant that negotiations could be opened up between the patient and their doctor regarding diagnosis and treatments.

#### **10.4. Balancing medications and balancing life**

Going on the internet, however, could not ameliorate problems that arose where pharmaceutical treatments had become unreliable due to individual differences in tolerances to psychotropic medications. In line with Proudfoot et al. (2009) and Schneck et al. (2008), among my participants, there was a tendency for moods to fluctuate even when taking pharmaceutical treatments. Therefore, participants needed to submit to the control of the clinic for adjustments, from time to time. The periodical balancing of medications brought uncertainty to participants about the efficaciousness of the medications and tended to exacerbate feelings of unpredictability already manifested within the condition. For example, Catherine and Deryn related their experiences regarding the need to have their medications clinically balanced for controlling mania, and possible self-harm. Due to the likelihood of severe reactions occurring, participants needed hospitalisation while their medications were adjusted. Arriving at the 'winning formula' for a stable life could also be 'exhausting' as energies escalated and moods fluctuated until the medications reached their efficacy. Experiencing mania, hospital admission, and subjecting the self to clinical control could be expected to take a toll on usual life performances. In agreement with Fullagar & O'Brien (2013) that medications are related to how people transform ideas of themselves, I found that while in need of medication adjustments, participants were willing to see themselves as the submissive person in need of pharmaceutical control. This dependency was unavoidable

when mania was felt to be so extreme and where participants had become aware of their own vulnerability.

Zoe, in particular, was most opinionated about the need to be aware of keeping the balance to life, even while being medicated. As Zoe explained, after all, ‘these things will still happen’, expressing the knowledge that moods will still cause disruption to life and that they are unpredictable. Jane had a similar idea about keeping a balance on life, and she had discovered that, for her, medications were ‘just one part of the treatment’. Medications were not, therefore, viewed as a panacea, but a part of a set of regimens that would need to be kept in order to readjust the balance. Balancing life, therefore, meant that there had to be a total commitment by the individual to making sure that they practised technologies of the self that would ensure their moods would be controllable.

These kinds of technologies of the self were outside of the clinical purview, and were mainly centred within the personhood; and they included looking out for warning signs of onset mania, such as being over-talkative, sleeping irregularly, being irritable and experiencing increased energy levels. Adjustments necessary in the self-monitoring of mood swings required adopting other forms of management, usually complementary to pharmaceutical treatments. Since complementary forms of management meant personal investment in gaining certain knowledges, and then performing tasks on the self, agency was paramount. This form of self-management is in contrast to pharmaceutical management where an individual submits themselves to being the subject of clinical control – used mainly where self-control could not be achieved.

In fact, this study found that complementary and alternative treatments were used more as a preventative form of management to avoid the mood imbalances of bipolar disorder. When using complementary and alternative therapies, mastering the self may be considered in terms of not just a matter of bringing back balance and order to the life of a person who is overtaken by mania, but also a way of preventing mania and depression. Prevention was of concern to participants who felt there was the need to maintain stability in order to achieve a maximum amount of personal productivity/accomplishment in life – not just for getting a ‘life back’.

Using CAMs involved considerable personal commitment to the ways in which management could be achieved. For example, participants needed to be constantly aware of any changes in moods so that management strategies could be put in place throughout their daily lives. Management strategies involved, for example, mindfulness, meditation, adherence to strict diet, going for walks and doing other physical exercise. From this type of commitment, it could be argued that self-management is a freedom due to the personal choices involved; however, the personal commitment involved requires strategies, or forms of negotiation, that are a personal obligation to the self and the society. As Martin (2007) argues, there is freedom in self-management due to being able to choose when to increase medication levels and make certain adjustments to daily living. However, I did find, through participants’ more detailed explanations of what tasks they set for themselves in the management of mood swings, that there was a certain obligation that they imposed upon themselves. I found that when participants engaged in the action of predicting mood swings and maintaining a balance to life, there was an ongoing and somewhat arduous commitment. Thus, to be free of mania was in line with Rose’s (1966, p. 100) concept that people are, in fact, ‘compulsorily enterprising’ or ‘obliged to be free’. For the participants for this research, freedom was

expressed through self-imposed practices brought about because of desires for a balanced and productive life – the choice determined by personal consent to conform within social boundaries where understandings of being normal and functional is to be without bipolar disorder.

Bringing back the balance to life through the use of CAMs was not proven to be lasting, since participants were still aware of the chronicity of bipolar disorder and the need to be continually vigilant of their mood swings. However, in view of the problems with the efficacy of pharmaceutical treatments and the inherent problem of fluctuating moods, CAMs, for most participants, proved a necessary addition to conventional clinical treatments.

### **10.5. Self-management and identity**

In nearly all cases, participants were willing to use pharmaceutical treatments to control mania and were prepared to accept changes in personal identity usually associated with the transformation from ‘natural’ characteristics of the person to a neuro-chemically-controlled person. However, this was not always the case, as some participants regretted having to give up the ‘natural’ self. Consistent with Malpass et al. (2009) and Fernandez, Breen and Simpson (2014) my participants needed to feel a sense of self-control and this feeling was associated with being aware of and controlling personal identity. Engaging in self-determining technologies associated with using ‘natural’ therapies was considered to be the way to retaining personal identities.

Participants found that problems associated with bipolar management that effected personal identity were largely due to side-effects experienced from taking medications because of the physical and emotional changes that were experienced (see also Jenkins 2010, p.9; Proudfoot et al. 2009, p. 124; Fullagar & O'Brien 2014). These problems are always in consideration for the person with bipolar disorder as they need to negotiate between personal losses due to mismanagement of life and the losses due to such side-effects. I found that participants were very aware of their personal losses due to using pharmaceutical treatments, such as losing high-functioning abilities, feeling dulled-out even to the extent of producing onset depression, and being 'changed' or losing the sense of being 'me'. For most participants it was hard to separate out the 'disease' from the person, as so much of the person's behaviour was felt to be as a result of mania or depression. However, as Zoe pointed out, there was the 'disease' that affected the personality because of its mood swings, but the 'disease', bipolar disorder, was not the actual personality. Thus, this is a case where biomedicine in the treatment of personality disorders may be seen to present tensions between curing the disease and leaving personhood intact. The need for retaining personal identities meant that there were some cautions towards taking medications that would interfere with personality. Moreover, such cautions became greater where side-effects were felt to be more severe. In such cases participants were likely to discontinue their medications. Thus, it became more important to retain the 'natural' self, treating the bipolar disorder as the foreign invader of the self that needed to be segregated out, and treated, by engaging in self-determined techniques.

One other self-disciplining technology, often mentioned by participants, was to be found in the use of the 'psy' sciences. Rose (1996, pp. 1-5) argues the 'psy' sciences are responsible for new ways in which people are able to see themselves, as well as discipline themselves. However, although these 'new' sciences carry quite different characteristics from those

related to the pharmaceutical treatments, they do have personality transforming effects for the individual (Rose 1996, pp. 1-5).

I found that participants were engaged in transforming their thinking, and controlling their moods by using treatments such as psychotherapy, stress-management regimens, mindfulness, and meditation. The benefits from using such forms of transforming techniques were that participants were able to learn how to put certain limitations upon themselves, allowing their 'natural' personality to continue while controlling their mood swings. Thus, participants felt they had more chance of retaining their personal and 'natural' identity.

Nevertheless, whatever forms of control were achieved through such technologies of the self, participants expressed that knowing the self was difficult to achieve due to the unpredictability of mood swings. The unpredictability and chronicity of bipolar disorder, in itself, was a major concern for participants because stability of the self was associated with normality. 'Normal' people were seen as able to predict their own behaviour and plan life events within the context of knowing the social reality. Thus, predictability was important to identity; that is, knowing who one is can depend upon how one knows one's behaviours, and how these behaviours can be controlled. This finding builds on Inder et al. (2011, 2008) findings that unpredictability with bipolar disorder was associated with experiences of 'confusion, contradiction and self-doubt' where people could not capture their identity (Inder et al. 2011, p. 429, 2008, p. 128). Prediction of one's mood swings, in a sense, is a form of self-control used to govern or guide life events. The balanced life that is a result of prediction is associated with being able to achieve daily tasks and being able to predict a 'happy'

disposition – as Jenkins (2010) notes, the required attributes for people living within a contemporary society.

## **10.6. In Summary**

Practising being the autonomous individual for people with bipolar disorder was difficult but possible. Except where mania was uncontrollable, participants demonstrated that they were rational individuals, engaging with the internet, making their own decisions about diagnosis and treatments, and participating in group support. However, the agency needed to achieve a balanced life in a self-reliant way requires much self-discipline over a life time due to the imbalances in moods and the chronicity of the disorder. In addition, since pharmaceutical treatments are not totally reliable participants felt the need to be able to manage the self as an imperative. Due to unexpected mood swings, the participants felt that they needed to be constantly self-reliant and engage in self-monitoring techniques of management. As a result of such practices, participants were able to keep a balance to their lives through dedicated regimens of self-control. However, such technologies of the self were only possible once a biomedical diagnosis had been made and accepted. Prior to diagnosis, participants reported difficulties with knowing when to seek help or clarify clinical explanations, mainly due to ideas about being ‘normal’. Moreover, when clinical help was sought, diagnosis was slow, having much life impairing effect upon individuals until satisfactory answers could be found.

The anonymity of the internet was appealing to participants and provided a global field in which to ‘lurk’ in comparison to the confines of the clinic where information is limited to the output of the doctor within a face-to-face setting. When searches are ‘unfiltered’ the scope to explore is unlimited providing much virtual space for finding information. However, as my

participants found, there is actually some sense in maintaining a ‘filter bubble’ when information needs to be narrowed down to meet bipolar disorder selective criteria. When individuals access trustworthy sites, much of the information acquired may still be regarded by some doctors to be challenging their professional authority. However, the narratives from my participants indicated a change in patient/doctor relationships, as doctors were becoming aware of their patient’s internet use. In any case, participants were ‘entrepreneurial’ and were at least able to demonstrate an ability to sieve out and understand knowledge formerly only privy to those who were considered qualified to use it. Any challenge to knowledges, therefore, lies within the difference between clinically trained knowledge and experiential knowledge; both, however, found within this study to be important in contributing to diagnosis and treatment of bipolar disorder. Through the internet, there could be much advantage to both the clinical professional and the patient because of the way in which knowledge is brought to the clinic and discussed. In addition, the type of information gained from the internet could be made to open up challenges to the biomedical model of mental illness such as for bipolar disorder. This is because shared experiential knowledge along with better understandings of CAMs bear the capability of further understanding the condition and how it should be treated. Hardey (1999) argued against the narrow concept of medicine as being Western, and pointed out that there are many options that construct the meaning of health quite differently. This point then predicts a wider variety in management due to different understandings of the condition and the ways in which the autonomous individual can combine information from the clinic and the internet.

Openings for future research are in wider studies on internet access for diagnostic problems, given the scientific status relating to diagnosis of bipolar disorder. More research about how to access online information about management of bipolar disorder would be useful. Such

studies could be focussed around CAMs in particular since this study has found them to be important to most participants. In addition, more critical sociological studies focussed on the internet and health would be advantageous. Such studies should examine internet access, both technologically and socially with regard to social status. This study has concerned the lives of some people living with bipolar disorder through the lens of a biomedical model. Future research directions should include critical studies about the culture within the internet concerning the internet's role in health that covers agency both inside and outside of the biomedical model.

This thesis has opened up an area of thought about the logic of practises of care that may even critique the Foucauldian notion of the technologies of the self. That is, the tools necessary in the techniques of the care of the self may become so many that 'normal' may blend into 'abnormal'. Such idea posits thinking around Jenkins and the *Pharmaceutical Self* and the ways in which people have come to accept 'enhancing' the self in such a way that almost anything is considered to be a problem; and, Martin's *Bipolar Expeditions*, where to be manic is a preferred identity where absolute achievement is seen to be absolute.

