Diagnostic Identity and the Legitimisation of Mental Health Problems: An Ethnographic Study with a focus on Bipolar Disorder

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This work has not been submitted in substance for any other degree or award at this or any other university or place of learning, nor is being submitted concurrently in candidature for any degree or other award.

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Abstract

Psychiatric diagnosis has become a pervasive aspect of modern culture, exerting an increasing influence on forms of personhood, identity practices, and modes of self-governing. Debates surrounding the classification of psychiatric disorders are also prevalent, with particular disputes surrounding the relative merits of 'biomedical' vs 'psychosocial' understandings of mental health difficulties. There is arguably a need for further empirical exploration into the social and cultural implications of psychiatric classification and categorising practices within mental health service interactions. Drawing on ethnographic research conducted within several UK mental health settings, this thesis considers the role of diagnosis in constituting patient identities and in shaping professional categorisation practices, with a particular focus on bipolar disorder. Observations were conducted within sites where diagnostic identities are particularly salient: Psychiatric diagnostic and screening assessments, and a psychoeducation programme for bipolar disorder.

Focusing on the formal and informal categorisation practices of service users and professionals, this study highlights the way in which psychiatric classifications can be negotiated, ascribed, and withheld in order to legitimate and contest particular kinds of suffering; in particular, it explores the way in which diagnostic categories – in particular bipolar disorder - can be used to interpret and medicalise morally problematic forms of experience and behaviour. Whilst diagnosis itself can function to medicalise aspects of moral life, its ability to perform this function is also shown to depend upon its conceptualisation as a biomedical disease entity. Findings suggest that bipolar disorder gives rise to particularly somatic concepts of personhood; its conceptualisation as an essentialised and reified illness category, with its cause located within the brain, enables a legitimisation of psychiatric 'symptoms' for both patients and professionals.

In seeking access to more specialised mental health services with limited resources, potential patients can face trivialisation and deligitimisation of their problems by professionals, which at times manifests in the withholding of diagnosis. This is particularly the case within a mental health policy context which has increasingly moved towards the prioritisation of those with 'severe mental illness'. As such, the study shows how the legitimising function of diagnoses such as bipolar disorder, can lead to a tendency for it to be both sought after by patients, but contested by professionals and amongst patients. In light of the apparent advantages conferred by this diagnosis, the moral and personal consequences of diagnostic membership, exclusion, and uncertainty are considered; in particular, the potential for this essentialised category to create divides between those considered to 'have' the disorder and those who are not, is contemplated.

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Chapter 1: Research Context & Background

Introduction

Psychiatric diagnoses have become increasingly important in shaping modern notions of selfhood: they are now a pervasive aspect of modern Western civilisation, extending far beyond medical settings into everyday popular culture, with frequent media coverage in film and television storylines, and common celebrity disclosures regarding mental health (Brinkmann, 2017). In a parallel but related trend, significant resources have been dedicated to destigmatising these same diagnostic categories through various 'anti-stigma' campaigns, often fronted by said celebrities, and often endorsing particular stances regarding the nature of these categories, emphasising their similarity to so-called 'physical' illnesses and suggesting that they are 'real' biomedical entities (e.g. Malla, Joober & Garcia, 2015; Read, Haslam, Sayce & Davies, 2006). This 'illness like any other' approach to anti-stigma campaigning has been aggressively contested by groups who feel that mental ill health (or 'distress', as some groups prefer to label such difficulties), are not best viewed through the lens of diagnostic categories or disease models of illness, but are in fact more helpfully conceptualised as 'natural reactions' to traumatic or difficult life events (e.g. Cook; 2017; Johnstone & Boyle, 2017). There has been little sign of convergence between these disparate stances, producing a hostile turf-war between advocates of so-called 'biomedical' models of mental disorder and proponents of more trauma-based 'psychosocial' understandings.

Psychiatric diagnosis has historically undergone periods of rapid change, instability, and heated controversy (North & Suris, 2017). Over the past several decades, the foundations of psychiatric knowledge have undergone profound changes, influenced by developments within neuropsychology, pharmacology, and technological advances. This has led to a social preoccupation with the biological basis of personhood[1] (Andreasen, 2001; White, Rickards, & Zeman, 2012; Walter, 2013) -

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[1] i.e. a focus upon the biological mechanisms through which mental states and subjective experiences are produced.

which some would argue – has come at the expense of the more subjective, relational, and contextual factors which shape human behaviour and health. For proponents of this naturalistic stance, mental disorders are essentially biological diseases, similar in nature to cancer, epilepsy, or diabetes, and requiring a similarly medical approach to treatment. Such accounts can involve optimistic claims about the potential for neuroscientific and genetic knowledge to guide psychiatric understanding into a future where treatment, prevention, and cure become real possibilities, owing to the discovery of distinct neurochemical pathways to psychiatric illness (Andreasen, 2001; White et al., 2012). Opponents of this medical narrative range from prominent anti-psychiatric critiques led by figures such as Szasz (1972) and Laing (1964) in the 1960s and 1970s, and more recently from survivor movements, such as the 'Hearing Voices Network', and 'mad studies' activists.

These psychiatric accounts and theories of causality permeate everyday thinking (Read, Bentall & Sanders, 2010), with some speculating that the proliferation of neuroscientific knowledge has produced a shift in everyday conceptions of personhood and patienthood (Ortega, 2009; Rose, 2007; Vidal, 2009). Drawing upon the work of Foucault (1977), Nikolas Rose introduced the term 'psy-complex' (Rose 1979) to describe the collection of disciplines and practices surrounding psychology, psychiatry and psychotherapy, that have increasingly come to influence the everyday lives of ordinary individuals. Similarly, Goodley and Parker (2000, p.4) describe the 'psy-complex' as "*that dense network of theories and practices which make up the apparatus of psychology inside and outside colleges and clinics, including its power to define what people think about themselves and their own personal resources for change*". Given the importance of common-sense psychological understandings in guiding everyday behaviour, perception and social interaction, examining neuroscience's - and other psy-disciplines' - influence on common conceptions of personhood is arguably an important task (O'Connor & Joffe, 2013).

This thesis explores how diagnostic categories and the underlying assumptions which often appear to underpin such classifications shape notions of patienthood and forms of self-governance, particularly focusing upon the diagnosis of bipolar disorder. It sets out to understand the implications of psychiatric categorisation practices and

conceptualisations for patient identities and practices of self, focusing particularly on professional categorisation practices as they occur within everyday mental health settings. Taking an ethnographic approach, employing methods of observation and interviewing (formal and informal), this study focuses upon three different settings. The first two settings - community mental health teams and a psychiatric second opinion clinic - illustrate the process of diagnostic screening, and the way in which prospective patients attempt to negotiate access to more specialised treatment, and/or diagnoses. Thirdly, a subsequent stage of the diagnostic journey within a psychoeducation setting, explores how patients with a diagnosis of bipolar disorder, 'learn' about their diagnosis.

The following section will begin with a short history of psychiatric classification, focusing particularly on the development of the modern concept of bipolar disorder. This section will consider some of the political and social forces which merged to shape the way in which this category has come to be understood, with a particular focus upon the current classification's emphasis on polarity, and its privileging of mania as a symptom. Drawing particularly from the work of David Healy (2008; 2010) on the development of bipolar disorder as a concept, I highlight the significance of social and political context in determining the classification, definitions of and understandings regarding psychiatric disorders. This section will end by considering some of the current controversies regarding psychiatric diagnosis, and the place (or lack of place) of bipolar disorder within these debates.

Key Developments in the Classification of Bipolar and Affective Disorders

This section provides a brief account of some of the main developments in the history of psychiatric diagnosis and classification, with a focus on bipolar disorder. It will begin by providing some context on the emergence and implications of modern psychiatric classification systems, before moving on to consider some of the trends and controversies in the classification of affective disorders. Since much of this thesis centres around the diagnosis of bipolar affective disorder, I will focus particularly on the historical development of bipolar disorder as a diagnostic entity, outlining how it

came to take its current form within contemporary Western cultures. I will also consider the bifurcation of 'unipolar' and 'bipolar' depressions, and their relative positioning in relation to the neurotic/psychotic divide.

This section is not intended to provide a comprehensive history of bipolar disorder, a task already attempted by David Healy (2010); instead, by providing an account of some of the important developments in the history of bipolar disorder as a clinical concept, I attempt to make explicit the social, political and historical forces which have shaped current popular and scientific conceptualisations of this diagnostic category. Rather than viewing this simply as a process of scientific progress and discovery over time, whereby scientific research has led to further refinements to knowledge regarding distinct disorders, the remainder of the chapter aims to illustrate the way in which "regimes of truth" (Rose, 1996, p. 110-111) regarding psychiatry have come to be constructed by social and conceptual authorities.

The development of modern psychiatric classification

The development of classificatory systems within mental health has often been attributed to Emil Kraepelin (1899), whose work has formed the basis for current psychiatric nosologies. Kraepelin sought to devise a system of psychiatric diagnosis that would form an organizing framework for research, suggesting a symptomological approach to the classification of mental disorders as discrete entities. This system took the assumption that patients suffering from the same disorder should have the same symptoms, indicating common brain abnormalities and aetiological processes. Grouping together patients with similar symptom patterns would thus allow the development of a classification system that would support the discovery of the biological origins of mental illness; these disorders were therefore considered to be natural ontological entities waiting to be named. In addition to the desire to develop more scientific understandings of the true nature of psychiatric disorders, the drive to develop a systematic psychiatric nomenclature was arguably also motivated by administrative and governmental needs to quantify, manage, and treat those with mental disorder (Grob, 1991; Kirk & Kutchins, 1992; see also Foucault, 1967).

The scientific basis of psychiatric diagnosis was however problematised by the anti-psychiatry movement of the 1960s, influenced by figures such as Szasz (1972), Goffman (1961), and Laing (1964), who strongly critiqued psychiatric constructs on the basis of their validity and reliability, as well as their potential for causing social harm. Such attacks provoked defensive reactions from within psychiatry, motivating a reinforcement of diagnosis within the profession, exemplified in the revisions of DSM-III (Diagnostic and Statistical Manual of Mental Disorders, 3rd Edition)[2], which were partly aimed at persuading outsiders of its legitimacy (Pilgrim, 2007). According to Pilgrim, the DSM became "a revisable political manifesto for the psychiatric profession, as well as a scientific document" (2007, p. 538). Similarly, Wilson (1993) suggests that the DSM-III revision was a 're-medicalisation strategy', represented by the movement away from aetiological assumptions (which in DSM-I and DSM-II had been largely psychodynamic), towards scientific descriptions based on groups of symptoms, whilst still retaining categories (see Kirk & Kutchins, 1992, for review).