Considering the great achievements the participants for this study have made within the management of bipolar disorder, including decisions around what type of person they should be and how they should transform themselves, it would appear that social expectations are that hard work and transformative accomplishments are what is needed. However, imagine if such personal constraints, due to personal endeavours to conform to social expectations about 'normal', had been practised by, for example, Van Gogh in his lifetime. Consider then what kind of art forms could be possible where personal transformations brought about mental

dulling, normal sleep patterns and a family life. It may, therefore, not be so unreasonable to say that social rules should ameliorate people with bipolar disorder, rather than imposing such autonomous responsibilities and technologies of the self that only permit a one way transaction – that is, that people with bipolar disorder take considerably arduous life responsibilities to transform themselves. Van Gogh painted more than one canvass per day over the last two months of his life in what he described as a frenzy of ‘one actually possessed’ (Zurcher 1985, p. 277). In his letters to his brother, Van Gogh said himself that his painting of the ‘Crows over the cornfields’ (Rijksmuseum, Amsterdam) expresses his troubled feelings, ‘sadness and extreme loneliness’ (Zurcher 1985, p. 277).



‘Crows over the cornfields’, by Vincent Van Gogh, Google images, accessed 20<sup>th</sup> November, 2017.

## Appendix

### List of participants as used within the thesis, by pseudonym

#### *From the SANE Australia internet site forum for bipolar disorder:*

Dale, Jo, Jodie, Kylie, Robin, Vivian, Moderator

#### *Interviews:*

Jane, Helen, Mayra, Graham, Catherine, Zoe, Maria, Jim, Deryn, Elyse

#### *Testimonies by title, with corresponding number as used in thesis:*

- (1) 'Dancing with the devil: managing the highs of bipolar disorder'
- (2) 'A part of the human race'
- (3) 'The casino bipolar'
- (4) 'A delicate fire'
- (5) 'Focus on mania'
- (6) 'Knowledge is power'
- (7) 'The staircase'
- (8) 'Of strategies paradox and wisdom'

## References

*Van Gogh Gallery*, Templeton Reid, L.L.C., viewed 20th November, 2017,

<<http://www.vangoghgallery.com/misc/mental.html>>.

Australian Bureau of Statistics (ABS) 2016, 8146.0 *Household use of information technology, Australia 2014-15*. Viewed 17<sup>th</sup> October, 2016.

<http://www.abs.gov.au/ausstats/abs@.nsf/mf/8146.0>

Australian Bureau of Statistics (ABS) 2008, 4326.0 *National Survey of Mental Health and Wellbeing: Summary of Results*, viewed 23rd March, 2015

<<http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4326.0Main%20Features320>>.

Australian Bureau of Statistics (ABS) 2009, 4233.0 *Health Literacy Australia 2006 Summary of Findings*, viewed 22<sup>nd</sup> June, 2017,

<http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4102.0Main+Features20June+2009>

Australian Government Department of Health 2013, Capability 3A *Promoting Autonomy and Self-determination*, viewed 20<sup>th</sup> November, 2017

<http://www.health.gov.au/internet/publications/publishing.nsf/Content/mental-pubs-n-recovgde-toc~mental-pubs-n-recovgde-app~mental-pubs-n-recovgde-app-3~mental-pubs-n-recovgde-app-3-a>

The Australian Government Department of Health, *Complementary and Alternative Therapies*, viewed 26<sup>th</sup> July, 2017

<http://www.health.gov.au/internet/publications/publishing.nsf/Content/palliative-agedcare-comm-familybkt-toc~palliative-agedcare-comm-familybkt-3~palliative-agedcare-comm-familybkt-3-therapies>

Department of Health and Human Services, US 2000, *Quick Guide to Health Literacy*, viewed 6th February 2018,

<<https://health.gov/communication/literacy/quickguide/factsbasic.htm>>.

National Center for Complementary and Integrative Health, US Department of Health and Human Services, viewed 26<sup>th</sup> July 2017,

<https://nccih.nih.gov/about>

*Diagnostic and Statistical Manual of Mental Disorders*, 2016, Fifth edition (ed.) American Psychiatric Association, viewed 25th October, 2016,

<http://dx.doi.org/10.1176/appi.books.9780890425596>.

Adams, S & de Bont, A 2007, 'Information Rx: Prescribing good consumerism and responsible citizenship', *Health Care Analysis*, vol. 15, no. 4, pp. 273-90, doi:

10.1007/s10728-007-0061-9

Altshuler, LI, Kupka, RW, Helleman, G, Frye, MA, Sugar, CA, McElroy, SL, Willem, AN, Heinz, G, Leverich, GS, Keck, PE, Zerneno, M, Post, RM & Suppes, T 2010, 'Gender and depressive symptoms in 711 patients with bipolar disorder evaluated prospectively in the Stanley Foundation bipolar treatment outcome network', *American Journal of Psychiatry*,

vol. 167, no. 6, pp. 708-15, viewed 6<sup>th</sup> December, 2017, <https://ajp-psychiatryonline-org.ezproxy.lib.monash.edu.au/doi/full/10.1176/appi.ajp.2009.09010105?code=ajp-site>.

Anderson, B 1983, *Imagined communities: Reflections on the origin and spread of nationalism*, Verso, London.

Anderson, JG, Rainey, MR & Eysenbach G 2003 'The impact of cyberhealthcare on the physician-patient relationship', *Journal of Medical Systems*, vol. 27, no. 1, pp. 67-83, viewed 24<sup>th</sup> October, 2017, <https://search-proquest-com.ezproxy.lib.monash.edu.au/docview/757015047?OpenUrlRefId=info:xri/sid:primo&accountid=12528>

Anderson, JM 1996, 'Empowering patients: issues and strategies', *Social Science & Medicine*, vol. 43, no. 5, pp. 697-705, viewed 4<sup>th</sup> December, 2017, <https://www-sciencedirect-com.ezproxy.lib.monash.edu.au/science/article/pii/0277953696001530>

Arber, S 2001, 'Designing Samples', in N Gilbert (ed.), *Researching Social Life*, 2nd edn, Sage, London, pp. 58 - 81.

Aycock, A 1995, 'Technologies of the self: Foucault and internet discourse', *Journal of Computer-Mediated Communication*, vol. 1, no. 2, viewed 24<sup>th</sup> October, 2017, <http://onlinelibrary.wiley.com.ezproxy.lib.monash.edu.au/doi/10.1111/j.1083-6101.1995.tb00328.x/full>

Badger, F & Nolan, P 2006, 'Concordance with antidepressant medication in primary care', *Nursing Standard*, vol. 20, no. 52, pp. 35-40, viewed 24<sup>th</sup> October, 2017, <http://go.galegroup.com.ezproxy.lib.monash.edu.au>

Bandura, A 1989, 'Human agency in social cognitive theory', *American Psychologist*, vol. 44, no. 9, p. 1175, viewed 24<sup>th</sup> October, 2017, <http://ovidsp.tx.ovid.com.ezproxy.lib.monash.edu.au>

Banjanin, N, Banjanin, N, Dimitrijevic, I & Pantic, I 2015, 'Relationship between internet use and depression: Focus on physiological mood oscillations, social networking and online addictive behaviour', *Computers in Human Behaviour*, vol. 43, p. 308, doi: 10.1016/j.chb.2014.11.013

Barlow, J, Wright, C, Sheasby, J, Turner, A & Hainsworth, J 2002, 'Self-management approaches for people with chronic conditions: a review', *Patient Education and Counselling*, vol. 48, no. 2, pp. 177-87, viewed 24<sup>th</sup> October, 2017, <https://www-sciencedirect-com.ezproxy.lib.monash.edu.au/science/article/pii/S0738399102000320>

Barratt, MJ, Ferris, JA & Lenton, S 2014, 'Hidden Populations, Online Purposive Sampling, and External Validity', *Field Methods*, vol. 27, no. 1, pp. 3-21, viewed 24<sup>th</sup> October, 2017, <http://journals.sagepub.com.ezproxy.lib.monash.edu.au/doi/abs/10.1177/1525822X14526838>

Bassman, R 2005, 'Mental illness and the freedom to refuse treatment: Privilege or right', *Professional Psychology, Research and Practice*, vol. 36, no. 5, pp. 488-588, viewed 6<sup>th</sup> December, 2017, <http://ovidsp.tx.ovid.com.ezproxy.lib.monash.edu.au>

Bauman, Z 2007, 'The reality principle and the pleasure principle strike a deal', in A Elliott (ed.), *Contemporary Bauman*, Routledge, London and New York.

Beck, U 1999, *World risk society*, Polity Press, Cambridge, UK.

——— 2011, 'Cosmopolitanism as imagined communities of global risk', *American Behavioural Scientist*, vol. 55, no. 10, pp. 1346 – 61, doi:10.1177/0002764211409739

Ben-Ari, A & Enosh 2012 'Power relations and reciprocity: Dialectics of knowledge construction', *Qualitative Health Research*, vol. 23, no. 3, pp. 422-429, viewed June 20<sup>th</sup>, 2018, doi:10.1177/1049732312470030

Bennett, A 2002, 'Researching youth culture and popular music: a methodological critique', *The British Journal of Sociology*, vol. 53, no. 3, pp. 451-66, viewed 24<sup>th</sup> October, 2017, <http://onlinelibrary.wiley.com/doi/10.1080/0007131022000000590/abstract;jsessionid=E45B9ACDBF16738C26FD4CB1229FFF6E.f04t04>

Beoku-Betts, J 1994, 'When black is not enough: Doing field research among Gullah women', *National Women's Studies Association Journal*, vol. 6, no. 3, pp. 413-33, viewed 24<sup>th</sup> October, 2017, <http://ezproxy.lib.monash.edu.au/au/stable/4316353>

Berg, BL 1998, *Qualitative Research Methods for the Social Sciences*, 3rd edn, Allyn & Bacon, Boston, U.S.A.

Bheenuck, S 2010, *Interrogating Identity and Belonging Through Life History*, (eds) A Bathmaker & P Harnett, Taylor & Francis, London.

Birch, M & Miller, T 2000, 'Inviting intimacy: The interview as therapeutic opportunity', *International Journal of Social Research Methodology*, vol. 3, no. 3, pp. 189-202, doi: 10.1080/13645570050083689

Bishop, R 2008, 'Freeing ourselves from neo-colonial domination in research', in NK Denzin & YS Lincoln (eds), *The Landscape of Qualitative Research*, Sage Publications, Los Angeles, London, pp. 145-79.

Blumberg, HH 1972, 'Communication of interpersonal evaluations', *Journal of Personality & Social Psychology*, vol. 23, pp. 157 – 62, viewed 24<sup>th</sup> October, 2017, <http://ovidsp.tx.ovid.com.ezproxy.lib.monash.edu.au>

Blumenthal, D 2002, 'Doctors in a wired world: Can professionalism survive connectivity?' *The Milbank Quarterly*, vol. 80, no. 3, pp. 525 – 45, viewed 24<sup>th</sup> October, 2017, [http://www.jstor.org.ezproxy.lib.monash.edu.au/stable/3350563?seq=1#page\\_scan\\_tab\\_contents](http://www.jstor.org.ezproxy.lib.monash.edu.au/stable/3350563?seq=1#page_scan_tab_contents)

Book Review 2002, 'Mad in America: Bad science, bad medicine, and the enduring treatment of the mentally ill', *JAMA*, vol. 287, no. 23, pp. 3149-50, viewed 18<sup>th</sup> June, 2018, 10.1001/jama.287.23.3149-JBK0619-5-1

Braun, B 2007, 'Biopolitics and the molecularization of life', *Cultural Geographies*, vol. 14, pp. 6 – 28, viewed 24<sup>th</sup> October, 2017,

<http://www.jstor.org.ezproxy.lib.monash.edu.au/stable/44243679>

Braun, V & Clarke, V 2006, 'Using thematic analysis in psychology', *Qualitative Research in Psychology*, vol. 3, pp. 77-101, viewed 24<sup>th</sup> October, 2017, [https://www-tandfonline-](https://www-tandfonline-com.ezproxy.lib.monash.edu.au/doi/abs/10.1191/1478088706qp063oa)

[com.ezproxy.lib.monash.edu.au/doi/abs/10.1191/1478088706qp063oa](https://www-tandfonline-com.ezproxy.lib.monash.edu.au/doi/abs/10.1191/1478088706qp063oa)

Breuer, F 2003, 'Subjectivity and reflexivity in the social sciences: Epistemic windows and methodical consequences', *Forum: Qualitative Social Research*, vol. 4, no. 2, viewed 19<sup>th</sup>