These allegations regarding the unscientific nature of psychiatry were also troubling because the profession faced competition from nonmedical professionals, such as clinical psychologists, counsellors, and psychiatric social workers, who seemed equally as able to treat the problems emphasised by the psychodynamic paradigm. Pilgrim (2007) argues that in order to establish a valid medical identity for psychiatry, it was necessary to create a diagnostic system based on discrete disease entities like those found in other medical specialties. This system would both establish psychiatry's primary dominion over the care and treatment of a well-defined and reliably measured group of medical conditions, whilst protecting it from challenges by other professions (Pilgrim, 2007).

While DSM-III seemingly moved away from aetiological underpinnings, today's classification still arguably retain assumptions regarding causality (see Castiglioni & Laudisa, 2014, for discussion). It has also been suggested that in constructing DSM-III (largely written by biological psychiatrists), that biological psychiatry would benefit

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[2] The Diagnostic and Statistical Manual of Mental Disorders is the primary diagnostic classification system within psychiatry, published by the American Psychiatric Association. It is currently on its fifth edition (2013).

from a labelling system which excluded the possibility of any non-biological causes; by getting rid of distinctions such as endogenous and exogenous depression, for instance, they were removing the implication that there could be any depression that *did not* have a biological origin (McPherson & Armstrong, 2006). Additionally, in retaining its commitment to a categorical (rather than a dimensional) approach, the DSM arguably implies the presence of unique aetiological factors for specific diagnostic categories.

The splitting of 'unipolar' and 'bipolar' depressions

According to those who have tracked the historical development of the bipolar diagnosis, the concept of a mental disease that combined the two states of mania and melancholia into one entity would have been unrecognisable prior to the nineteenth century (Berrios, 1988, 2004; Del Porto, 2004; Healy, 2008; 2010). The component parts of this construct – mania and melancholia – have both evolved considerably in recent history. For instance, during the early twentieth century, those with suicidal tendencies, senility, or symptoms of schizophrenia (any state of overactive insanity) were all labelled with mania (Healy, 2008). Mania had been used to describe uncontrollable rage, excitement, and seemingly unintelligible behaviour up until the eighteenth century (Berrios, 2004), whilst current conceptualisations emphasise the affective aspect of mania. Melancholia also underwent significant changes according to historical accounts, becoming increasingly 'psychologised', and eventually replaced by the (more scientific) term 'depression', in the nineteenth century (Peeters, 1996). Melancholia also acquired moral connotations (Berrios, 1988), incompatible with attempts to establish the scientific status of psychiatry by emphasising the physiological nature of madness (Peeters, 1996), and arguably relegating melancholia to a lesser and more socially understandable form of disorder.

The First and Second World Wars precipitated a shift in the focus and practice of psychiatry from a medical to a more psychodynamic orientation. In part, this was due to the emergence of trauma induced psychopathology, which led to a focus upon previously well individuals, who were experiencing psychiatric symptoms following

traumatic war related events (e.g. 'shell shock'). This allegedly led to an expansion of psychiatric concerns to the more minor psychopathologies of everyday life, and a growth in concerns with mental health more generally (Kirk & Kutchins, 1992). This expansion has been a continuing trend, with a significant increase in the number of disorders categorised by the manual, from the original DSM (APA, 1952), to the current version (DSM-5, APA, 2013).

Horwitz (2011) has shown how the DSM-III diagnostic criteria transformed depression - a condition that was thought to be fairly rare, and associated with psychosis and 'severe mental illness' - into one that was extremely common, with estimates that depression affects as much as 20% of the population (Kessler et al., 2005); depression thus became conflated with the category of common psychiatric disorders. Depression has also come to be particularly strongly aligned with anxiety, cementing its conception as a neurotic disorder. Shorter and Tyrer (2003), for instance, have suggested reunifying the separate categories of anxiety and depression, reclassifying them as "nervousness" (p.158). Depression (and particularly dysthymia[3], e.g. see McPherson & Armstrong, 2006) has also been associated with personality disorder, with suggestions that neurotic depression might be better understood as a temperament or personality type, rather than a disease (e.g. Eysenck, 1970).

Having been more amenable to connection with everyday life and its difficulties, unipolar depression has tended to be distinguished from 'madness', although it has also been distinguished (by lay people and medical professionals) from mere sadness (Rogers & Pilgrim, 1997). The version of depression that was originally linked with madness and insanity (and encompassed within Kraepelin's 'manic-depressive disease' concept), became translated into manic depression and then bipolar disorder; meanwhile, the unipolar depression concept grew from the incidence of shell shock following the First World War, believed to be reactions to stress and loss (Leonhard, 1959; Stone, 1985).

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[3] Dysthymia – recently renamed as Persistent Depressive Disorder – describes a chronic form of depression or low mood, lasting for two years or more (DSM 5, 2013).

Pilgrim (2007) suggests that the emergence of these two distinct concepts also encouraged a division between endogenous depression (a biologically driven form of depression, linked to madness), and exogenous/ reactive depression (reactions to life events); thus, unipolar depression has straddled two competing concepts. Conceptualisations of depression have been inconsistent, and subject to debate and controversy, with some arguing for a 'unimodal' distribution of depressive cases (Kendell, 1968), and others for a bimodal distribution model which distinguished between endogenous and exogenous depression (Parker, 2000). The removal of the 'bereavement exclusion clause' from DSM-V has been the focus of particular criticism (e.g. see Frances, 2013; Wakefield & First, 2012), since those suffering from bereavement would be classed - and potentially treated - in the same way as an individual suffering with chronic or recurring depression. This endogenous-reactive distinction, although largely rejected by contemporary psychiatry, has retained some of its meaning and status both as a Western common-sense belief (Castiglioni & Laudisa, 2014; Shorter, 2009), and in medical practise, with sub-types such as endogenous depression remaining in use clinically, for many years after being discarded by the DSM (McPherson & Armstrong, 2006).

As with other mental disorders, biological and medicalised explanations for depression have also proliferated. According to Pilgrim (2007), the rise of anti-depressant treatments has been interpreted as supposed proof of the biological aetiology of serotonin deficiency (e.g. Zoloft, 2002)[4]. Drug companies have helped to maintain the legitimacy of depression as a diagnosis (Koerner, 2002), with several depression campaigns having been sponsored by drug companies. In recent years, there has also been a shift towards viewing depression as an inflammatory disease (Raison & Miller, 2011), with suggestions that anti-inflammatory medications may provide a future role in treating depression (Feltes et al., 2017). Nevertheless, unipolar depression has arguably remained closely aligned with the everyday, the neurotic, and the psychological.

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[4] Although the placebo effect of such drugs has undermined this argument somewhat (Pilgrim, 2007).

Unlike its unipolar counterpart, bipolar disorder came to be more closely aligned with psychotic disorders; within DSM 5, bipolar and related disorders are given a chapter on their own, between depressive disorders and schizophrenia spectrum disorders, "in recognition of their place as a bridge between the two diagnostic classes in terms of symptomatology, family history, and genetics" (APA, 2013, p.123)[5]. Similar to schizophrenia, it has retained the status of a 'serious mental disorder' (e.g. Angst, 2007)[6]. The following section will trace the development of bipolar disorder, specifying the context in which it came to be separated from its unipolar relation, achieving its status as a chronic and severe disorder, whilst simultaneously becoming increasingly broadened, and difficult to separate from normal variations in mood.

The emergence of bipolar disorder as a distinct entity

A detailed historical account of the concept of bipolar disorder has been outlined by David Healy (2008; 2010), who traces the progression of the concept of manic-depression, to its modern-day counterpart, bipolar disorder. In 1899, Emil Kraepelin distinguished between two disease entities, – dementia praecox and manic-depressive insanity (Kraepelin, 1899). Manic-depressive illness emerged in contrast to dementia praecox, which was described as a disorder of cognitive function where the sufferer never returns to normal. By contrast, Kraepelin's version of manic-depressive illness was a disorder where sufferers recovered from acute episodes but were at risk of a relapse. Kraepelin did not view bipolar fluctuations between excitement and stupor as a classificatory principle, since a similar alternation happened in many states of dementia praecox or general paralysis of the insane. Periodic, circular and simple manias, in addition to melancholic disorders, however, could all be regarded as manifestations of the one illness if they were remitting in nature. Kraepelin proposed that manic-depressive insanity included a manifestation of the disease that displayed

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[5] In the DSM-IV-TR, bipolar disorder had remained under the wider Mood Disorders category.
[6] For instance, the UK mental health charity – Hafal – provide services for those with 'serious mental illness', which includes "schizophrenia, bipolar disorder and other diagnoses which typically involve psychosis or high levels of care, and which may require hospital treatment" (http://www.hafal.org/about, retrieved, 19/12/2017).

recurrent and severe depressive episodes,[7] and a rarer form that alternated between depression and mania (Healy, 2010). Kraepelin was also the first to formulate depression as a discrete disease entity (Georgotas & Cancro, 1988), and Healy (2010) suggests that the success of Kraepelin's manic-depression concept may have derived largely from the fact that depression as a term had gained popularity at the time, replacing the previously dominant melancholia.

The current notion of the bipolar disease entity first took shape in the 1850s with descriptions of an alternating mania and melancholia, such as those proposed by Esquirol in 1854, the 'insanity of double-form' by Baillarger (1854), and 'circular insanity' by Falret (1854), two of Esquirol's pupils. These conceptions of the condition were however different to current conceptions of bipolar disorder, since they were conceived of not as mood disorders, but as degenerative psychotic disorders, with regular and stable features (Healy, 2008). According to Healy (2010), the first approach to modern bipolar disorder came from Karl Kahlbaum, who in 1882 described cyclothymia as a specific mood disorder from which patients could recover.

The distinction between unipolar and bipolar depression has largely been attributed to the discovery of supposed mood stabilising drugs (such as Lithium), which not only seemed to help treat mania, but also seemed to treat depressive symptoms. In 1957, shortly after lithium was discovered as a successful treatment for mania in 1954, Karl Leonhard distinguished between affective disorder on the basis of polarity, separating pure depression/melancholia from manic-depressive illness; a distinction which was then picked up by other researchers and clinicians (Healy, 2010). The apparent success of lithium in treating manic depression, and in its apparent effect as a mood stabiliser (effective for both depression and mania), seemed to affirm the concept of the manic-depressive construct, whilst also influencing its classification as an affective rather than a psychotic disorder. These shifts towards the concept of bipolar disorder led to its emergence in the mid-1960s and its incorporation within the DSM-III in 1980.

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[7] Interestingly, recent research has again suggested that recurrent forms of unipolar depression may bear closer resemblance to bipolar disorder than to other forms of unipolar depression (e.g. Smith & Craddock, 2011)

The growth of the bipolar concept was also influenced by the research-led drive to distinguish between subtypes of illness, in order to discover markers (by reducing the heterogeneity of samples), which led to an emphasis upon different categories of affective disorder, e.g. psychotic and neurotic depression, endogenous and reactive, unipolar and bipolar, etc. In renaming manic-depressive disorder as *bipolar disorder*, the DSM-III also distinguished between bipolar disorders and major depressive disorders (Gruenberg, Goldstein & Pincus, 2005). This involved a reconceptualisation, since polarity was positioned as the defining feature of bipolar disorder; unlike previous conceptions of manic-depressive disorder, it was insufficient to have recurrent episodes of severe depression to obtain a diagnosis, but necessary to have also experienced at least one episode of mania in addition (although for the purposes of diagnosis, it was (and remains) possible to meet the criteria for diagnosis of bipolar type I, having only experienced symptoms of mania, arguably making mania the dominant pole of bipolar disorder[8]). This emphasis on polarity still dominates in current times, and is used to structure diagnostic research and services accordingly, e.g. services such as bipolarUK and the BPC programme.

In the 1980s and 90s, the term manic-depression was still more widely used (for instance, Goodwin and Jamison's famous text published in 1990 was titled *Manic-Depressive Illness* (Goodwin & Jamison, 1990). With the introduction of Depakote in 1995 – licensed for the treatment of mania, but marketed as a 'mood-stabiliser' (a term not commonly used prior to 1995), the terms 'bipolar disorder' and 'mood stabiliser' both grew in prominence, and proliferated in research circles and publications (Healy, 2010). Healy (2010) argues that although bipolar disorder may constitute a distinct clinical type, there is insufficient evidence to validate its status as a distinct disease entity; he suggests instead that bipolar disorder became more a brand than a scientifically valid concept, since the replacement of manic depression by bipolar disorder was based more upon marketing than clinical research.

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[8] It has been posited that mania – as opposed to mood 'swings', should be considered the true distinguishing feature of bipolar disorder, and that the disorder should be primarily approached as a manic disorder with a range of co-morbid conditions such as depression (e.g., Joffe, Young, & MacQueen, 1999; Schweitzer et al., 2005).

A part of this marketing strategy was also in convincing primary care clinicians (who would generally be treating more 'common' mental disorders, rather than those people hospitalised with bipolar or schizophrenia), to be able to 'recognise' bipolar symptomatology within patients traditionally thought of as anxious or depressed. Bipolar disorder thus became reconceptualised as something that was being under-detected in particular groups of patients, who were displaying non-traditional symptom patterns (e.g. those with hypomania rather than mania, cyclothymia etc.) (Healy, 2010). Indeed, Healy argues that the current conceptions of bipolar disorder (and their historic counterparts, circular insanity or insanity of double-form) were not used in many asylums prior to 1900 because too few patients were involved, and that the viability of the modern concept of a bipolar affective disorder has depended upon the diagnosis of hypomanic or cyclothymic states (i.e. less extreme states) in the community (Healy, 2008). A revision to DSM-III-R (APA, 1987), expanded the bipolar concept by separating bipolar subtypes I and II, where type II involves less extreme episodes of 'hypomania' in conjunction with depressive episodes, as opposed to mania (type I). Further widening of the concept led to the addition of cyclothymia, to the addition of a rapid cycling variant in DSM-IV (APA, 1994), and bipolar type III (drug induced mania); there have been suggestions of up to seven subtypes (e.g. Klerman, 1981), with one subtype even representing those with recurrent depression and a family history of bipolar disorder (type V).

In the current diagnostic manual - DSM-5 - in addition to bipolar I, II, and cyclothymia (present in DSM-IV), there are now separate diagnostic criteria for "manic-like phenomena" associated with the use of substances (either illegal or prescribed), or with medical conditions. In order to encourage further study (a stated aim of DSM-5), bipolar-like phenomena that do not fulfill the diagnostic criteria for bipolar I disorder, bipolar II disorder or cyclothymic disorder[9], are summarized under the label 'other specified bipolar and related disorders' (APA, 2013). This last category arguably further widens the bipolar category, since criteria for major depressive, manic, or

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[9] i.e. short-duration hypomanic episodes and major depressive episodes, hypomanic episodes and major depressive episodes with insufficient symptoms, hypomanic episodes without prior major depressive episode, and short-duration cyclothymia.

hypomanic episodes do not need to be met to obtain a diagnosis. This also arguably provides clinicians with considerable discretion in granting a diagnosis.

The apparent difficulties in differentiating between unipolar and bipolar mood disorders, (particularly with regards to bipolar type II), led to the concept of a spectrum of affective disorders, which incorporated different categories involving some element of mood disruption, such as cyclothymia, dysthymia, and also borderline and narcissistic personality disorder (Akiskal, 1983). The idea of a hierarchical spectrum, was also emphasised by stress-vulnerability models of illness, which suggested that mania constituted a more severe form of mood disorder, involving individuals who require lower levels of stress to trigger illness (Tsuang, Farrone, & Fleming, 1985). Notions of the bipolar spectrum are still prevalent, and often include psychotic disorders such as schizophrenia (e.g. Craddock & Owen, 2005), and personality disorders (especially borderline personality disorder), although the latter suggestion remains debated and controversial (e.g. Angst, 2007).

Current controversies surrounding psychiatric diagnosis

The publication of DSM's fifth edition in 2013 has been surrounded by strong debate and controversy, both within the scientific community and in the media (Angell, 2011; Spitzer, 2011; Frances, 2013; Wakefield, 2010; 2016). Simultaneously, there has been a resurgence of anti-psychiatry movements, influenced by user-led groups such as the 'Hearing Voices Network', who reject psychiatric labels and dominance, but also by clinical psychology, who have adopted alternate models and theories regarding the diagnosis and treatment of psychiatric conditions (Tyrer, 2013). For instance, the recent re-publication of the British Psychological Society's (BPS) guide to 'Understanding Psychosis and Schizophrenia' (Cook, 2017), and the BPS 'Power/Threat/Meaning framework' (Johnstone & Boyle, 2018), both advocate non-diagnostic frameworks for understanding mental distress and unusual states. These publications have met with resistance from psychiatry (particularly regarding the

scientific quality of cited research)[10] (e.g. The Lancet Psychiatry, 2017), and from psychiatric survivor groups (e.g. 'Recovery in the Bin'[11]), fuelling the ongoing dispute amongst professionals and politicised groups of patients.

These publications have explicitly criticised diagnosis, suggesting the need for a paradigm shift away from the 'disease' model, and recommending psychological 'collaborative formulation' as an alternative to diagnosis in clinical practise. They question the ontological 'reality' of mental illness (i.e. whether it exists in a concrete way), criticising their lack of diagnostic biomarkers, reliability, validity and utility, and the continuum between normal and psychotic experiences[12]. In addition to criticising diagnosis, these publications have also questioned the usefulness and the dominance of biomedical understandings of mental distress. The BPS (Cook, 2017) is critical of the focus on genetic and biological focus of causality (and its lack of evidence base), advocating a move towards an understanding of life events, and people's interpretations of those. They criticise pharmaceutical companies' tendencies to promote the brain disease/chemical imbalance model of schizophrenia (and other mental illnesses), arguing that evidence does not support the 'brain disease model' of psychotic experiences.   Those positioned on this side of the debate tend to frame psychiatric diagnosis and medicalised models of psychiatric illness as stigmatising, inflicting a pessimistic and individualistic view of pathology onto individual sufferers.

Often, these disputes surrounding diagnosis have centred around critiques regarding the validity of the schizophrenia construct and aetiology (e.g. Bentall, 2004; Moncrieff, 2009; Murray, 2017; Van Os, 2016; Timimi, 2014; see also Pilgrim, 2007); the concept of ADHD has also been the focus of considerable criticism (Visser & Jehan, 2009; Timimi, 2014), and there have been major concerns regarding the removal of the bereavement exclusion from major depressive disorder (Wakefield, 2016). In contrast,

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[10] https://www.nationalelfservice.net/publication-types/report/understanding-psychosis-and-schizophrenia-a-critique-by-laws-langford-and-huda/
[11] https://recoveryinthebin.org/2018/01/16/power-threat-meaning-threat-power-power-power-review-by-scheherazade/
[12] The continuum-based approach also links to the NIMH 'Research Domain Criteria' (RDoC) approach to classifying problems for research purposes; it attempts to measure symptoms, signs and risk factors which are continuous.

bipolar disorder has been much less visible in these debates[13], with schizophrenia remaining the central object of anti-psychiatric critique.

Conclusion

By highlighting some of the key historical forces shaping current classifications of bipolar and mood disorders, this chapter illustrates how understandings of mental illness relate intimately to social and political contexts, such as the influences of the pharmaceutical industry, professional rivalries within mental health, and shifts towards community care. This historical positioning of the bipolar concept draws attention to the social and political construction of medical categories, illustrating how the 'carving of nature at the joints' (Khalidi, 1993), is not solely the product of scientific progress. Many different ways of understanding and categorising mood disorders (and of positioning its constituent parts, mania and depression, within this wider category) have been proposed in recent history, and those emerging as the most influential are not necessarily successful because of research alone. As this chapter has outlined, Kraepelin's original manic-depressive disease was inclusive of recurrent unipolar forms of depression, and current understandings which separate unipolar and bipolar depressions appear to have emerged at least partly as a result of marketing strategies (Healy, 2010). Similarly, the dominance of categorical (as opposed to dimensional) models of mental disorder may also be influenced by pharmaceutical interests (Shorter & Tyrer, 2003). The establishing of diagnostic criteria and boundaries has important consequences: definitions emphasising polarity still tend to dominate current thinking regarding bipolar disorder, and are used to structure diagnostic research and services. This is important within the current study, since two of the research organisations and settings – BipolarUK and the BPC programme, are informed by this specific understanding of the diagnosis.