June, 2018, [https://search-proquest-](https://search-proquest-com.ezproxy.lib.monash.edu.au/doxview/868195240?accountid=12528)

[com.ezproxy.lib.monash.edu.au/doxview/868195240?accountid=12528](https://search-proquest-com.ezproxy.lib.monash.edu.au/doxview/868195240?accountid=12528)

Brewer, T 2001, 'Rethinking our maxims: Perceptual salience and practical judgment in Kantian ethics', *Ethical Theory & Moral Practice*, vol. 4, pp. 219 – 30, viewed 24<sup>th</sup> October,

2017, <http://www.jstor.org.ezproxy.lib.monash.edu.au/stable/27504194>

Brijnath, B & Antoniadou, J 2016, "I'm running my depression:" Self-management of depression in neoliberal Australia', *Social Science & Medicine*, vol. 152, pp. 1-8, viewed 9<sup>th</sup>

December, 2017, [https://www-sciencedirect-](https://www-sciencedirect-com.ezproxy.lib.monash.edu.au/science/article/pii/S0277953616300223)

[com.ezproxy.lib.monash.edu.au/science/article/pii/S0277953616300223](https://www-sciencedirect-com.ezproxy.lib.monash.edu.au/science/article/pii/S0277953616300223)

Broom, A 2005, 'Medical specialists' accounts of the impact of the internet on doctor-patient relationships', *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and*

*Medicine*, vol. 9, no. 3, pp. 319 – 37, viewed 24<sup>th</sup> October, 2017,

<http://journals.sagepub.com.ezproxy.lib.monash.edu.au/doi/abs/10.1177/1363459305052903>

Butler, J 2014, *Bodies that matter: On the discursive limits of sex*, Taylor & Francis Group, Pro Quest Ebook Central, viewed 20<sup>th</sup> June, 2018,

<http://ebookcentral.prquest.com/lib/monash/detail.action?docID=1779047>

Burck, C 2005, 'Comparing qualitative research methodologies for systemic research: the use of grounded theory, discourse analysis and narrative analysis', *Journal of Family Therapy*, vol. 27, pp. 237 – 62, viewed 24<sup>th</sup> October, 2017,

<http://onlinelibrary.wiley.com.ezproxy.lib.monash.edu.au/doi/10.1111/j.1467->

[6427.2005.00314.x/full](http://onlinelibrary.wiley.com.ezproxy.lib.monash.edu.au/doi/10.1111/j.1467-6427.2005.00314.x/full)

Caiata-Zufferey, M, Abraham, A, Sommerhalder, K & Schulz, PJ 2010, 'Online health information seeking in the context of the medical consultation in Switzerland', *Qualitative Health Research*, vol. 20, no. 8, pp. 1050-61, doi: 10.1177/1049732310368404

Calear, AL, Griffiths, KM & Christensen, H 2011, 'Personal and perceived depression stigma in Australian adolescents: Magnitude and predictors', *Journal of Affective Disorders*, vol. 129, pp. 104 – 8, viewed 24<sup>th</sup> October, 2017, <https://www-sciencedirect-com.ezproxy.lib.monash.edu.au/science/article/pii/S0165032710005549?via%3Dihub>

Chan, A & Garrick, J 2003, 'The moral "Technologies" of knowledge management', *Information, Communication & Society*, vol. 6, no. 3, pp. 291-306, doi:

10.1080/1369118032000155258

Chan, E, Rappaport, LA & Kemper, KJ 2003, 'Complementary and alternative therapies in childhood attention and hyperactivity problems', *Journal of Developmental & Behavioral Pediatrics*, vol. 24, no. 1, pp. 4-8, viewed 24<sup>th</sup> October, 2017, <http://ovidsp.tx.ovid.com.ezproxy.lib.monash.edu.au>

Charland, LC 2004, 'A madness for identity: Psychiatric labels, consumer autonomy, and the perils of the Internet', *Philosophy, Psychiatry, & Psychology*, vol. 11, no. 4, pp. 335-49, viewed 5<sup>th</sup> December, 2017, <https://muse-jhu-edu.ezproxy.lib.monash.edu.au/article/181792>

Charmaz, K 1990, 'Discovering' chronic illness: Using grounded theory', *Social Science & Medicine*, vol. 30, no. 11, pp. 1161 – 72, viewed 24<sup>th</sup> October, 2017, <https://www-sciencedirect-com.ezproxy.lib.monash.edu.au/science/article/pii/027795369090256R?via%3Dihub>

——— 1995, 'The body identity and self: Adapting to impairment', *Sociological Quarterly*, vol. 36, no. 4, pp. 657-80, viewed 24<sup>th</sup> October, 2017, <http://www.jstor.org.ezproxy.lib.monash.edu.au/stable/4121346>

——— 2000, 'Grounded theory: Objectivist and constructivist methods', in NK Denzin & YS Lincoln (eds.), *Handbook of qualitative Research*, Sage Publications, Thousand Oaks, U.S.A.

——— 2006, *Constructing grounded theory: A practical guide through qualitative analysis*, Sage Publications Ltd., London.

Chenail, RJ 2011, 'Interviewing the investigator: Strategies for addressing instrumentation and researcher bias concerns in qualitative research', *The Qualitative Report*, vol. 16, pp. 255-62, viewed 24<sup>th</sup> October, 2017, <https://search-proquest-com.ezproxy.lib.monash.edu.au/docview/854984835?OpenUrlRefId=info:xri/sid:primo&accountid=12528>

Christensen, H & Griffiths, K 2000, 'the internet and mental health literacy', *Australian and New Zealand Journal of Psychiatry*, vol. 34, pp. 975 – 9, viewed 24<sup>th</sup> October, 2017, <http://journals.sagepub.com.ezproxy.lib.monash.edu.au/doi/abs/10.1080/000486700272>

Churchill, CJ 2010, 'The parity cure: Solving unequal treatment of mental illness health insurance through federal legislation', *Georgia Law Review*, 44, issue 3, p. 511, viewed 24<sup>th</sup> October, 2017, <http://heinonline.org.ezproxy.lib.monash.edu.au/HOL/Page?public=false&handle=hein.journals/geolr44&page=511&collection=journals>

Clifford, M 2001, *Political Genealogy after Foucault*, Routledge, New York, London.

Cline, RJW & Haynes, KM 2001, 'Consumer health information seeking on the internet: the state of the art', *Health Education Research*, vol. 16, no. 6, pp. 671-92, viewed 24<sup>th</sup> October, 2017, <https://academic-oup-com.ezproxy.lib.monash.edu.au/her/article/16/6/671/571640>

Cole, DA 1991, 'Change in self-perceived competence as a function of peer and teacher evaluation', *Development psychology*, vol. 27, pp. 682 – 8, viewed 24<sup>th</sup> October, 2017, <http://ovidsp.tx.ovid.com.ezproxy.lib.monash.edu.au>

Conboy, L, Kaptchuk, TJ, Eisenberg, DM, Gottlieb, B & Acevedo-Garcia, D 2007, 'The relationship between social factors and attitudes toward conventional and CAM practitioners', *Complementary Therapies in Clinical Practice*, vol. 13, no. 3, pp. 146-57, viewed 24<sup>th</sup> October, 2017, <https://www.sciencedirect.com/science/article/pii/S1744388106001083?via%3Dihub>.

Conrad, P 1992, 'Medicalisation and social control', *Annual Review Sociology*, vol. 18, pp. 209 – 32 viewed 24<sup>th</sup> October, 2017, <https://www-annualreviews-org.ezproxy.lib.monash.edu.au/doi/10.1146/annurev.so.18.080192.001233>

Conrad, P 2007, *The medicalization of society*, The John Hopkins University Press, Maryland, USA.

Corbetta, P 2003, *Social Research*, Sage Publications, London, Thousand Oaks, New Delhi.

Corbin, J & Strauss, A 2008, *Basics of qualitative research*, 3rd edn, Sage Publications, Los Angeles, London.

Correa, R, Akiskal, H, Gilmer, W, Nierenberg, AA, Trivedi, M & Zisook, S 2010, 'Is unrecognized bipolar disorder a frequent contributor to apparent treatment resistant depression?', *Journal of Affective Disorders*, vol. 127, no. 1, pp. 10-8, viewed 24<sup>th</sup> October, 2017, [http://www.jad-journal.com/article/S0165-0327\(10\)00464-7/fulltext](http://www.jad-journal.com/article/S0165-0327(10)00464-7/fulltext)

Danzer, G & Wilkus-Stone, A 2015, 'The give and take of freedom: The role of involuntary hospitalisation and treatment in recovery from mental illness', *Bulletin of the Menninger Clinic, New York*, vol. 79, no. 3, pp. 255-80, viewed 6<sup>th</sup> December, 2017, [https://search-proquest-com.ezproxy.lib.monash.edu.au/docview/1711532453?accountid=12528&rfr\\_id=info%3Axri%2Fsid%3Aprimo](https://search-proquest-com.ezproxy.lib.monash.edu.au/docview/1711532453?accountid=12528&rfr_id=info%3Axri%2Fsid%3Aprimo)

Davidoff, F, Dixon-Woods, M, Leviton, L & Michie, S 2015, 'Demystifying theory and its use in improvement', *BMJ Quality & Safety*, vol. 24, no. 3, pp. 228 - 238, viewed 24<sup>th</sup> October, 2017, <http://qualitysafety.bmj.com.ezproxy.lib.monash.edu.au/content/24/3/228>

Davis, TC & Wolf, MS 2004, 'Health literacy: Implications for family medicine', *Family Medicine*, vol. 36, no. 8, pp. 595-8, viewed 31<sup>st</sup> October, 2017, <http://www.stfm.org/FamilyMedicine/Vol36Issue8/Davis595>

Deacon, BJ 2013, 'The biomedical model of mental disorder: A critical analysis of its validity, utility, and effects on psychotherapy research', *Clinical Psychology Review*, vol. 33, pp. 846-61, viewed 24<sup>th</sup> October, 2017, <https://www-sciencedirect-com.ezproxy.lib.monash.edu.au/science/article/pii/S0272735813000482>

Denzin, N & Lincoln, YS 2000, *Handbook of Qualitative Research*, 2nd edn, Sage Publications, Thousand Oaks, California.

——— 2008, *Landscape of qualitative research*, Sage Publications, Los Angeles.

Depp, CA, Stricker, J.L., Zagorsky, D, Goodale, L.C., Eyler, L.T., Patterson, T.L., Lebowitz, B.D. & Jeste, D.V. 2009, 'Disability and self-management practices of people with bipolar disorder: A web-based survey', *Community Mental Health Journal*, vol. 45, pp. 179 – 87, viewed 24<sup>th</sup> October, 2017, <https://search-proquest-com.ezproxy.lib.monash.edu.au/docview/228365893?OpenUrlRefId=info:xri/sid:primo&accountid=12528>

Derrida, J 1996, *Archive fever: A Freudian impression*, University of Chicago Press, Chicago, London.

Downer, SM, Cody, MM, McCluskey, P, Wilson, PD, Arnott, SJ, Lister, TA & Slevin, ML 1994, 'Pursuit and practice of complementary therapies by cancer patients receiving conventional treatment', *Bmj*, vol. 309, no. 6947, pp. 86-9, doi: 10.1136/bmj.309.6947.86

Dos Santos, B & Beavan, V 2015, 'Qualitatively exploring voices network support groups', *The Journal of Mental Health Training, Education and Practice*, vol. 10, no. 1, pp. 26-38, viewed 20<sup>th</sup> June, 2018, doi:10.1108/JMHTEP-07-2014-0017

Dworkin, SL 2012, 'Sample size policy for qualitative studies using in-depth interviews', *Arch Sex Behav*, vol. 41, pp. 1319 – 20, doi: 10:1007/s10508-012-0016-6

Earle, R 2014, 'Insider and Out', *Qualitative Inquiry*, vol. 20, no. 4, pp. 429-38, doi: 10.1177/1077800413515832

Ecks, S 2005, 'Pharmaceutical citizenship: Antidepressant marketing and the promise of demarginalisation in India', *Anthropology & Medicine*, vol. 12, no. 3, pp. 239-54, doi: 10.1080/13648470500291360

Ellison, N, Mason, O & Scior, K 2015, 'Public beliefs about attitudes towards bipolar disorder: Testing theory based models of stigma', *Journal of Affective Disorders*, vol. 175, pp. 116-23, viewed 24<sup>th</sup> October, 2017, <https://www-sciencedirect-com.ezproxy.lib.monash.edu.au/science/article/pii/S0165032714008337>

Eysenbach, G & Kohler, C 2003, 'What is the prevalence of health-related searches on the World Wide Web?', in *AMIA 2003 Symposium Proceedings*, Toronto, Canada, pp. 225 – 9.