This chapter also outlines how unipolar depression has tended to be conflated with the everyday and the neurotic, while manic depression and bipolar disorder have

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[13] Although there have been concerns expressed regarding the increasing diagnosis of paediatric bipolar   disorders in the US (e.g. Moreno et al., 2007; Parens, & Johnston, 2010).

remained associated with severe endogenous mental illness, and (to some extent) psychosis. Simultaneously, however, the category of bipolar disorder has also widened, with notions of bipolar spectrums incorporating varying levels and classes of mood, psychotic and personality disorders. As such, there are some apparent contradictions in current ways of thinking about this diagnosis: on the one hand, bipolar disorder has been conceptualised as a discrete disease entity; on the other hand, the category has been widened to the extent that it is difficult to clearly distinguish between bipolar and other disorders (and between bipolar and normal mood variation). Subsequent chapters will explore some of the difficulties associated with this contradiction, by examining both the processes of diagnostic decision making, and the identity practices surrounding diagnostic categories, i.e. how those with (or without) a diagnosis negotiate their diagnostic identities. In light of the historical and contextual specificity of psychiatric classification, I argue that - while medical conceptualisations tend to emphasise diagnostic categories as underlying, disease entities waiting to be identified - psychiatric categories, such as bipolar disorder, can usefully be viewed as resulting from complex networks of practices and interactions. Such practices include diagnostic encounters and interactions, where descriptions and narratives regarding the self are interpreted, constructed, and made locally relevant (Garfinkel, 1967).

Thesis Outline & Structure

Following on from this historical account of psychiatric diagnosis and bipolar disorder, chapter 2 provides an overview of theoretical and empirical work surrounding identity and psychiatric diagnosis. I begin by positioning the thesis within a growing field within the social sciences, which concerns the sociology of diagnosis. Some key concepts are introduced, such as medicalisation, the 'sick role' (Parsons, 1951), Hacking's 'looping effect in human kinds' (1995), and Brinkmann's notion of 'diagnostic cultures' (2016). After considering the notion of contested illnesses, and the importance of aetiological factors in establishing illness legitimacy, I move on to trace the importance of

neuroscientific knowledge on current conceptions of selfhood. This includes a review of empirical literature on the relationship between causal explanations for mental disorder and stigma, which concludes by highlighting some of the gaps in this body of literature, which has tended to be quantitative, with little research in relation to bipolar disorder specifically. This points to the need for an ethnographic and context-specific approach to studying the social and personal impacts of neurobiological information on psychiatric disorders.

Chapter 3 outlines the conduct of the research itself. Ethnography – as a methodological approach - is explained and justified, followed by a description of the preparatory work involved in planning clinical fieldwork, such as obtaining ethical approval from an NHS Research Ethics Committee (REC), initiating contact with gatekeepers and establishing access to research sites. A description of the research sites is provided, in addition to a reflection upon the fieldwork process, and its difficulties and successes. Lastly, an outline of the process of analysis is given, which explains how particular themes were developed from the data.

Chapters 4, 5, and 6 outline the main empirical findings which emerged from analysis of the fieldwork data. Firstly, chapter 4 will focus mainly upon the observations of 'diagnostic' interactions, highlighting the tendencies of patients to actively seek out a diagnosis, in the attempt to upgrade their status within the system, and the opposing tendency of professionals to both downgrade the severity of patient's difficulties, at times manifesting in a tendency to withhold diagnosis. Chapters 5 and 6 both focus upon interview data and the observational material from the bipolar psychoeducation courses. Firstly, chapter 5 depicts the tendency for participants to emphasise the neuro-biological nature of bipolar disorder, through the privileging of explanations involving genetics, neurotransmitters, and chemical imbalances. This way of understanding the disorder is also shown to have consequences for the types of self-management which participants engage in, with a similar emphasis on somatic forms of intervention, and a resistance towards psychological (particularly cognitive) therapies.

Continuing from chapter 5, chapter 6 suggests the way in which bipolar disorder comes to fulfil an important role in participants understandings of themselves and

their behaviour, providing individuals with an important explanatory narrative for their own conduct, and providing a sense of group belonging and identity. This tendency to positively relate to the bipolar category in order to promote social cohesion and positive self-understandings is described as a form of strategic essentialism. While this form of essentialism might be useful for many, it is also associated with tendencies towards diagnostic possessiveness, whereby individuals undermine the diagnostic claims of others. Finally, chapter 7 brings together and further discusses the findings from the three empirical chapters, both in relation to current controversies within psychiatry, and in relation to relevant literature.

Chapter 2: Psychiatric Diagnosis and its Explanatory Function

This chapter begins by situating the thesis within the sociological study of diagnosis, considering some of the influential theories regarding the role of diagnosis within social life, and introducing key concepts that are central to the thesis, such as Parson's 'sick role' (1951), Hacking's 'looping effects' (1995), Rose's 'neurochemical self' (2007), and Brinkmann's more recent work on the subject of 'diagnostic cultures' (2016; 2017). The thesis will consider the infusion of psychiatric diagnosis into everyday language and common-sense notions of the self, partly as a product of its ability to explain and legitimise illness and to offset moral blame.

The ability of diagnosis to perform this explanatory function appears to vary; however, I suggest in this chapter that this may partly be a result of the aetiological conceptions underlying particular diagnoses, with those considered as psychological or psychosomatic deemed to be less valid than those of biological origin. As such, the understandings and conceptions of disorder, distress, and deviance which underlie these diagnostic terms will also be a central focus of this work. These conceptions have arisen within particular cultural and historical contexts; for instance, with the expansion of neuroscientific knowledge regarding the brain and other developments, some have claimed that our self-understandings have become increasingly somatic. The second part of this chapter will proceed to explore the relationship between stigma and the explanatory frameworks for mental disorder, outlining some of the key empirical findings on this topic. A review of empirical literature on the relationship between stigma and causal explanations for mental disorder suggests that much of this body of work has been quantitative, often focusing on the effects of 'biomedical' or 'psychosocial' models on public attitudes to mental illness. I argue that there is a need for a more qualitative ethnographic approach to this topic, which can account for the complex and contradictory ways in which people utilise different explanatory discourses for particular purposes, and in context specific ways.

The Sociology of Diagnosis

This thesis situates itself within the expanding field of the sociology of diagnosis, which aims to study the potential impacts of medical diagnoses on sociocultural life (Jutel, 2009; Jutel & Nettleton, 2011). This field is primarily concerned with studying how diagnoses are formulated and function in order to make an individual's symptoms comprehensible, how patient identities are formed around diagnoses, and how patient groups operate and campaign for rights and recognition (Jutel, 2009). There is also a concern regarding the place of diagnosis in the institution of medicine, the social framing of disease definitions, and the means by which diagnosis confers authority to medicine or how this authority comes to be undermined (Jutel, 2009). The current work approaches the sociology of psychiatric diagnosis with these questions in mind, considering how mental health diagnoses can engender particular forms of personhood and modes of self-governing, with a particular focus on the diagnosis of bipolar disorder and its implications for patient identities and practices.

As Jutel (2009) argues, diagnosis is integral to the system of medicine and its creation of social order. Through categorisation practices, diagnosis organises illness, identifies treatment options, predicts outcomes, and provides explanatory frameworks. According to Zola (1972), diagnosis enables the process of medicalisation; it serves wider social and administrative purposes by enabling access to services and status, from insurance reimbursement to restricted-access medication, sick leave and support group membership. A diagnosis can also serve a validating role, providing individuals with permission to be ill, through the process of reinterpreting something previously treated as a complaint as a disease; in his theory of the 'sick role', Talcott Parsons (1951) suggests that this can result in a claim for exemption, whereby various forms of social deviance (e.g., non-participation in work or other responsibilities) are vindicated, releasing individuals from their usual obligations, and freeing them from moral responsibility. The categorising and dividing process involved in diagnosis is consequently one which can involve the valorisation of some bodily states and the discounting of others (Bowker & Star, 1999). As such, diagnosis performs an important moral function within contemporary social life, determining who may be held morally accountable for their behaviour and who is exempt from responsibility.

Diagnosis also functions to delineate what is culturally considered as normal, and what should be considered abnormal and treated medically (Jutel, 2009). This tendency has been particularly apparent in the case of psychiatric diagnosis, exemplified by the now infamous cases of homosexuality and drapetomania (the tendency of slaves to abscond), which were previously diagnosable as diseases (Mendelson, 2003; Cartwright, 1981). Normative social assumptions regarding what is considered to be problematic are also central to the emergence and demise of diagnostic categories, as identified in Chapter 1; in regard to psychiatric diagnoses, Kirk and Kutchins (1992) exposed how political and social forces have shaped modern psychiatric taxonomies, citing the inclusion and subsequent removal of homosexuality from the Diagnostic and Statistical Manual of Mental Disorders (DSM), following strong objections from gay activists during the preparation of the DSM-III.

Several scholars have commented on the processes through which specific diagnostic categories have emerged at particular moments in history, arising from political action, cultural context, and technological advances (e.g. Brown, 1995; Hacking, 2001; Jutel, 2009; Scott, 1990). Social activism has also played a key role in both the emergence and removal of disease labels. As diagnosis is a relational process where different groups confront illness with differing explanations, understandings, values and beliefs, this renders it an important area of contest and compromise. A misfit between patient and professional explanatory frameworks has the potential to incite a collective politicisation of illness, with social movements and disease advocacy groups battling for recognition, funding and other forms of support (Brown & Zavestoski, 2004). Scott's (1990) account of the inclusion of Post-Traumatic Stress Disorder (PTSD) within the DSM-III provides a detailed description of the individual and collective work involved in securing acknowledgement that the psychological distress suffered by Vietnam veterans was qualitatively different from either psychotic illness or behavioural manifestations of cowardice and malingering (Scott, 1990). Although the effort involved in establishing PTSD as a verified diagnosis was arguably a political and social one, Scott suggests that the 'discovery' of PTSD illustrates the manner in which diagnosis tends to establish conditions as "always-already-there objects in the world…. a discovery of what was present but previously unseen" (Scott,

1990, p.295), through the presentation of ostensibly objective evidence. Similarly, Hacking comments on the tendency to search for "the right classification, the classification that is true to nature, a fixed target if only we can get there" (Hacking, 2001, p.11). As such, the assignment of illness labels can have the effect of reifying and naturalising a category, thus disguising its social and political nature.

Negotiating Diagnosis

Hence, in addition to decreasing isolation for sufferers, the collective identities formed around a particular diagnosis have the political potential to shape and challenge professional authority, policy priorities and social identity through the formation of 'embodied health movements' (Brown & Zavestoski, 2004). As the above example of PTSD suggests, the meaning of diagnosis is to a certain extent politically negotiated by various groups with a stake in medicalising a condition; while larger organisations such as pharmaceutical companies and advocacy associations may play an obvious role in such processes, this also includes individual patients with contested diagnoses who have an interest in obtaining sick leave or disability benefits, and who require a narrative to define their suffering (Anspach, 2011).

In addition to this social and political negotiation of diagnosis, there is also frequently an element of negotiation at the individual and micro-level. Psychiatric diagnoses in particular are subject to individual negotiation, since they are currently largely based upon patient (and family) narratives, as opposed to observable signs (Healy, 2008). With the democratisation of medical knowledge, patients have often come to possess a "hybrid diagnostic repertoire" (Anspach, 2011), which consists of an assortment of medical information – often from online sources: a medical narrative, including history, diagnosis and prognosis; an understanding of how the disease has affected their lives and relationships; and ideas about doctors and the health system. These 'diagnostic repertoires' will inevitably shape diagnostic encounters. While the medical encounter has often been viewed as a site of medical dominance, whereby professionals exert their power by defining a patient's illness and determining the framework of meaning applied to the patient (e.g. Freidson, 1970), some have

suggested that this power-dynamic may be shifting due to wider access to health information (particularly from the Internet), which has increasingly empowered patients to challenge their doctor, dispute findings, or seek advice outside the doctor-patient relationship (Lupton, 1997).

One manifestation of this trend has been the tendency for service users to actively seek and negotiate their own diagnoses within clinical encounters, or to claim diagnostic membership in the absence of official diagnosis (e.g., Singh, 2011). This may be partly because achieving a medical diagnosis or gaining access to the healthcare system can function to authenticate suffering. As Parsons (1951) argued, reconceptualising human problems as medical entities through the lens of diagnosis can promote more humane and flexible treatment, resisting the framing of difficulties as 'human' as opposed to 'medical'. In confirmation of this, research has found that the denial of diagnosis can equate to the denial of the sick role and its related access to services, status and resources, leaving individuals open to accusations of malingering (Clarke & James, 2003; Jackson, 2000; Lillrank, 2003; Ware & Kleinman, 1992). In contrast, when a patient's condition is perceived as medical, this can facilitate access to previously unauthorised privileges, such as the access to priority parking, permission to be absent from work or to receive reasonable adjustments within working environments, reimbursement for treatment or access to services (Jutel, 2009).

Diagnostic cultures of psychiatry

Modern commentaries on mental disorders habitually begin by citing shocking 'facts and figures' regarding the growing prevalence and global costs of mental illness; for instance, it has been cited that the global cost of mental illness has been estimated to be 2.5 trillion US dollars – a number that is expected to increase to an alarming 6 trillion dollars by 2030 (Kincaid & Sullivan, 2014, p. 1). Many studies have estimated that approximately 25% of the population in Western countries will suffer from at least one mental disorder during the course of a year (e.g. Kessler, 2010), while the estimated life-time prevalence for any psychiatric disorder is often suggested to be

around 50% (Brinkmann, 2017). While some have viewed these increasing diagnoses of mental illness as a sign of decreased stigma and improvements in diagnostic services, others have argued that increases in illness and distress have been generated by the stresses associated with modern life (e.g., Petersen, 2011; Keohane & Petersen, 2013).

While recognising both interpretations, the current work follows a different path, attempting to understand the cultural meanings implicated within this increasing social concern for psychiatric diagnosis. In particular, this thesis expands on the work which highlights the development of what Brinkmann refers to as 'diagnostic cultures' (2016; 2017), which alludes to the ways in which psychiatric diagnoses are now used – not only to understand and treat mental disorders, but as ways "to interpret, regulate, and mediate various forms of self-understanding and activity" (Brinkmann, 2017, p. 170). Brinkmann identifies how psychiatric diagnosis has become a pervasive aspect of modern culture, not only within medicine, but an often-present feature of communication within any prospective environment; this has increasingly resulted in the use of diagnostic terminology as a means of interpreting suffering and behaviour. For example, psychiatric diagnoses are now heavily featured within mainstream entertainment, with numerous celebrities 'coming out' in recent years by revealing and openly discussing their psychiatric diagnoses, often under the guise of reducing stigma. Bipolar disorder has been particularly well-represented amidst this movement, with well-known celebrities all openly disclosing their diagnosis, such as Stephen Fry, Britney Spears, Catherine Zeta-Jones, Carrie Fisher, and Demi Lovato, amongst others. Perhaps because of this association with celebrity culture, bipolar disorder has been labelled a 'trendy' diagnosis, with a growing tendency for individuals to attend services and actively seek or self-diagnose with the disorder (Chan & Sierling, 2010).

Such popular representations of psychiatric problems arguably have an impact on how psychiatric diagnoses are understood and mobilised by lay (and professional) audiences. Human experience is, in part, co-constructed through the stories and other symbolic resources that circulate in the media, which offer particular ways of interpreting the self. These celebrity accounts of diagnosis are arguably fed into the

public arena, offering audiences resources for self-interpretation, and providing examples of diagnostic performativity which create new ways of enacting disorder (Martin, 2007). This process engenders what Ian Hacking has defined as the 'looping effects of human (or interactive) kinds' (1995), which represent interactions between those classified (e.g., people with mental health problems) and the classification systems, mediated by systems of experts, forms of knowledge and institutions (Tekin, 2014). Hacking (1995) argued that 'feedback loops' occur when descriptions of a particular diagnostic category enter popular culture, and people become aware of the ways in which they are being categorised and judged; since 'human kinds' contain strong moral connotations, people are motivated to change how they are classified, and as their behaviour changes, so do the categories themselves. In Brinkmann's opinion (2017, p.179), this public promotion of mental illness has led to its commodification, whereby psychiatric diagnoses can now be perceived as 'products' advertised by the media and the pharmaceutical industry, who have an interest in 'selling sickness' (or 'disease mongering') by making diagnoses publicly visible (Moynihan & Cassels, 2005).

Some have argued that the prevalence of psychiatric terminology has led to the increased tendency to over-pathologise human suffering (e.g. Horwitz, 2002), and that this may be damaging due to its propensity to disguise other more social and historical factors that shape human social and psychological lives (Conrad, 2007). In addition to claims regarding the formal over-diagnosis of conditions (e.g., depression caused by bereavement etc.), diagnostic terminology is often used in an everyday (often humorous) sense to explain and describe behaviour; for instance, the term 'OCD' (obsessive compulsive disorder) is commonly used to describe people who are zealously clean, tidy or organised with terms such as 'anxiety' or 'depression' also being loosely used as everyday descriptors. This liberal usage of diagnostic terminology has led to the 'pathologisation of the normal' as well as the 'normalisation of the pathological' (Brinkmann, 2017), with concerns that this normalisation might dilute the meaning and seriousness associated with diagnostic categories, thus trivialising the associated suffering.

Nevertheless, this normalisation relates to one of the central dilemmas regarding psychiatric diagnosis in current times (Brinkmann, 2017); whilst diagnostic labels may be stigmatising and pathologising, they also confer certain advantages to those assigned the labels, such as the access to social welfare, services, sympathy, among other factors. There has been a tendency to either sensationalise or dehumanise the mentally ill (e.g., media reporting of schizophrenia and psychosis which emphasises violence and dangerousness), or to trivialise and normalise the condition. This tendency has been linked to the aetiological factors associated with mental disorder, whereby more medicalising, biological accounts lead to essentialising and risk-based discourses, whereas more social and psychological (normalising) accounts lead to trivialisation and blaming tendencies – referred to as the 'brain or blame' dilemma (Boyle, 2013).

Diagnosis, medicalisation, and deviance

A common suggestion is that medicalisation can manifest itself in the application of diagnostic labels assigned to socially and morally deviant behaviour (Zola, 1983; Conrad, 1975, 1979, 1992; Conrad & Schneider, 1980). For instance, a large body of research has examined the medicalisation of 'social' problems, ways of being and behaviours, through the assigning of diagnostic labels and medical intervention, e.g. compulsive gambling (Rosecrance, 1985), hyperactivity (Conrad, 1975), alcoholism (Blaxter, 1978), nicotine addiction (Dingel, Karkazis, & Koenig, 2011), sexuality (Tiefer, 1996), obesity (Jutel, 2012), adult ADHD (Conrad, 1979), and even compulsive buying (Lee & Mysyk, 2004; Hemler, 2013). As Rosenberg (2002) commented, the persistent use of mechanism-defined disease entities (e.g., bipolar disorder, schizophrenia etc.) as explanatory categories can serve to naturalise and legitimate conceptions of difference and deviance, and are "fundamental in negotiating the ever-shifting boundary between disease and deviance" (Rosenberg, 2006, p.407).

Since not all diagnoses are medicalised to the same degree, some are endowed with greater legitimising power and a higher medical status than others. The ability of diagnosis to mediate the disease/deviance boundary may depend upon the underlying

conception of the disorder, with those accepted as valid disease categories perhaps more amenable for use as explanatory frameworks, and those perceived as psychological/psychosomatic (as opposed to biological/organic) often seen as weakening the legitimacy of suffering (Glenton, 2002). It is plausible that mental health diagnoses constitute medically contested illnesses, like conditions such as CFS (chronic fatigue syndrome) and MCS (multiple chemical sensitivity) which, because of their uncertain and debated aetiology, 'fuzzy boundaries' (overlapping and linking with other conditions), and lack of diagnostic biomarkers, have become contested illnesses which "you have to fight to get" (Dumit, 2006). Eating disorders (Giles, 2006) and post-partum depression (Taylor, 2016), for example, have previously represented contested disease entities, necessitating a battle for medical and social legitimacy, with sufferers resorting to biological explanations as a way of persuading others of the legitimacy of their suffering. In an interview study conducted by Easter (2014), genetic causation was presented as evidence that affirmed the medical status of eating disorders as 'real diseases', which was perceived as a means of reducing individual responsibility for those diagnosed.