Eysenbach, G & Till, JE 2001, 'Ethical issues in qualitative research on internet communities', *Bmj*, vol. 323, no. 7321, pp. 1103-5, viewed 7<sup>th</sup> February, 2018, <http://ovidsp.tx.ovid.com.ezproxy.lib.monash.edu.au>

Fernandez, ME, Breen, LJ & Simpson, TA 2014, 'Renegotiating identities: Experiences of loss and recovery for women with bipolar disorder', *Qualitative Health Research*, vol. 24, no. 7, pp. 890-900, viewed 24<sup>th</sup> October, 2017, <http://journals.sagepub.com.ezproxy.lib.monash.edu.au/doi/abs/10.1177/1049732314538550>

Finn, C 1997, *Social Reality*, Routledge, London.

Fisher, J, Burstein, F, Lynch, K & Lazarenko, K 2008, ““Usability + Usefulness = Trust””: An exploratory study of Australian health web sites', *Internet Research*, vol. 18, no. 5, pp. 477-

98, viewed 24<sup>th</sup> October, 2017,

<http://www.emeraldinsight.com.ezproxy.lib.monash.edu.au/doi/full/10.1108/10662240810912747>

Fisher, P & Freshwater, D 2014, 'Methodology and mental illness: Resistance and restorying', *Journal of Psychiatric and Mental Health Nursing*, vol. 21, pp. 197-205, doi: 10.1111/jpm.12073

Flick, U 2004, 'Triangulation in qualitative research', in U Flick, E von Kardoff & I Steinke (eds), *A companion to qualitative research*, Sage Publications, London, Thousand Oaks, pp. 179 - 83.

Foster, D 2016, "“Keep complaining til someone listens”": Exchanges of tacit healthcare knowledge in online illness communities', *Social Science & Medicine*, vol. 166, pp. 25-32, viewed 4<sup>th</sup> December, 2017, <https://www-sciencedirect-com.ezproxy.lib.monash.edu.au/science/article/pii/S0277953616304294>

Foucault, M 1973, *Birth of the clinic: An archaeology of medical perception*, Tavistock Publications Ltd., London, U.K.

Foucault, M 1976, *The will to knowledge: The history of sexuality: Volume 1*, Penguin Books, London, England.

Foucault, M 1979, *Discipline and Punish: The birth of the prison*, (ed.) A Sheridan, Vintage Books, New York, viewed 27th January, 2018, <<https://soth-alexanderstreet->

com.ezproxy.lib.monash.edu.au/cgi-bin/asp/philo/soth/sourceidx.pl?sourceid=S10021788&showfullrecord=on>.

Foucault, M 1980, *Power/Knowledge: Selected interviews and other writings 1972 - 1977*, The Harvester Press Ltd., Brighton, Sussex, UK.

—— 1982, 'The subject and power', *Critical Inquiry*, vol. 8, no. 4, pp. 777-95, viewed 8<sup>th</sup> March, 2018,

[http://www.jstor.org.ezproxy.lib.monash.edu.au/stable/1343197?seq=1#page\\_scan\\_tab\\_contents](http://www.jstor.org.ezproxy.lib.monash.edu.au/stable/1343197?seq=1#page_scan_tab_contents).

—— 1984, 'Michel Foucault: An interview: Sex, power and the politics of identity: interview with Bob Gallagher & Alexander Wilson', *The Advocate*, vol. 400, pp. 26-30, 58.

Foucault, M 1987, 'The ethic of care for the self as a practice of freedom: An interview with Michel Foucault, by Fornet-Betancourt, R., Becker, H. & Gomez-Muller, A.', *Philosophy & social criticism*, vol. 12, no. 2-3, pp. 112-31, viewed 8<sup>th</sup> March, 2018,

<http://journals.sagepub.com.ezproxy.lib.monash.edu.au/doi/abs/10.1177/01914537870120020>

2

Foucault, M 1988, 'Technologies of the Self', in LH Martin, H Gutman & PH Hutton (eds.), *Technologies of the Self: A Seminar with Michel Foucault*, The University of Massachusetts Press, Amherst, USA.

Foucault, M 1989, *The birth of the clinic: an archeology of medical perception*, e-book, viewed 5th February, 2018, <https://ebookcentral-proquest-com.ezproxy.lib.monash.edu.au/lib/monash/detail.action?docID=178505>

Foucault, M 1991, 'Governmentality', in G Burchell, C Gordon & P Miller (eds), *The Foucault effect: Studies in governmentality: with two lectures by and an interview with Michael Foucault*, Harvester Wheatsheaf, London, pp. 5 - 21.

—— 1995, *Discipline and Punish: The birth of the prison*, Vintage Books, New York.

—— 2000, *Ethics of concern of the self as a practice of freedom*, Penguin, London, England.

—— 2001, *Fearless Speech*, Semiotext(e), Los Angeles, U.S.A.

—— 2004, 'The crisis of medicine or the crisis of antimedicine?' *Foucault Studies*, vol. 1, pp. 5-19, viewed 24<sup>th</sup> October, 2017, <https://rauli.cbs.dk/index.php/foucault-studies/article/view/562/607>

Frank, AW 1994, 'Reclaiming an orphan genre: The first-person narrative of illness', *Literature and Medicine*, vol. 13, no. 1, pp. 1 – 21, viewed 24<sup>th</sup> October, 2017, <https://muse-jhu-edu.ezproxy.lib.monash.edu.au/article/376886/pdf>

Frank, AW 1995, *The Wounded Storyteller*, The University of Chicago Press, Chicago, London.

Fullagar, S 2002, 'Governing the healthy body: Discourses of leisure and lifestyle within Australian health policy', *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, vol. 6, no. 1, pp. 69-84, viewed 31<sup>st</sup> October, 2017, <http://journals.sagepub.com.ezproxy.lib.monash.edu.au/doi/abs/10.1177/136345930200600104>

——— 2008, 'Leisure practices as counter-depressants: Emotion-work and emotion-play within women's recovery from depression', *Leisure Sciences*, vol. 30, pp. 35-52, viewed 6<sup>th</sup> December, 2017, <https://www-tandfonline-com.ezproxy.lib.monash.edu.au/doi/abs/10.1080/01490400701756345>

Fullagar, S 2008b, 'Sites of subjectivity: E-scaped mental health promotion and the biopolitics of depression', *Social Theory & Health*, vol. 6, no. 4, pp. 323-341, viewed 19<sup>th</sup> June, 2018, <http://dx.doi.org.ezproxy.lib.monash.edu.au/10.1057/5th.2008.7>

——— 2009, 'Negotiating the neurochemical self: Anti-depressant consumption in women's recovery from depression', *Health*, vol. 13, no. 4, pp. 389-406, doi: 10.1177/1363459308101809

Fullagar, S & O'Brien, W 2013, 'Problematizing the neurochemical subject of anti-depressant treatment: The limits of biomedical responses to women's emotional distress', *Health*: vol. 17, no. 1, pp. 57-74, doi:10.1016/j.socscimed.2014.07.041

Fullagar, S & O'Brien, W 2014, 'Social recovery and the move beyond deficit models of depression: A feminist analysis of mid-life women's self-care practices', *Social Science & Medicine*, vol. 117, pp. 116-24, doi:10.1016/j.socscimed.2014.07.041

Gardner, P 2007, 'Re-gendering depression: Risk, web health campaigns, and the feminised pharmaco-subject', *Canadian Journal of Communication*, vol. 32, pp. 537-555, viewed 19<sup>th</sup> June, 2018, <http://ezproxy.lib.moash.edu.au>

Garfield, S, Smith, F & Francis, S-A 2003, 'The paradoxical role of antidepressant medication - returning to normal functioning while losing the sense of being normal', *Journal of Mental Health*, vol. 12, no. 5, pp. 521-35, doi:10.1080/09638230310001603582

Gibson, L, Sloan, D & Moncur, W 2012, 'Chapter 12: E-health and digital inclusion' in Smedberg, A. (ed.), *E-health communities and online self-help groups: Applications and usage*, IGI Global, Hershey, Pennsylvania, U.S.A, doi:"10.4018/978-1-60960-866-8.ch012.

Giles, DC & Newbold, J 2011, 'Self and other diagnosis in user-led mental health online communities', *Qualitative Health Research*, vol. 2, no. 3, pp. 419 – 28, viewed 24<sup>th</sup> October, 2017,  
<http://journals.sagepub.com.ezproxy.lib.monash.edu.au/doi/abs/10.1177/1049732310381388>

Givens, JL, Datto, CJ, Ruckdeschel, K, Knott, K, Zubritsky, C, Oslin, DW, Nyshadham, S, Vanguri, P & Barg, FK 2006, 'Older patients' aversion to antidepressants', *Journal of General Internal Medicine*, vol. 21, no. 2, pp. 146-51, viewed 24<sup>th</sup> October, 2017, [https://search-](https://search-proquest-)  
proquest-

com.ezproxy.lib.monash.edu.au/docview/208151356?OpenUrlRefId=info:xri/sid:primo&accountid=12528

Glaser, BG & Strauss, A, L. 1967, *The discovery of grounded theory*, Aldine Publishing Company, Chicago, Illinois, U.S.A.

Goffman, E 1961, *Asylums*, Aldine Publishing Company, Chicago.

—— 1963, 'Stigma and social identity', in *Stigma: Notes on the management of spoiled identity*, Penguin Books, London.

Grace, S & Higgs, J 2010, 'Practitioner–client relationships in integrative medicine clinics in Australia: A contemporary social phenomenon', *Complementary Therapies in Medicine*, vol. 18, no. 1, pp. 8-12, viewed 24<sup>th</sup> October, 2017, <https://www-sciencedirect-com.ezproxy.lib.monash.edu.au/science/article/pii/S0965229909000843>

Greenhalgh, T 2009, 'Chronic illness: beyond the expert patient', *BMJ: British Medical Journal*, vol. 338, no. 7695, pp. 629-31, viewed 24<sup>th</sup> October, 2017, [http://www.jstor.org.ezproxy.lib.monash.edu.au/stable/20512333?seq=1#page\\_scan\\_tab\\_contents](http://www.jstor.org.ezproxy.lib.monash.edu.au/stable/20512333?seq=1#page_scan_tab_contents).

Grime, J & Pollock, K 2004, 'Information versus experience: a comparison of an information leaflet on antidepressants with lay experience of treatment', *Patient Education and Counselling*, vol. 54, no. 3, pp. 361-8, viewed 24<sup>th</sup> October, 2017, <https://www-sciencedirect-com.ezproxy.lib.monash.edu.au/science/article/pii/S0738399104000746>.

Hardey, M 1999, 'Doctor in the house: The internet as a source of lay health knowledge and the challenge to expertise', *Sociology of health and illness*, vol. 21, no. 6, pp. 820 – 35, viewed 24<sup>th</sup> October, 2017,

<http://onlinelibrary.wiley.com.ezproxy.lib.monash.edu.au/doi/10.1111/1467-9566.00185/full>

Harrer, S 2005, 'The theme of subjectivity in Foucault's lecture series 'Hermeneutique du sujet'', *Foucault Studies*, no. 2, pp. 75-96, accessed 17<sup>th</sup> June, 2018,

<http://dx.doi.org/10.22439/fs.vOi2.861>

Haslam, C, Brown, S, Atkinson, S & Haslam, R 2004, 'Patients' experiences of medication for anxiety and depression: effects on working life', *Family Practice*, vol. 21, no. 2, pp. 204-12, viewed 24<sup>th</sup> October, 2017, <https://academic-oup-com.ezproxy.lib.monash.edu.au/fampra/article/21/2/204/509539>

Hemphill, RE 1961, 'The Illness of Vincent Van Gogh', *Proceedings of the Royal Society of Medicine*, vol. 54, no. 12, pp. 1083-8, doi: 10.1177/003591576105401206

Hillis, K, Petit, M & Jarrett, K 2012, *Google and the Culture of Search*, Taylor and Francis, London, UK, viewed 25<sup>th</sup> February, 2018, <<http://ebookcentral.proquest.com/lib/monash/detail.action?docID=1046868>>.