The ability of particular psychiatric diagnoses to minimise moral accountability therefore appears to be linked to their perceived aetiology and authenticity. For instance, people with drug dependencies are considered to be more responsible for their problems than those with depression or schizophrenia, with drug dependence not widely considered as a mental illness (Link, Phelan, Bresnahan, Stueve, & Pescosolido, 1999; Crisp, Gelder, Rix, Meltzer, & Rowlands, 2000). Diagnoses with perceived biological mechanisms may appear to influence psychological experience directly, diminishing the roles of individual agency and personality; for example, Williams and Healy (2001) found that - unlike other types of depression - pre-menstrual syndrome (PMS), post-natal depression (PND), and the menopause were perceived as conditions which "bypassed the self" and were therefore not a reflection of an individual's personal strength (Williams & Healy, 2001).

Those deemed to have a personality disorder appear to be particularly vulnerable to blaming responses, particularly from professionals, who are also more likely to contest its validity (Kendall et al., 2009). As a group of disorders located on the boundary

between deviance and medical disorder, personality disorders may be less medicalised than other mental health disorders. There is a growing body of literature on the stigma surrounding personality disorders, a vast proportion of which relates to the blaming and moralising responses from staff within the mental health system (e.g., Bonnington & Rose, 2014; Lam, Salkovskis & Hogg, 2016; Nehls, 1998; Markham, 2003). In an ethnography of US Community Mental Health Teams, Dobransky found that clients informally labelled as 'not severely mentally ill' elicited moralising responses from professionals and were held more accountable for their actions than those labelled in medicalising terms as 'severely mentally ill': "*Because these clients were seen as able to control their behaviour, failure to do so was seen as a moral failing*" (Dobransky, 2009). When clients given a diagnosis of psychotic disorders exhibited behaviour indicating a loss of contact with reality, such as responding to voices only they could hear or to delusions that were not shared by others, staff were more likely to informally label the client as being severely mentally ill, and such clients were not held morally responsible for their disruptive or non-compliant behaviour. For these types of clients, compliance or non-compliance was a clinical and practical problem not a moral one, whereas those who were disruptive or problematic but were not viewed as fitting the criteria for psychotic and mood disorders were subject to 'exclusionary social control', and risked being labelled as personality disordered, most commonly borderline personality disorder (Dobransky, 2009).

Thus, in addition to exploring the role of diagnosis in shaping forms of selfhood, the current work focuses on the way in which diagnostic identities can be mediated by the aetiological assumptions underpinning particular diagnoses. It would appear that certain aetiological beliefs are embedded within common conceptions of disorder; in particular, there are often assumptions regarding the neurobiological aetiology underlying the classification of different types of people and illnesses (Choudhury, Nagel & Slaby, 2009; Dumit, 2004; O'Connor, Rees, & Joffe, 2012), and Western understandings of illness itself have traditionally tended to emphasise biological factors, often at the exclusion of emotional, spiritual or cognitive dimensions (Cooke, 2017). The following section explores the impact of developments in the bio-sciences (e.g., neuroscience, molecular genetics etc.) on conceptions of selfhood and beliefs

regarding the appropriate management of mental disorders, based on some of the empirical literature related to aetiological models and stigma.

Biomedical expertise and neurochemical selfhood

Several terms have been coined to capture recent trends towards the assimilation of bioscientific ideas into conceptions of self and identity, such as the 'neurochemical self' (Rose, 2007), 'cerebral subject' (Ortega, 2009) and 'brainhood' (Vidal, 2009). In particular, Nikolas Rose has written extensively about how conceptions of the mind-brain relationship have been shaped by developments in brain imaging, neuroscience, psychopharmacology and behavioural genetics, arguing that bioethics has become fundamental in the process of understanding and managing ourselves and others. In a process he terms 'somatic individualisation', aspects of the self, such as mood, cognition, emotion, volition, are opened to potential intervention; selfhood has become increasingly imagined in terms of the brain, while the psychological aspects of personhood (the 'psy-shaped' space) have become increasingly de-emphasised and compressed (Rose, 2007).

As argued by Rose, biogenetic knowledge is fundamental in of the process of "making up citizens" (2007, p140), and in reshaping the ways in which individuals are understood by authorities; for example, whether they are grouped into categories such as the chronically sick, children with ADHD, psychopaths, and the severely mentally ill, among others. The categories produced and supported by bioscientific 'knowledge' provide a means of organising "*the diagnostic, forensic and interpretative gaze of professionals and experts. Classification of this sort is both dividing and unifying. It delimits the boundaries of those who get treated in a certain way – in punishment, therapy, employment, security, benefit or reward. And it also unifies those within the category, overriding specific differences*" (2007, p140). This process of "making up" biological citizens involves developing individuals and groups who relate to themselves and one another in certain ways, using biology to describe aspects of the self, such as unhappiness or vulnerability to stress. Since predicaments become visualised in biological terms, this in turn imposes assumptions regarding the

appropriate ways of acting in relation to problems – thereby shaping self-techniques as well as self-understandings. Such ideas regarding the biological responsibilities of citizens then become embodied within contemporary norms of health and practices of health education. Rose (2007) wrote in particular about the merging of genetic notions of personhood with lay notions of somatic individualisation, linking the development of the new genetics to a new vision of life (and interventions upon life) as operating at a molecular level.

Others have also made broad claims about the potential impacts of neuroscientific knowledge on notions of selfhood; for example, it has been asserted that neuroscientific insights "will fundamentally alter the dynamic between personal identity, responsibility and free will" (Illes & Racine, 2005, p. 14), and that humanity has entered a "neuro-age" - "whereby human behaviour and the other aspects that define us as a species are predominantly formulated in neurochemical terms" (Abi-Rached, 2008, p. 1162). O'Connor and Joffe (2013), meanwhile, provide a more cautious assessment:

> *Research from a variety of theoretical standpoints converges on the conclusion that people selectively attend to and interpret science in ways that cohere with their pre-existing values, identities and beliefs (Joffe & Haarhoff, 2002; Kahan et al., 2011; Morton et al., 2006; Munro, 2010; Wynne, 1993). New scientific information can indeed challenge and modulate existing understandings; however, it can also assimilate into and reinforce established ideas. It is therefore not self-evident that neuroscience will substantively alter understandings of personhood in predictable directions. Delineating the influences neuroscience exerts on contemporary society requires careful empirical research* (O'Connor & Joffe, 2013).

In attempting to collate the empirical evidence regarding the influence of neuroscience on common-sense conceptions of personhood, these authors emphasise that there is limited evidence showing that neuroscientific ideas dominate public conceptions of selfhood, citing interview studies which demonstrate that behaviour is rarely understood conceived of in purely biological terms (Pickersgill, Cunningham-Burley, & Martin, 2011; Choudhury, McKinney, & Merten, 2012).

Nevertheless, research has suggested that the incorporation of neurobiological information into self-perception is more likely within clinical populations; for instance, in a survey of 72 patients diagnosed with major depressive disorder, a majority (92%) stated that they would opt to have a brain scan to diagnose depression if possible, reporting that this would increase acceptance from both others and themselves, increase confidence in the diagnosis and improve treatment adherence. Furthermore, the majority of participants who blamed themselves for their condition (57%) believed that a scan would reduce their sense of responsibility, although many also expressed concern about the implications of such a scan for health insurance coverage (Illes, Lombera, Rosenberg, & Arnow, 2008). Similarly, in a Danish study, patients with schizophrenia, depression, bipolar, and anxiety disorder predominantly expressed the desire to have genetic testing, although some concerns regarding the potential for discrimination similarly emerged (Laegsgaard, Kristensen, & Mors, 2009). Buchman et al.'s (2013) interview study also revealed that the participants had a strong tendency to favour 'chemical imbalance' explanations for depression.

The differing findings between clinical and non-clinical populations suggest that experiences such as diagnosis and medical treatment (e.g., with medication) may influence the extent to which individuals are prompted to consider themselves in terms of neuroscientific self-understandings; the brain may thus become more salient as an explanatory system when something appears to go wrong with it (Pickersgill Cunningham-Burley, & Martin, 2011). However, when neuroscientific ideas are embraced, this is often only partial and conditional, and they are often combined with other ways of understanding the self. A Q-methodology study by Bröer and Heerings (2013), for instance, found that participants' understandings of their ADHD diagnosis consisted of a range of psychological, sociological and holistic concepts that existed alongside neurological conceptualisations.

Stigma & Causality

As neurobiological knowledge has generated new classifications, there is some evidence suggesting that new social identities are forming around neuroscientific understandings regarding human difference and disorder; for instance, individuals have grouped and collectively mobilised around particular diagnostic categories and their related neurobiological explanations to advocate for research, treatment, services and de-stigmatisation (Brown & Zavestoski, 2004; Rose, 2007). The neurodiversity movement within ASD (autistic spectrum disorder) groups has particularly exemplified this tendency, although groups representing a range of disorders, differences, and behaviours – such as addiction, mental illness, juvenile justice and homosexuality – have embraced neuroscientific explanations, hailing their potential to deter social tendencies towards blame and moral judgement (Corrigan & Watson, 2004; Hall, Carter, & Morley, 2004; Walsh, 2011).

Neuroscientific understandings of behaviour – for example, representing addiction or mental illness as brain diseases – have widely been expected to promote tolerance towards stigmatised groups. In particular, attribution theory predicts that biogenetic explanations should decrease stigma, since such explanations appear to place the cause of the problem outside the individual's responsibility (Corrigan, 2000; Weiner, Perry, & Magnusson, 1988). Research has also indicated that patients themselves may expect that biomedical explanations will reduce the stigma related to their mental health problems (Buchman, Borgelt, Whiteley, & Illes, 2013; Easter, 2012; Illes, Lombera, Rosenberg & Arnow, 2008). Consequently, many anti-stigma campaigns have adopted biomedical explanations as a means of deflecting blame from sufferers of mental disorders (Pescosolido et al., 2010).

However, according to empirical findings, the actual effect of neuroscientific explanations on attitudes towards stigmatised groups appears to be somewhat more complex. A large body of research has explored the association between causal explanations and various components of stigma, often generating mixed and conflicting results. One explanation for this may be that stigma itself is a complex and multi-dimensional construct, which can be measured in different ways, with multiple

components, including perceived stigma, internalised stigma, reluctance to disclose, perceived dangerousness, perceived weakness of character, desire for social distance, emotional reactions and discriminatory behaviour towards people with mental disorders, as well as structural discrimination, amongst others[14]. The multi-faceted nature of stigma has contributed to the complexity of this topic, since particular diagnoses and explanations seem to be associated with particular aspects of stigma.

The following section will review the complex body of literature relating to stigma and the explanatory models of mental disorder, distinguishing between the following broad aspects of stigma emphasised within the literature: 1) blame and volitional stigma; 2) social distancing and perceived dangerousness; 3) prognostic pessimism; and 4) essentialisation. Some of the potential mediating factors shaping this relationship will also be considered.

Blame and 'volitional stigma'

Attribution theory has suggested that when the onset (or continuation) of a stigmatised condition is perceived to be something that is beyond the control of the individual, others will tend to view that individual as personally responsible for the condition, leading to negative emotional reactions and stigmatisation (Bos, Schaalma, & Pryor, 2008; Bos et al., 2009; Phelan, Bromet, & Link, 1998; Weiner, Perry, & Magnusson, 1988). This line of thinking has led to the widely held belief that biogenetic[15] explanations should reduce the blame and stigma surrounding mental disorders by reducing perceived responsibility.

Several studies have found that genetic explanations for mental illnesses are associated with reduced blame and perceived responsibility (Phelan, Cruz-Rojas, & Reiff, 2002; Goldstein & Rosselli, 2003; Rusch et al., 2010; Corrigan & Watson, 2004). Experimental studies have also indicated that mental-behavioural causal attributions

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[14] To further complicate matters, illness-related blaming can also be separated into 'onset' and 'offset' blame (Corrigan, 2004); i.e. an individual may not be blamed for the onset of their illness, but may later be blamed for not recovering.

[15] 'Biogenetic' within this context refers to groups of explanations which emphasise genetic and/or other biological causal factors (such as biochemical, neurological, or other biological brain-based explanations).

can increase blame and anger aimed at sufferers (Angermeyer & Matschinger, 2003; Weiner, Perry, & Magnusson, 1988), and that biogenetic explanations decrease blame (Mehta & Farina, 1997; Boysen & Vogel, 2008; Crisafulli, Von Holle, & Bulik, 2008; Lincoln, Arens, Berger, & Rief, 2008; Lebowitz, Pyun, & Ahn, 2014). A meta-analysis of experimental studies (Kvaale, Haslam, & Gottdiener, 2013), found that biogenetic (but not genetic explanations alone) explanations appear to reduce blame, but only for student samples.

Kvaale, Gottdiener, and Haslam (2013) conducted a meta-analysis of 25 correlational studies on the relationship between biogenetic explanations and three types of stigma: blame, perceptions of dangerousness, and social distance. They also assessed for consistency of effects across subgroups, considering the differences between specific disorders ('schizophrenia', 'depression', and 'other mental illness'), populations studied (student vs. general population), and different types of biogenetic explanations (i.e., genes/heredity, brain disorder/chemical imbalance, and general and unspecified biogenetic explanations). Overall, they found that those holding biogenetic explanations for mental disorder tended to assign less blame to individuals for their disorders, but also viewed them as more dangerous and desired to increase their distance from them socially. This seemed to provide support for attribution theory, although biogenetic explanations only seemed to reduce blame for schizophrenia and genetic explanations specifically (not for other disorders and not for other varieties of biological explanations); similarly, increased social distancing was also only apparent for schizophrenia. The association of biogenetic attributions with dangerousness applied generally across disorders, types of biogenetic explanation, and populations. However, despite attempting to consider the variation between different disorders, the authors only specifically investigated depression and schizophrenia due to the lack of studies on other disorders. The category 'other mental illness' encompassed those studies that focused on 'mental illness' in general (where stigma was reported as an average for multiple disorders) or where stigma was measured for disorders other than depression and schizophrenia, including such diverse disorders as obsessive compulsive disorder (Pirutinsky, Rosen, Safran, & Rosmarin, 2010), substance abuse (Pescosolido et al., 2010; Schnittker, 2008; Sears et

al., 2011), autism, generalised anxiety disorder, attention deficit hyperactivity disorder, and bipolar disorder (Sears et al., 2011). This conflation of different disorders into one category may be problematic, since these disorders are considerably diverse. It is also notable that only one study was related to the diagnosis of bipolar disorder.

To summarise, there is some evidence supporting the notion that biogenetic explanations can – in some circumstances – reduce the allocation of blame to those with mental disorders, while personality-based explanations may increase blaming tendencies. What is less well-researched is whether such attitudes translate into behavioural differences towards those with mental disorders. One German study found that perceptions of self-responsibility increased the public's reported *willingness* to reduce healthcare spending on depression (not schizophrenia or alcoholism) (Schomerus, Matschinger, & Angermeyer, 2006), thereby indicating a potential effect upon behaviour. Meanwhile, other studies have suggested a potentially more complex effect of responsibility beliefs on resulting actions or feelings towards individuals with a mental disorder. For instance, Mehta and Farina (1997) found that a person whose disorder was explained biogenetically was punished more severely for making errors in a learning task, despite being blamed less for their poor performance. By contrast, Aspinwall, Brown, and Tabery (2012) found that a biogenetic explanation for psychopathy reduced the level of aggravation judges reported in cases involving a diagnosis of psychopathy, but did not influence their estimation of moral and legal responsibility for the crime. There appear to be subtle differences between these measures in terms of the types of stigma they detect, which are important factors that should be considered.

As several researchers have suggested (De Brigard, Mandelbaum, & Ripley, 2009; Rose, 2007; Schweitzer et al., 2011), there is limited evidence indicating that neuroscientific knowledge regarding the brain will undermine beliefs in free will and moral responsibility in a straightforward manner. For instance, a qualitative study by Callard et al. (2012) demonstrated how genetic explanations for schizophrenia are used in complex and contradictory ways, often displacing rather than eliminating responsibility and blame within a family. As O'Connor and Joffe (2013, p.258) attest, "*Research thus suggests that attributions of responsibility are complex and*

multifaceted, and a direct 'more neurologically determined–less personal responsibility' effect appears unlikely". In fact, they suggest that biogenetic explanations actually complement and support individualistic attributions, by locating problems within individual brains (Choudhury, Nagel, & Slaby, 2009; Vidal, 2009). In this way, neuroscientific understandings may strengthen tendencies to neglect the social contexts that shape mental health and wellbeing.

Social distancing and perceived dangerousness

The blaming responses described above have tended to be linked with forms of discrimination which manifest in angry or punitive reactions towards those with mental health problems (see Corrigan et al., 2002). A contrasting aspect of stigma, which involves beliefs regarding the dangerousness of individuals with mental health problems, has more often been associated with public tendencies towards increased fear and social distancing (i.e. avoidance) from those with mental health problems (Corrigan, et al., 2002). A number of studies have indicated that biomedical attributions are linked to increases in desired social distance from those with mental disorders (Angermeyer & Matschinger, 2005; Bag et al., 2006; Dietrich et al., 2006; Lauber et al., 2004; Pescosolido et al., 2010; Read & Harré, 2001; Rüsch et al., 2010), perceived dangerousness (Corrigan & Watson, 2004; Dietrich et al., 2006; Jorm, Reavley, & Ross, 2012; Read & Harré, 2001; Walker & Read, 2002), fear (Dietrich et al., 2006), and perceived unpredictability (Walker & Read, 2002).

The picture from the empirical research has been decidedly complex however, with many contradictory patterns emerging. A meta-analysis of experimental studies (Kvaale, Haslam, & Gottdiener, 2013) found that biogenetic explanations (including genetic explanations alone) seemed to increase perceptions of dangerousness and prognostic pessimism, but appeared to have no effect on social distance. A review of correlational and experimental studies on social distancing and causal attributions by Jorm and Oh (2009) concluded that biogenetic explanations appear to have no causal effect on social distancing. The authors highlighted the heterogeneity in their findings,

suggesting that different types of biogenetic explanations relate differently to stigma (Jorm & Oh, 2009). For instance, they noted how 'brain disease' explanations have been associated with social distancing, whereas there is considerably less evidence of this for 'chemical imbalance' explanations, and mixed findings for genetic explanations. They also found little evidence of 'psychosocial' explanations reducing social distancing, but evidence in several studies indicated that attributing mental disorder to character weakness/bad character was associated with greater social distance (Dietrich et al., 2004; Grausgruber et al., 2007; Jorm & Griffiths, 2008; Martin, Pescosolido, Olafsdottir, & Mcleoud, 2007; Martin, Pescosolido, & Tuch, 2000; Van t' Veer et al., 2006). Interestingly, Jorm and Griffiths (2008) found that weakness of character attributions were positively associated with social distancing and beliefs in dangerousness for both depression and schizophrenia, whilst bereavement attributions were associated with less social distancing for schizophrenia, suggesting that certain 'psychological' explanations can be more harmful than others. Jorm, Reavley, and Ross (2012) also found that character-based moral explanations increased perceptions of dangerousness, providing further evidence that personality-based explanations can be particularly stigmatising.

In a review of correlational and experimental studies, Read, Haslam, Sayce, and Davies (2006), found that both 'biogenetic' explanations and diagnostic labelling as 'illness' were internationally associated with perceptions of dangerousness and unpredictability, as well as social distancing. They also cited evidence of the public's general preference for 'psychosocial' explanations, suggesting that 'psychosocial' explanations can improve attitudes. However, this review presents some of the problems with this body of literature more generally: firstly, Read et al., (2006) focused on studies which involved either 'mental illness' generally (i.e., people responding to a generic mental illness label), or schizophrenia, a disorder for which the stereotypes of violence and unpredictability abound. The study also generalised across time-periods and populations, ignoring the importance of social context and variation; for example, several of the included studies were conducted in the 1970s and 1980s, and public opinion regarding mental illness is likely to have evolved considerably since those periods. The more recently cited studies only examined

attitudes towards schizophrenia, and the authors tended to assign less importance to findings which contradicted their conclusions (e.g. Magliano et al, 2004; Martin, Pescosolido, & Tuch, 2000). Additionally, they did not consider blame as one of the dimensions of stigma. It may be worth noting that the lead author of the review – John Read - is a central figure within the 'International Hearing Voices Network', a political movement which seeks to challenge the biomedicalisation of mental distress; as such, he arguably has an ideological investment in undermining the biomedical understanding of mental disorder.