Hsu, C 2012, *Scientists find truth in mad scientist stereotype: There is a link between genius and insanity*, Newsweek Media Group, article, viewed 19th November, 2017,

<<http://www.medicaldaily.com/scientists-find-truth-mad-scientist-stereotype-there-link-between-genius-and-insanity-240684>>.

Inder, M, Crowe, M, Moor, S, Carter, J, Luty, S & Joyce, P 2011, 'It wouldn't be me if I didn't have bipolar disorder': managing the shift in self -identity with bipolar disorder', *Journal of Nursing and Healthcare of Chronic Illness*, vol. 3, no. 4, pp. 427-35, viewed 24<sup>th</sup> October, 2017, <http://onlinelibrary.wiley.com.ezproxy.lib.monash.edu.au/doi/10.1111/j.1752-9824.2011.01117.x/full>

Inder, ML, Crowe, MT, Moor, S, Luty, SE, Carter, JD & Joyce, PR 2008, 'I actually don't know who I am': The impact of bipolar disorder on the development of self', *Psychiatry*, vol. 71, no. 2, pp. 123-33, viewed 24<sup>th</sup> October, 2017, <https://www-tandfonline-com.ezproxy.lib.monash.edu.au/doi/abs/10.1521/psyc.2008.71.2.123>

Isabella, S 2007, 'Ethnography of online role-playing games: The role of virtual and real contest in the construction of the field', *Forum: Qualitative Social Research*, vol. 8, no. 3, viewed 24<sup>th</sup> October, 2017, [https://search-proquest-com.ezproxy.lib.monash.edu.au/docview/869235997?accountid=12528&rfr\\_id=info%3Axri%2Fsid%3Aprimo](https://search-proquest-com.ezproxy.lib.monash.edu.au/docview/869235997?accountid=12528&rfr_id=info%3Axri%2Fsid%3Aprimo)

Jaye, C, Egan, T. & Parker, S. 2006, 'Do as I say, not as I do': Medical education and Foucault's normalizing technologies of self', *Anthropology & Medicine*, vol. 13, no. 2, pp. 141 – 55, viewed 24<sup>th</sup> October, 2017, <https://www-tandfonline-com.ezproxy.lib.monash.edu.au/doi/abs/10.1080/13648470600738450>

Jenkins, JH 2010, *Pharmaceutical Self*, School for Advanced Research Press, New Mexico.

—— 2015, 'Cultural chemistry in the Clozapine clinic', in *Extraordinary Conditions: Culture and Experience in Mental Illness*, e-book, University of California Press, California, viewed 5<sup>th</sup> February, 2018, pp. 23 – 40, <https://ebookcentral-proquest-com.ezproxy.lib.monash.edu.au/lib/monash/reader.action?docID=2025589&ppg=40>

Jenkins, JH & Karno, M 1992, 'The meaning of expressed emotion: Theoretical issues raised by cross-cultural research', *Am J Psychiatry*, vol. 149, no. 1, pp. 9-21, viewed 5<sup>th</sup> December, 2017, <https://ajp-psychiatryonline-org.ezproxy.lib.monash.edu.au/doi/pdf/10.1176/ajp.149.1.9>

Johnson, FR, Özdemir, S, Manjunath, R, Hauber, AB, Burch, SP & Thompson, TR 2007, 'Factors that affect adherence to bipolar disorder treatments: a stated-preference approach', *Medical care*, vol. 45, no. 6, pp. 545-52, viewed 24<sup>th</sup> October, 2017, <http://ovidsp.tx.ovid.com.ezproxy.lib.monash.edu.au>

Jones, P 2003, *Michel Foucault: Discourse theory and the body-centredness of modernity*, Polity Press, Cambridge, U.K.

Jorm, AF, Kitchener, BA, Fischer, J-A & Cvekovski, S 2010, 'Mental health first aid training by e-learning: A randomised controlled trial', *Australian and New Zealand Journal of Psychiatry*, vol. 44, no. 12, pp. 1072-81, viewed 6<sup>th</sup> December, 2017, <http://journals.sagepub.com.ezproxy.lib.monash.edu.au/doi/abs/10.3109/00048674.2010.5164>

Jorm, AF & Reavley, NJ 2013, 'Depression and stigma: from attitudes to discrimination', *The Lancet*, vol. 381, no. 9860, pp. 10 – 1, viewed 24<sup>th</sup> October, 2017, <https://www-sciencedirect-com.ezproxy.lib.monash.edu.au/science/article/pii/S0140673612614573>

Karimov, FP, Brengman, M & Van Hove, L 2011, 'The effect of website design dimensions on initial trust: A synthesis of the empirical literature', *Journal of Electronic Commerce Research*, vol. 12, no. 4, pp. 272-301, viewed 24<sup>th</sup> October, 2017, [https://search-proquest-com.ezproxy.lib.monash.edu.au/docview/914166186?accountid=12528&rfr\\_id=info%3Axri%2Fsid%3Aprimo](https://search-proquest-com.ezproxy.lib.monash.edu.au/docview/914166186?accountid=12528&rfr_id=info%3Axri%2Fsid%3Aprimo)

Katz, J & Joiner, TE 2002, 'Being known, inmate and valued: Global self-verification and dyadic adjustment in couples and roommates', *Journal of Personality*, vol. 10, no. 1, pp. 33 – 58, viewed 24<sup>th</sup> October, 2017, <http://onlinelibrary.wiley.com.ezproxy.lib.monash.edu.au/doi/10.1111/1467-6494.00177/full>

Keil, FC, Stein, C, Webb, L, Billings, VD & Rozenblit, L 2008, 'Discerning the division of cognitive labor: An emerging understanding of how knowledge is clustered in other minds', *Cognitive science*, vol. 32, no. 2, pp. 259-300, viewed 9<sup>th</sup> December, 2017, <http://onlinelibrary.wiley.com.ezproxy.lib.monash.edu.au/doi/10.1080/03640210701863339/full>

Kekewich, MA 2014, 'Market Liberalism in Health Care: A Dysfunctional View of Respecting “Consumer” Autonomy', *Journal of Bioethical Inquiry*, vol. 11, no. 1, pp. 21-9,

viewed 25<sup>th</sup> January, 2018, <https://link-springer-com.ezproxy.lib.monash.edu.au/article/10.1007/s11673-013-9492-1>

Kelleher, D 1988, 'Coming to terms with diabetes: Coping strategies and non-compliance', in R Anderson & M Bury (eds.), *Living with chronic illness*, Unwin Hyman, London, pp. 137-55.

Kelly, BD 2006, 'The power gap: Freedom, power and mental illness', *Social Science & Medicine*, vol. 63, pp. 2118-28, viewed 6<sup>th</sup> December, 2017, <https://www-sciencedirect-com.ezproxy.lib.monash.edu.au/science/article/pii/S0277953606002711>

Kelly, L, Jenkinson, C., and Ziebland, S. 2013, 'Measuring the effects of online health information for patients: Item generation for an e-health impact questionnaire', *Patient Education and Counseling*, vol. 93, pp. 433-8, viewed 24<sup>th</sup> October, 2017, <https://www-sciencedirect-com.ezproxy.lib.monash.edu.au/science/article/pii/S0738399113001213>

Kendrick, PK & Costello, J 2000, 'Healthy viewing? Experiencing life and death through a voyeuristic gaze', *Nursing Ethics*, vol. 7, no. 1, pp. 15 – 22, viewed 24<sup>th</sup> October, 2017, <https://search-proquest-com.ezproxy.lib.monash.edu.au/docview/201356349?OpenUrlRefId=info:xri/sid:primo&accountid=12528>

Kirmayer, LJ, Raikhel, E & Rahimi, S 2013, 'Cultures of the internet: Identity, community and mental health', *Transcultural Psychiatry*, vol. 50, no. 2, pp. 165 – 91, viewed 24<sup>th</sup>

October, 2017,

<http://journals.sagepub.com.ezproxy.lib.monash.edu.au/doi/abs/10.1177/1363461513490626>

Kleinman, A 1988, *The illness narratives*, Basic Books, U.S.A.

Kleinman, A, Eisenberg, L & Good, B 1978, 'Culture, illness, and care: clinical lessons from anthropologic and cross-cultural research', *Ann. Intern. Med.*, vol. 88, no. 2, pp. 251-8, doi: 10:7326/0003-4819-88-2-251

Kortum, P, Edwards, C & Richards-Kortum, R 2008, 'The impact of inaccurate internet health information in a secondary school learning environment', *Journal of medical Internet research*, vol. 10, no. 2, viewed 31<sup>st</sup> October, 2017, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2483927/>

Krysiak, JL & Finn, J 2013, *Research for effective social work practice*, 3rd edn, Routledge, New York, London.

Laing, A, Hogg, G & Winkleman, D 2004, 'Healthcare and the information revolution: re-configuring the healthcare service encounter', *Health Services Management Research*, vol. 17, no. 3, pp. 188 – 99, viewed 24<sup>th</sup> October, 2017, <https://search-proquest-com.ezproxy.lib.monash.edu.au/docview/236475733?OpenUrlRefId=info:xri/sid:primo&accountid=12528>

Lakhan, SE & Vieira, KF 2008, 'Nutritional therapies for mental disorders', *Nutrition journal*, vol. 7, no. 1, p. 2, viewed 9<sup>th</sup> December, 2017,

<https://nutritionj.biomedcentral.com/articles/10.1186/1475-2891-7-2>

Lauritzen, SO & Hyden, L-C 2006, *Medical Technologies and the Life World: The social construction of normality*, Taylor and Francis, Florence, US, viewed 20<sup>th</sup> February, 2018,

[https://ebookcentral-proquest-](https://ebookcentral-proquest-com.ezproxy.lib.monash.edu.au/lib/monash/detail.action?docID=292800)

[com.ezproxy.lib.monash.edu.au/lib/monash/detail.action?docID=292800](https://ebookcentral-proquest-com.ezproxy.lib.monash.edu.au/lib/monash/detail.action?docID=292800)

Lawn, S, McMillan, J & Pulvirenti, M 2011, 'Chronic condition self-management:

Expectations of responsibility', *Patient Education and Counseling*, vol. 84, no. 2, pp. e5-e8,

viewed 24<sup>th</sup> October, 2017, [https://www-sciencedirect-](https://www-sciencedirect-com.ezproxy.lib.monash.edu.au/science/article/pii/S073839911000409X?via%3Dihub)

[com.ezproxy.lib.monash.edu.au/science/article/pii/S073839911000409X?via%3Dihub](https://www-sciencedirect-com.ezproxy.lib.monash.edu.au/science/article/pii/S073839911000409X?via%3Dihub)

Leask, I 2012, 'Beyond subjection: Notes on the later Foucault and education', *Education,*

*Philosophy and Theory*, vol. 44, no. 1, pp. 57-73, viewed 6<sup>th</sup> December, 2017, DOI:

10.1111/j.1496-5812.2011.00774.x.

Leibing, A 2009, 'Lessening the evils online: Embodied molecules and the politics of hope in

Parkinson's disease', *Science & Technologies Studies*, vol. 22, no. 2, pp. 80-101, viewed 31<sup>st</sup>

October, 2017, [https://scholar-google-com-](https://scholar-google-com-au.ezproxy.lib.monash.edu.au/scholar?hl=en&as_sdt=0%2C5&q=lessening+the+evils+online)

[au.ezproxy.lib.monash.edu.au/scholar?hl=en&as\\_sdt=0%2C5&q=lessening+the+evils+online](https://scholar-google-com-au.ezproxy.lib.monash.edu.au/scholar?hl=en&as_sdt=0%2C5&q=lessening+the+evils+online)

[+embodied+molecules+and+the+politics+of+hope+in+Parkinson%27s+disease&btnG=](https://scholar-google-com-au.ezproxy.lib.monash.edu.au/scholar?hl=en&as_sdt=0%2C5&q=lessening+the+evils+online)

Leimeister, JM, Schweizer, KJ & Krcmar, H 2012, 'Do Virtual Communities Have an Effect on the Social Network of Cancer Patients? : Empirical Insights from Germany', in *E-Health Communities and Online Self-Help Groups: Applications and Usage*, IGI Global, pp. 72-84, doi: 10.4018/978-1-60960-866-8.

Lemire, M, Sicotte, C, Paré, G 2008, 'Internet use and the logics of personal empowerment in health', *Health policy*, vol. 88, no. 1, pp. 130-40, viewed 24<sup>th</sup> October, 2017, <https://www-sciencedirect-com.ezproxy.lib.monash.edu.au/science/article/pii/S0168851008000808>

Lemke, T 2001, 'The birth of bio-politics - Michel Foucault's lecture at the College de France on neo-liberal governmentality', *Economy & Society*, vol. 30, no. 2, pp. 190 – 207, viewed 24<sup>th</sup> October, 2017, <https://www-tandfonline-com.ezproxy.lib.monash.edu.au/doi/abs/10.1080/03085140120042271>

Liang, MH, Couto, MC, Duarte, CC, Gall, V, White, P, Naides, S, Schumacher, HR, Hwang, AS, Holers, VM & Deane, KD 2015, 'An Internet-based technique for the identification of persons with symptoms of inflammatory polyarthritis of less than 12 weeks', *Clinical rheumatology*, vol. 34, no. 3, pp. 465-70, accessed 24<sup>th</sup> October, 2017, <https://search-proquest-com.ezproxy.lib.monash.edu.au/docview/1660316630?OpenUrlRefId=info:xri/sid:primo&acountid=12528>

Lindseth, A & Norberg, A 2004, 'A phenomenological hermeneutical method for researching', *Scandinavian Jjournal of Caring Sciences*, vol. 18, no. 2, pp. 145-153, viewed 19<sup>th</sup> June, 2018, <https://doi-org.ezproxy.lib.monash.edu.au/10.1111/j.1471-6712.2004.00258.x>

Lloyd, LC, Giaroli, G, Taylor, D & Tracy, DK 2011, 'Bipolar depression: clinically missed, pharmacologically mismanaged', *Therapeutic Advances in Psychopharmacology*, vol. 1, no. 5, pp. 153-62, viewed 23<sup>rd</sup> January, 2018,  
<http://journals.sagepub.com.ezproxy.lib.monash.edu.au/doi/abs/10.1177/2045125311420752>

Lorig, KR & Holman, HR 2003, 'Self-management education: history, definition, outcomes, and mechanisms', *Annals of behavioral medicine*, vol. 26, no. 1, pp. 1-7, viewed 24<sup>th</sup> October, 2017, [https://doi-org.ezproxy.lib.monash.edu.au/10.1207/S15324796ABM2601\\_01](https://doi-org.ezproxy.lib.monash.edu.au/10.1207/S15324796ABM2601_01)

Luhrmann, T 2010, 'Medication on the street: Homeless women in Uptown Chicago', in JH Jenkins (ed.), *Pharmaceutical Self*, School for Advanced Research Press, Santa Fe, New Mexico, pp. 161-86.

Luxon, N 2004, 'Truthfulness, risk, and trust in the late lectures of Michel Foucault', *Inquiry*, vol. 47, no. 5, pp. 464-89, viewed 24<sup>th</sup> October, 2017, <https://doi-org.ezproxy.lib.monash.edu.au/10.1080/00201740410004269>

Mager, A 2009, 'Mediated health: sociotechnical practices of providing and using online health information', *New Media & Society*, vol. 11, no. 7, pp. 1123-42, viewed 31<sup>st</sup> October, 2017,  
<http://journals.sagepub.com.ezproxy.lib.monash.edu.au/doi/abs/10.1177/1461444809341700>

Malpass, A, Shaw, A, Sharp, D, Walter, F, Feder, G, Ridd, M & Kessler, D 2009, "Medication career" or "Moral career"? The two sides of managing antidepressants: A meta-ethnography of patients' experience of antidepressants', *Social Science & Medicine*, vol. 68, no. 1, pp. 154-68, viewed <https://doi-org.ezproxy.lib.monash.edu.au/10.1016/j.socscimed.2008.09.068>.

Martin, C 2010(b), 'Exhibition: Vincent Van Gogh's life and work through his letters', *The Lancet*, vol. 375, no. 9715, pp. 629-30, viewed 4<sup>th</sup> December, 2017, [https://doi-org.ezproxy.lib.monash.edu.au/10.1016/S0140-6736\(10\)60253-X](https://doi-org.ezproxy.lib.monash.edu.au/10.1016/S0140-6736(10)60253-X)

Martin, E 2007, *Bipolar Expeditions: Mania and depression in American culture*, Princeton University Press, Princeton, U.S.A., viewed 30th April, 2015, <<http://portal.igpublish.com.ezproxy.lib.monash.edu.au/iglibrary/search/PUPB0000387.html?1>>.

——— 2010, 'Sleepless in America', in JH Jenkins (ed.), *Pharmaceutical Self*, School for Advanced Research Press, Santa Fe, New Mexico, pp. 187-207.

Martin, JK, Pescosolido, BA, Olafsdottir, S & McLeod, JD 2007, 'The construction of fear: Americans' preferences for social distance from children and adolescents with mental health problems', *Journal of Health and Social Behaviour*, vol. 48, no. 1, pp. 59 – 67, viewed 24<sup>th</sup> October, 2017, [http://www.jstor.org.ezproxy.lib.monash.edu.au/stable/27638690?seq=1#page\\_scan\\_tab\\_contents](http://www.jstor.org.ezproxy.lib.monash.edu.au/stable/27638690?seq=1#page_scan_tab_contents)

Marx, M 2001, 'Invisibility, interviewing, and power: A researcher's dilemma', *Resources for Feminist Research*, vol. 28, no. 3-4, p. 131, viewed 24<sup>th</sup> October, 2017,

<http://go.galegroup.com.ezproxy.lib.monash.edu.au/ps/i.do?&id=GALE|A81220835&v=2.1&u=monash&it=r&p=AONE&sw=w&authCount=1>

Maxwell, M 2005, 'Women's and doctors' accounts of their experiences of depression in primary care: the influence of social and moral reasoning on patients' and doctors' decisions', *Chronic Illness*, vol. 1, no. 1, pp. 61-71, viewed 25<sup>th</sup> February, 2018,

<http://journals.sagepub.com.ezproxy.lib.monash.edu.au/doi/abs/10.1177/17423953050010010401>

McLean, A 1995, 'Empowerment and the psychiatric consumer/ex-patient movement in the United States: Contradictions, crisis and change', *Social Science & Medicine*, vol. 40, no. 8, pp. 1053 – 71, viewed 24<sup>th</sup> October, 2017, [https://doi-](https://doi-org.ezproxy.lib.monash.edu.au/10.1016/0277-9536(94)00179-W)

[org.ezproxy.lib.monash.edu.au/10.1016/0277-9536\(94\)00179-W](https://doi-org.ezproxy.lib.monash.edu.au/10.1016/0277-9536(94)00179-W)

McMullan, M 2006, 'Patients using the internet to obtain health information: How this affects the patient health-professional relationship', *Patient Education and Counselling*, vol. 63, pp. 24 – 8, viewed 24<sup>th</sup> October, 2017, [https://doi-](https://doi-org.ezproxy.lib.monash.edu.au/10.1016/j.pec.2005.10.006)

[org.ezproxy.lib.monash.edu.au/10.1016/j.pec.2005.10.006](https://doi-org.ezproxy.lib.monash.edu.au/10.1016/j.pec.2005.10.006)

McNulty, SE, Swann, WB & William, B 1994, 'Identity negotiation in roommate relationships: The self as architect and consequence of social reality', *Journal of personality and social psychology*, vol. 67, no. 6, pp. 1012 – 23, viewed 21<sup>st</sup> February, 2018,

<http://ovidsp.tx.ovid.com.ezproxy.lib.monash.edu.au>

Merikangas, KR, Jin, R, He, J & et al. 2011, 'Prevalence and correlates of bipolar spectrum disorder in the world mental health survey initiative', *Archives of General Psychiatry*, vol. 68, no. 3, pp. 241-51, viewed 24<sup>th</sup> October, 2017, DOI: 10.1001/archgenpsychiatry.2011.12

Merleau-Ponty, M 2013, *Phenomenology of Perception*, Taylor and Francis, Florence, e-book, viewed 24<sup>th</sup> October, 2017, <https://ebookcentral-proquest-com.ezproxy.lib.monash.edu.au/lib/monash/detail.action?docID=1433878>

Mir, RA 2010, 'Book Review: Paul tenHave "Doing conversation analysis: A practical guide"', *Organizational Research Methods*, vol. 13, no. 3, pp. 608 – 9, viewed 24<sup>th</sup> October, 2017, <http://journals.sagepub.com.ezproxy.lib.monash.edu.au/doi/abs/10.1177/1094428108325127>

Mitchell, P 2013, 'Bipolar disorder', *Australian Family Physician*, vol. 42, pp. 616-9, viewed 24<sup>th</sup> October, 2017, <https://www.racgp.org.au/afp/2013/september/bipolar-disorder/>

Monroe, RR 1978, 'The episodic psychoses of Vincent van Gogh', *The Journal of nervous and mental disease*, vol. 166, no. 7, pp. 480-8, viewed 26<sup>th</sup> February, 2018, <http://ovidsp.tx.ovid.com.ezproxy.lib.monash.edu.au/>

Mooney, S 2014, *Qualitative Interviewing with Vulnerable Populations: Ethical Considerations When Conducting Narrative Interviews with Young People with Cancer*, Sage Research Methods Cases, viewed 24<sup>th</sup> October, 2017,

<<http://methods.sagepub.com/case/qualitative-interviewing-vulnerable-ethical-narrative-young-cancer>>.

Moore, D & Ayers, S 2016, 'Virtual voices: social support and stigma in postnatal mental illness internet forums', *Psychology, Health & Medicine*, pp. 1-6, viewed 24<sup>th</sup> October, 2017, <https://doi-org.ezproxy.lib.monash.edu.au/10.1080/13548506.2016.1189580>

Moses, T 2014, 'Determinants of mental illness stigma for adolescents discharged from psychiatric hospitalization', *Social Science & Medicine*, vol. 109, pp. 26 – 34, viewed 24<sup>th</sup> October 2017, <https://doi-org.ezproxy.lib.monash.edu.au/10.1016/j.socscimed.2013.12.032>

Murthy, D 2008, 'Digital ethnography: An examination of the use of new technologies for social research', *Sociology*, vol. 42, no. 5, pp. 837-46, viewed 24<sup>th</sup> October, 2017, [http://www.jstor.org.ezproxy.lib.monash.edu.au/stable/42857191?seq=1#page\\_scan\\_tab\\_contents](http://www.jstor.org.ezproxy.lib.monash.edu.au/stable/42857191?seq=1#page_scan_tab_contents)

Naghieh, A & Parvizi, M 2016, 'Exercising soft closure on lay health knowledge? Harnessing the declining power of the medical profession to improve online health information', *Social Theory & Health*, vol. 14, no. 3, pp. 332-50, viewed 31<sup>st</sup> January, 2018, [https://search-proquest-com.ezproxy.lib.monash.edu.au/docview/1960533487?accountid=12528&rfr\\_id=info%3Axri%2Fsid%3Aprimo](https://search-proquest-com.ezproxy.lib.monash.edu.au/docview/1960533487?accountid=12528&rfr_id=info%3Axri%2Fsid%3Aprimo)

Naslund, JA, Grande, SW, Aschbrenner, KA & Elwyn, G 2014, 'Naturally occurring peer support through social media: the experiences of individuals with severe mental illness using

YouTube', *PLoS ONE*, vol. 9, no. 10, p. e110171, viewed 4<sup>th</sup> December, 2017,  
<http://dx.doi.org.ezproxy.lib.monash.edu.au/10.1371/journal.pone.0110171>

Palumbo, R 2017, *The Bright Side and the Dark Side of Patient Empowerment: Co-creation and Co-destruction of Value in the Healthcare Environment*, e-book Springer, viewed 1<sup>st</sup> February, 2018, <https://link-springer-com.ezproxy.lib.monash.edu.au/book/10.1007%2F978-3-319-58344-0>

Paré, G, Malek, J-N, Sicotte, C & Lemire, M 2009, 'Internet as a source of health information and its perceived influence on personal empowerment', *International Journal of Healthcare Information Systems and Informatics (IJHISI)*, vol. 4, no. 4, pp. 1-18, viewed 4<sup>th</sup> December, 2017, <http://www.igi-global.com.ezproxy.lib.monash.edu.au/>

Parikh, SV, Hawke, LD, Velyvis, V, Zaretsky, A, Beaulieu, S, Patelis-Siotis, I, MacQueen, G, Young, LT, Yatham, LN & Cervantes, P 2015, 'Combined treatment: Impact of optimal psychotherapy and medication in bipolar disorder', *Bipolar Disorders*, vol. 17, pp. 86-96 viewed 24<sup>th</sup> October, 2017,  
<http://onlinelibrary.wiley.com.ezproxy.lib.monash.edu.au/doi/10.1111/bdi.12233/full>

Parikh, SV & Huniewicz, P 2015, 'e-Health: An overview of the issues of the internet social media, apps and websites for mood disorders', *Current Opinion in Psychiatry*, vol. 28, no. 1, pp. 13 – 7, viewed 24<sup>th</sup> October, 2017, <http://ovidsp.tx.ovid.com.ezproxy.lib.monash.edu.au/>

Pariser, E 2011, *The Filter Bubble*, Penguin Press, New York.

Parker, G 2007, 'Bipolar disorder: assessment and management', *Australian Family Physician*, vol. 36, no. 4, p. 240, viewed 24<sup>th</sup> October, 2017, [https://search-informit-com-au.ezproxy.lib.monash.edu.au/fullText;dn=359194454748476;res=IELHEA](https://search.informit-com-au.ezproxy.lib.monash.edu.au/fullText;dn=359194454748476;res=IELHEA)

Paterson, B, Thorne, S, Crawford, J & Tarko, M 1999, 'Living with diabetes as a transformational experience', *Qualitative Health Research*, vol. 9, no. 6, pp. 786-802, viewed 6<sup>th</sup> December, 2017, <http://journals.sagepub.com.ezproxy.lib.monash.edu.au/doi/abs/10.1177/10497329912912228>

Pescosolido, BA, Perry, BL, Martin, JK, McLeod, JD & Jensen, PS 2007, 'Stigmatising attitudes and beliefs about treatment and psychiatric medications for children with mental illness', *Psychiatric Services*, vol. 58, no. 5, pp. 613 – 8, viewed 24<sup>th</sup> October, 2017, <https://ps-psychiatryonline-org.ezproxy.lib.monash.edu.au/doi/full/10.1176/ps.2007.58.5.613?code=ps-site>

Petersen, A & Lupton, D 1996, *The new public health: Health and self in the age of risk*, Allen & Unwin, Sydney.

Phillips, ML & Kupfer, DJ 2013, 'Bipolar disorder diagnosis: challenges and future directions', *The Lancet*, vol. 381, no. 9878, pp. 1663-71, viewed 31<sup>st</sup> October, 2017, [https://doi-org.ezproxy.lib.monash.edu.au/10.1016/S0140-6736\(13\)60989-7](https://doi-org.ezproxy.lib.monash.edu.au/10.1016/S0140-6736(13)60989-7)

Pilgrim, D & Tomasini, F 2012, 'On being unreasonable in modern society: are mental health problems special?' *Disability & Society*, vol. 27, no. 5, pp. 631-46, viewed 5<sup>th</sup> December,

2017, <https://www-tandfonline-com.ezproxy.lib.monash.edu.au/doi/abs/10.1080/09687599.2012.669108>

Plummer, K 2001, *Documents of life 2: An invitation to a critical humanism*, Sage Publications, London.

Pols, J 1989, 'Mental illness and rationality: A critique', *International journal of law and psychiatry*, vol. 12, no. 1, pp. 71-9, viewed 24<sup>th</sup> October, 2017, [https://doi-org.ezproxy.lib.monash.edu.au/10.1016/0160-2527\(89\)90015-0](https://doi-org.ezproxy.lib.monash.edu.au/10.1016/0160-2527(89)90015-0)

Pound, P, Britten, N, Morgan, M, Yardley, L, Pope, C, Daker-White, G & Campbell, R 2005, 'Resisting medicines: a synthesis of qualitative studies of medicine taking', *Social Science & Medicine*, vol. 61, no. 1, pp. 133-55, viewed 24<sup>th</sup> October, 2017, <https://doi-org.ezproxy.lib.monash.edu.au/10.1016/j.socscimed.2004.11.063>

Proudfoot, JG, Parker, GB, Benoit, M, Manicavasagar, V, Smith, M & Gayed, A 2009, 'What happens after diagnosis? Understanding the experiences of patients with newly-diagnosed bipolar disorder', *Health Expectations*, vol. 12, no. 2, pp. 120-9, viewed 24<sup>th</sup> October, 2017, <http://onlinelibrary.wiley.com.ezproxy.lib.monash.edu.au/doi/10.1111/j.1369-7625.2009.00541.x/full>

Purse, M 2017, *Vincent Van Gogh brilliance and bipolar disorder*, verywell, 20th November, 2017, <<https://www.verywell.com/vincent-van-gogh-brilliance-and-bipolar-disorder-379751>>.

Rabinow, P (ed.) 1984, *The Foucault Reader*, Penguin Books, Middlesex, England, New York, U.S.A.

Rabinow, P & Rose, N 2003, 'Foucault today', in P Rabinow & N Rose (eds), *The essential Foucault: Selections from the essential works of Foucault, 1954-1984*, New Press, New York, pp. vii - xxxv.

Reavley, N, Cvetkovski, S & Jorm, A 2011, 'Sources of information about mental health and links to help seeking: Findings from the 2007 Australian National Survey of Mental Health and Wellbeing', *Social Psychiatry and Psychiatric Epidemiology*, vol. 46, no. 12, pp. 1267-74, viewed 6<sup>th</sup> December, 2017, <https://search-proquest-com.ezproxy.lib.monash.edu.au/docview/903499902?OpenUrlRefId=info:xri/sid:primo&accountid=12528>

Rice, T 2001, 'Individual autonomy and state involvement in health care', *Journal of Medical Ethics*, vol. 27, pp. 240-4, viewed 31<sup>st</sup> October, 2017, <http://jme.bmj.com.ezproxy.lib.monash.edu.au/content/27/4/240>

Riessman, CK 2008, *Narrative methods for the human sciences*, Sage Publications, California, U.S.A.

Roller, MR & Lavrakas, PJ 2015, *Applied Qualitative Research Design: A total quality framework approach*, Guilford Publications, The Guilford Press, New York, London.

Rose, N 1993, 'Government, authority and expertise in advanced liberalism', *Economy and Society*, vol. 22, no. 3, pp. 283-99, viewed 24<sup>th</sup> October, 2017, <https://www-tandfonline-com.ezproxy.lib.monash.edu.au/doi/abs/10.1080/03085149300000019>

——— 1996, *Inventing ourselves: Psychology, power and personhood*, Cambridge University, Cambridge, England.

——— 1999, *Governing the soul: The shaping of the private self*, 2nd edn, Free Association Books, London.

——— 2001, 'The politics of life itself', *Theory, Culture & Society*, vol. 18, no. 6, pp. 1 – 30, viewed 24<sup>th</sup> October, 2017, <http://journals.sagepub.com.ezproxy.lib.monash.edu.au/doi/abs/10.1177/02632760122052020>

——— 2013, 'The human sciences in a biological age', *Theory Culture & Society*, vol. 30, no. 1, pp. 3 – 34, viewed 24<sup>th</sup> October, 2017, <http://journals.sagepub.com.ezproxy.lib.monash.edu.au/doi/abs/10.1177/0263276412456569>

——— 2014, *Governing enterprising individuals*, 7, Cambridge University Press, Cambridge, England, New York.

——— 2016, 'Powers of freedom, governmentality and the psy knowledges: dialogues with Nikolas Rose (Part 2)', *Interface, Comunicacao Saude Educacao*, vol. 20, no. 58, pp. 797-808.

Rosenbaum, L 2016, 'Liberty versus need - Our struggle to care for people with serious mental illness', *New England Journal of Medicine*, vol. 375, pp. 1490-5, viewed 6<sup>th</sup> December, 2017, <http://www.nejm.org.ezproxy.lib.monash.edu.au/doi/full/10.1056/NEJMms1610124>

Salonen, A, Ryhanen, AM & Leino-Kilpi, H 2014, 'Educational benefits of internet and computer-based programmes for prostate cancer patients: A systematic review', *Patient Education and Counseling*, vol. 94, pp. 10-9, viewed 1<sup>st</sup> November, 2017, <https://doi-org.ezproxy.lib.monash.edu.au/10.1016/j.pec.2013.08.022>

Schneck, CD, Miklowitz, DJ, Miyahara, S, Wisniewski, S, Gyulai, L, Allen, MH, Thase, ME & Sachs, GS 2008, 'The prospective course of rapid-cycling bipolar disorder: Findings from the STEP-BD', *The American Journal of Psychiatry*, vol. 165, no. 3, pp. 370-7, viewed 24<sup>th</sup> October, 2017, <https://ajp-psychiatryonline-org.ezproxy.lib.monash.edu.au/doi/full/10.1176/appi.ajp.2007.05081484?code=ajp-site>

Schramme, T 2015, *New perspectives on paternalism and health care*, e-book, (ed.) T Schramme, Springer, Cham, viewed 25th January, 2018, <<https://link-springer-com.ezproxy.lib.monash.due.au/book/10.1007%2F978-3-319-17960-5>>.

Schrank, B, Sibitz, I, Unger, A & Amering, M 2010, 'How patients with schizophrenia use the internet: qualitative study', *Journal of medical Internet research*, vol. 12, no. 5, viewed 18<sup>th</sup> January, 2017, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3057320/>

Searle, JR 1995, *The Construction of Social Reality*, Penguin Books, New York.

Segal, L 1998, 'The importance of patient empowerment in health system reform', *Health policy*, vol. 44, no. 1, pp. 31-44, viewed 24<sup>th</sup> October, 2017, <https://www-sciencedirect-com.ezproxy.lib.monash.edu.au/science/article/pii/S0168851098000074>

Sibbritt, D, Davidson, P, DiGiacomo, M, Newton, P & Adams, J 2015, 'Use of Complementary and Alternative Medicine in Women With Heart Disease, Hypertension and Diabetes (from the Australian Longitudinal Study on Women's Health)', *The American Journal of Cardiology*, vol. 115, no. 12, pp. 1691-5, viewed 24<sup>th</sup> October, 2017, <https://doi-org.ezproxy.lib.monash.edu.au/10.1016/j.amjcard.2015.03.014>

Smith, DJ, Griffiths, E, Pool, R, Di florio, A, Barnes, E, Kelly, MJ, Craddock, N, Hood, K & Simpson, S 2011, 'Beating bipolar: Exploratory trial of a novel internet based psychoeducational treatment for bipolar disorder', *Bipolar Disorders*, vol. 13, pp. 571 – 7, viewed 24<sup>th</sup> October, 2017, <http://onlinelibrary.wiley.com.ezproxy.lib.monash.edu.au/doi/10.1111/j.1399-5618.2011.00949.x/full>

Smith, J 2012, 'Reflections on using life history to investigate women teachers' aspirations and career decisions', *Qualitative Research*, vol. 12, no. 4, pp. 486-503, viewed 24<sup>th</sup> October, 2017, <http://journals.sagepub.com.ezproxy.lib.monash.edu.au/doi/abs/10.1177/1468794111433090>

Spinzy, Y, Nitzan, U, Becker, G, Bloch, Y & Fennig, S 2012, 'Does the Internet offer social opportunities for individuals with schizophrenia? A cross-sectional pilot study', *Psychiatry*

*Research*, vol. 198, no. 2, pp. 319-20, viewed 21<sup>st</sup> January, 2018, <https://doi-org.ezproxy.lib.monash.edu.au/10.1016/j.psychres.2012.02.022>

Steinke, I 2004, 'Quality criteria in qualitative research', in U Flick, E Von Kardoff & I Steinke (eds), *A companion to qualitative research*, Sage Publications, London, Thousand Oaks, pp. 184 - 90.

Stepeney, M 2014, 'The rise and fall of 'girlsdrinkdiaries.com': Dilemmas and opportunities when creating online forums to investigate health behaviour ', *Health & Place*, vol. 27, pp. 51 – 8, viewed 24<sup>th</sup> October, 2017, <https://doi-org.ezproxy.lib.monash.edu.au/10.1016/j.healthplace.2014.01.001>

Stokken, R & Eikli, G 2012, 'Living a Healthier Life Online: On Blending Professional and Experiential Knowledge in Online Self-Help Groups', in A. Smedberg (ed.), *E-Health Communities and Online Self-Help Groups: Applications and Usage*, e-book IGI Global, pp. 155-76, viewed 24<sup>th</sup> October, 2017, <https://www-igi-global-com.ezproxy.lib.monash.edu.au/gateway/book/50112>.

Strik, WK 1997, 'The psychiatric illness of Vincent van Gogh', *Der Nervenarzt*, vol. 68, no. 5, pp. 401-9, viewed 26<sup>th</sup> February, 2018, <https://link-springer-com.ezproxy.lib.monash.edu.au/article/10.1007/s001150050142>

Strong, P 1979, 'Sociological imperialism and the profession of medicine: A critical examination of the thesis of medical imperialism', *Social Science & Medicine Part A:*

*Medical psychology and medical sociology*, vol. 13, pp. 199 – 215, viewed 24<sup>th</sup> October, 2017, [https://doi-org.ezproxy.lib.monash.edu.au/10.1016/0271-7123\(79\)90030-0](https://doi-org.ezproxy.lib.monash.edu.au/10.1016/0271-7123(79)90030-0)

Sundar, SS, Rice, RE, Hyang-Sook, K & Sciamanna, CN 2011, 'On-line health information: Conceptual challenges and theoretical opportunities', in TL Thompson, R Parrott & JF Nussbaum (eds), *Routledge Handbook of Health Communication*, Taylor and Francis, Hoboken.

Taylor, J 2011, 'The intimate insider: negotiating the ethics of friendship when doing insider research', *Qualitative Research*, vol. 11, no. 1, pp. 03-22, doi: 10.1177/1468794110384447

tenHave, P 2007, 'Introducing the CA paradigm', in *Doing Conversation Analysis*, 2<sup>nd</sup> edn., Sage Publications Ltd., London, viewed 24<sup>th</sup> October, 2017, <<http://d.doi.org/10.4135/9781849208895.n1>>.

Thomm, E & Bromme, R 2012, ' "It should at least seem scientific!": Textual features of "Scientificness" and their impact on lay assessments of online information', *Science Education*, vol. 96, no. 2, pp. 187-211, viewed 9<sup>th</sup> December, 2017, <http://onlinelibrary.wiley.com.ezproxy.lib.monash.edu.au/doi/10.1002/sce.20480/full>

Thompson, R 2012, 'Looking healthy: Visualizing mental health and illness online', *Visual Communications*, vol. 11, no. 14, pp. 395 – 420, viewed 9<sup>th</sup> December, 2017, <http://journals.sagepub.com.ezproxy.lib.monash.edu.au/doi/abs/10.1177/1470357212453978>

Thorpe, R, Hawkes, G, Dune, T, Fileborn, B, Pitts, M & Minichiello, V 2017, 'Hidden boundaries and shared meanings: The roles of researcher characteristics and cultural norms in shaping understandings of sexuality in the unstructured interview setting', *International Journal of Social Research Methodology*, vol. 21, no. 2, pp. 205-217, viewed 20<sup>th</sup> June, 2018, doi:10.1080/13645579.2017.1350016

Treichler, P 1992, 'AIDS, HIV and the cultural construction of reality', in G.Herd & S Linderman (eds.), *The time of AIDS: Social analysis, theory and method*, pp. 65-98, Sage, Newbury Park, CA.

Vayreda, A & Antaki, C 2009, 'Social support and unsolicited advice in a bipolar disorder online forum', *Qualitative Health Research*, vol. 9, no. 7, pp. 931 – 42, viewed 24<sup>th</sup> October, 2017,  
<http://journals.sagepub.com.ezproxy.lib.monash.edu.au/doi/abs/10.1177/1049732309338952>

Ventura, P 2012, *Neoliberal Culture: Living with American Neoliberalism*, e-book Taylor and Francis, Abingdon, Oxon, viewed 21st February, 2018,  
<<http://ebookcentral.proquest.com/lib/monash/detail.action?docID=1002996>>.

Verkerk, M 1999, 'A care perspective on coercion and autonomy', *Bioethics*, vol. 13, no. 3-4, pp. 358-69, viewed 24<sup>th</sup> October, 2017,  
<http://onlinelibrary.wiley.com.ezproxy.lib.monash.edu.au/doi/10.1111/1467-8519.00163/full>

Wade, DT & Halligan, PW 2017, 'The biopsychosocial model of illness: a model whose time has come', *Clinical Rehabilitation*, vol. 31, no. 8, pp. 995 – 1004, viewed 7<sup>th</sup> March, 2018, <http://journals.sagepub.com.ezproxy.lib.monash.edu.au/doi/abs/10.1177/0269215517709890>

Wald, HS, Dube, CE & Anthony, DC 2007, 'Untangling the web - the impact of internet use on health care and the physician-patient relationship', *Patient Education and Counseling*, vol. 68, no. 3, pp. 218 – 24, viewed 24<sup>th</sup> October, 2017, <https://doi-org.ezproxy.lib.monash.edu.au/10.1016/j.pec.2007.05.016>

Weiner, T 2011, 'The (un)managed self: Paradoxical forms of agency in self-management of bipolar disorder', *Culture Medicine Psychiatry*, vol. 35, pp. 448 – 83, viewed 24<sup>th</sup> October, 2017, <https://search-proquest-com.ezproxy.lib.monash.edu.au/docview/901748035?OpenUrlRefId=info:xri/sid:primo&accountid=12528>

Weir, A 2009, 'Who are we? Modern identities between Taylor and Foucault', *Philosophy & social criticism*, vol. 35, no. 5, pp. 533-53, viewed 7<sup>th</sup> March, 2018, <https://doi-org.ezproxy.lib.monash.edu.au/10.1177%2F0191453709103426>

Whittemore, R, Chase, SK & Mandle, CL 2001, 'Validity in Qualitative research', *Qualitative Health Research*, vol. 11, no. 4, pp. 522 – 37, viewed 24<sup>th</sup> October, 2017, <http://journals.sagepub.com.ezproxy.lib.monash.edu.au/doi/abs/10.1177/10497320112911929>

Widemalm, M & Hjarthag, F 2015, 'The forum as a friend: Parental mental illness and communication to open internet forums', *Social Psychiatry Psychiatric Epidemiology*, vol. 50, no. 10, pp. 1601 – 1607, viewed 24<sup>th</sup> October, 2017, <https://search-proquest-com.ezproxy.lib.monash.edu.au/docview/1717972305?OpenUrlRefId=info:xri/sid:primo&accountid=12528>

Williams, S 2000, 'Reason, emotion and embodiment: is 'mental' health a contradiction in terms?', *Sociology of Health & Illness*, vol. 22, no. 5, pp. 559-81, viewed 24<sup>th</sup> October, 2017, <http://onlinelibrary.wiley.com.ezproxy.lib.monash.edu.au/doi/10.1111/1467-9566.00220/full>

Williams, SJ 2001, 'Sociological imperialism and the profession of medicine revisited: Where are we now?' *Sociology of Health & Illness*, vol. 23, no. 2, pp. 135-58, viewed 24<sup>th</sup> October, 2017, <http://onlinelibrary.wiley.com.ezproxy.lib.monash.edu.au/doi/10.1111/1467-9566.00245/full>

Wisdom, JP, Bruce, K, Saedi, GA, Weis, T & Green, CA 2008, 'Stealing me from myself: Identity and recovery in personal accounts of mental illness', *Australian and New Zealand Journal of Psychiatry*, vol. 42, no. 6, pp. 489-95, viewed 6<sup>th</sup> December, 2017, <http://journals.sagepub.com.ezproxy.lib.monash.edu.au/doi/abs/10.1080/00048670802050579#articleCitationDownloadContainer>

Wong, C, Harrison, C, Britt, H & Henderson, J 2014, 'Patient use of the internet for health information', *Australian Family Physician*, vol. 43, no. 12, pp. 875 – 77, viewed 25<sup>th</sup> February, 2018, <https://search-informit-com-au.ezproxy.lib.monash.edu.au/fullText;dn=796476172571963;res=IELHEA>

Yen, J-Y, Yen, C-F, Wu, H-Y, Huang, C-J & Ko, C-H 2011, 'Hostility in the real world and online: The effect of internet addiction, depression and online activity', *Cyberpsychology, Behaviour & Social Networking*, vol. 14, no. 11, pp. 649-55, viewed 24<sup>th</sup> October, 2017, [http://web.a.ebscohost.com.ezproxy.lib.monash.edu.au/ehost/detail/detail?vid=0&sid=11759327-17e5-4a3c-9780-](http://web.a.ebscohost.com.ezproxy.lib.monash.edu.au/ehost/detail/detail?vid=0&sid=11759327-17e5-4a3c-9780-6cda866cc89a%40sessionmgr4007&bdata=JnNpdGU9ZWwhvc3QtbGl2ZSZzY29wZT1zaXRl#AN=67482643&db=bth)

[6cda866cc89a%40sessionmgr4007&bdata=JnNpdGU9ZWwhvc3QtbGl2ZSZzY29wZT1zaXRl#AN=67482643&db=bth](http://web.a.ebscohost.com.ezproxy.lib.monash.edu.au/ehost/detail/detail?vid=0&sid=11759327-17e5-4a3c-9780-6cda866cc89a%40sessionmgr4007&bdata=JnNpdGU9ZWwhvc3QtbGl2ZSZzY29wZT1zaXRl#AN=67482643&db=bth)

Yen, L, Jowsey, T & McRae, IS 2013, 'Consultations with complementary and alternative medicine practitioners by older Australians: results from a national survey', *BMC Complementary and Alternative Medicine*, vol. 13, no. 1, p. 73, viewed 24<sup>th</sup> October, 2017, <https://doi.org/10.1186/1472-6882-13-73>

Žaja, N, Vukušić Rukavina, T, Brborović, O, Prošev, A & Perušić, D 2017, 'Reasons for using schizophrenia Internet forums in Croatia', *European Psychiatry*, vol. 41, p. S149, viewed 18<sup>th</sup> January, 2018, <https://www-sciencedirect-com.ezproxy.lib.monash.edu.au/science/article/pii/S0924933817320151?via%3Dihub>

Zermatten, A, Khazaal, Y, Coquard, O, Chatton, A & Bondolfi, G 2010, 'Quality of web-based information on depression', *Depression and Anxiety*, vol. 27, no. 9, pp. 852-58, viewed 24<sup>th</sup> October, 2017, <http://onlinelibrary.wiley.com.ezproxy.lib.monash.edu.au/doi/10.1002/da.20665/full>

Ziebland, S 2004, 'The importance of being expert: The quest for cancer information on the internet', *Social Science & Medicine*, vol. 59, no. 9, pp. 1783 – 93, viewed 24<sup>th</sup> October, 2017, <https://doi-org.ezproxy.lib.monash.edu.au/10.1016/j.socscimed.2004.02.019>

Ziebland, S & Wyke, S 2012, 'Health and illness in a connected world: How might sharing experiences on the internet affect people's health?' *Milbank Quarterly*, vol. 90, no. 2, pp. 219 – 49, doi: 10.1111/j.1468-0009.2012.00662.x.

Zurcher, B 1985, *Vincent Van Gogh, Art, Life and Letters*, Rizzoli, New York.