Another difficulty with this review is that a number of studies demonstrating a correlation between 'brain disease' explanations and social distancing (Dietrich et al., 2004; Read, 2004) are included to represent 'biogenetic' causal explanations. However, the term 'brain disease' may have significantly more negative connotations compared with other biomedical explanations, thus potentially skewing the results; this term is also not used prominently in mental health promotion programmes, and is therefore not a good representation of 'biogenetic' causal models (Jorm & Griffiths, 2008). 'Brain disease' explanations have been particularly linked to social distancing in several countries (Dietrich et al., 2004), whereas the evidence regarding genetic and other biological explanations has been more mixed. Several studies have found positive associations between genetic explanations and social distancing, particularly for schizophrenia (e.g., Bag, Yilmaz, & Kirpinar, 2006; Dietrich et al., 2004; Jorm & Griffiths, 2008; Kermode, Bowen, Arole, Pathare, & Jorm, 2009; Read & Harre, 2001; Rusch, Todd, Bodenhausen, & Corrigan, 2010). However, several studies have *not* demonstrated any association between genetic beliefs and social distancing (Grausgruber et al., 2007; Martin, Pescosolido, & Tuch, 2000; Phelan, 2005; Van 't Veer, Kraan, Drosseart, & Modde, 2006; Goldstein & Rosseli, 2003; Bennett, Thirlaway, & Murray, 2008). Lee et al., (2014) found that genetic attributions increase perceptions of dangerousness, and negatively impact on self-reported helping decisions towards those with schizophrenia, although not towards those with depression and bipolar disorder. This provides some evidence for Schnittker's theory (2008), which argues that genetic explanations will only increase stigma for disorders that are associated with dangerousness, such as schizophrenia.

Another systematic review exploring the relationship between biogenetic explanations and public acceptance of mental illness also found that patterns of stigma differed according to diagnosis in that biogenetic attributions were associated with stronger social rejection in the case of schizophrenia, but not for other disorders (Angermeyer, Holzinger, Carta, & Schomerus, 2011). For alcohol addiction, responsibility was a salient predictor of social distancing, whereas for schizophrenia, perception of dangerousness was a greater predictor. The authors argued that stereotypes of self-responsibility are uncommon among the general population, compared with beliefs regarding unpredictability and dangerousness for 'general mental illness', schizophrenia, and depression (although in Germany, Japan, Brazil and India, stereotypes of responsibility dominated over those of violence and unpredictability for depression); they suggested that this explains why biogenetic explanations have seemingly not led to a decrease in stigmatising attitudes.

Prognostic pessimism

Research has also suggested that biological explanations operate as self-fulfilling prophecies for those to whom they are applied, resulting in fatalistic and pessimistic beliefs regarding prognosis and recovery. Evidence from *experimental studies indicates that* biogenetic explanations for mental illness can increase prognostic pessimism for various mental (and physical) health problems, including obesity, depression, anxiety, and schizophrenia *(*Bennett, Thirlaway, & Murray, 2008; Dar-Nimrod & Heine, 2011; Lebowitz, Pyun, & Ahn, 2014; *Phelan, 2005;* Phelan, Yang, & Cruz-Rojas, 2008*).* Several studies have found that biological explanations lead to more pessimistic beliefs regarding recovery than psychological explanations for a range of different psychiatric problems (Lam & Salkovskis, 2007; Lam, Salkovskis, & Warwick, 2005). Some studies have also found associations between prognostic pessimism and biogenetic beliefs in depression (Deacon & Baird, 2009; Lebowitz, Ahn, & Nolen-Hoeksema, 2013; Lebowitz, 2014), and eating disorders (Easter, 2012). A rare study on bipolar disorder by Meiser et al. (2007) also demonstrated a correlation

between genetic causal attributions and a reduced willingness to have children (in family members of those diagnosed with bipolar disorder), suggesting a pessimism that extended into future generations.

In contrast, Lebowitz (2014) emphasised that biogenetic causal beliefs can actually produce *prognostic optimism* when they are associated with increased beliefs in the efficacy of anti-depressants (Budd, James, & Hughes, 2008; Iselin & Addis, 2003). Significantly, a recent experiment by Lebowitz et al. (2013) demonstrated that biological explanations focusing on the malleability of genetic and neurochemical causality (as opposed to casting them as static influences) appeared to reduce prognostic pessimism and hopelessness among individuals with depression, increasing their sense of agency regarding their own moods. This highlights the non-inevitability regarding the implications of biomedical (and other) explanation types.

Psychological Essentialism

In contrast to attribution theory, genetic and neuro-essentialism theory holds that biogenetic explanations depict illnesses as fundamental aspects of a person; the individual thus becomes intimately tied to their condition. According to Wagner, Holtz, and Kashima (2009), essentialism constitutes the attribution of a group's characteristics to an immutable and causal 'essence', which involves: (a) establishing discrete, impermeable category boundaries; (b) perceived homogeneity within the category; (c) using the essence to explain and predict the group's surface traits; and (d) naturalisation of the category. The biomedical construction of disorders as 'natural kinds' - categories perceived to occur naturally as opposed to socially - implies immutability, and thus, poor prognoses (Haslam & Ernst, 2002). In contrast, psychosocial explanations have been posited to be less stigmatising, purportedly as they encourage people to understand psychiatric symptoms as 'normal' reactions to life events (e.g. Read, Haslam, & Sayce, 2007).

It has been argued that current representations of neuroscience tend to support harmful and stereotypical ways of understanding social groups by framing supposedly negative attributes as inevitable features of a group's 'natural' state (Fine, 2010; Kelly, 2012; O'Connor, Rees. & Joffe, 2012). As such, it has also been argued that essentialism tends to deepen social divides, thus making differences between groups seem wider, more unbridgeable, inevitable, and inherently natural (Haslam, 2011), and casting particular groups biologically as 'other' (O'Connor & Joffe, 2013). Neuroimaging data in particular has tended to convey the 'otherness' of mental disorders; for instance, the common tendency within academic and popular literature on mental disorders is to display differently coloured brain images side-by-side, suggesting a categorical distinction between 'normal' and 'disordered' brains (Dumit, 2003, 2004; Buchman, Illes, & Reiner, 2010). In this way, mental disorders are depicted as categorical and homogenous, rather than as occupying a specific point on a continuum. This essentialised version promoted by neuroscience encourages discrimination and stigma by almost depicting those with a mental disorder as a different species (O'Connor & Joffe, 2013). There is some evidence indicating that genetic explanations can be related to genetic essentialist biases (Dar-Nimrod & Heine, 2011; Phelan, 2005), which are associated with increased prejudice (Bastian & Haslam, 2006) and have implications for beliefs about recovery, treatability and agency.

A contrasting argument suggests that neuroscientific explanations can function to legitimise people's experiences and difficulties, by implying an objective and morally neutral quality to what otherwise may be deemed as contested diagnostic categories. For instance, qualitative research by Dumit (2003) and Cohn (2004) suggests that the visual 'evidence' provided by brain scans can be viewed as validating, providing a means for patients with contested diagnoses to legitimise their suffering and develop a positive sense of self. Moreover, essentialising neurobiological explanations can be adopted for positive purposes; Fein (2011), Rapp (2011) and Singh (2011), for example, found that individuals with developmental disorders such as ASD and ADHD can use neuroscientific language to emphasise the neurological basis of their unique challenges and aptitudes. This form of neurological selfhood – which has characterised

the neurodiversity movement – has enabled autism to be defined not as a disorder, but as a biological difference that is equally as valid as 'neurotypicality' (Vidal, 2009).

In its positive adoption of a traditionally stigmatised social identity category, the neurodiversity movement seems to exemplify what Haslam (2011) referred to as 'strategic essentialism' within stigmatised groups, whereby groups actively emphasise their difference to other groups in a way that promotes within-group cohesiveness, and helps to promote a positive sense of identity and agency. As Nikolas Rose (2007) argued about those deemed to be genetically at risk, such groups are in fact brought into wider family and social networks with others also at risk, rather than being individualised. Such biosocial groupings have led to 'informational bio-citizenship' and 'rights bio-citizenship', where groups form around particular biological categories, becoming engaged in activities such as campaigning for better treatment, combating stigma, and gaining access to services (Rose, 2007).

Similarly, some have referred to the economy of hope surrounding contemporary biomedicine and biological citizenship (Conrad, 2001; Novas, 2001; Rose, 2007). In parallel with theories associating biogenetic explanations and prognostic pessimism, a discourse of optimism surrounding genetics has also emerged, arguing that the genes responsible for causing mental illness are on the verge of being discovered, which will subsequently lead to improved treatments or even cures (Conrad, 2001). Contemporary ideas regarding genetic causation (referred to as the 'new genetics') are also less deterministic, potentially leading to an increased hopefulness regarding mental health prognosis. In fact, Rose (2007) has identified that new genetic risk models are in fact linked with the with prevailing notions of responsible personhood, and thus entail obligations in terms of self-management in addition to obligations in relation to others (family members, etc.). This challenges the assumption that genetic (and perhaps biomedical explanations in general) are necessarily deterministic and pessimistic, or that such explanations will exempt individuals from blame and social judgement.

The following section will further develop the concept that biomedical discourses may in fact assume a distinctly moralistic flavour within a neoliberal context, where trends towards health optimisation and self-control - termed 'healthism'- necessitate

working upon the body in order to work upon the self, thus establishing the self as a virtuous, disciplined citizen (Crawford, 2006; Rabinow, 1992).

Optimisation, Self-Determination & Responsibility

According to Rose (2007, p107), the new genetics are evolving in a society in which individuals are obliged to empower themselves to manage their own lives and potentials, as life has increasingly become a "strategic enterprise"; biogenetic forms of thought and expertise have become central resources that can be employed in the compulsion to "live one's life as a project…." (p.129). There have been social trends towards increasing the allocation of responsibility to subjects for successfully 'managing' their own illnesses, who are increasingly being encouraged (and expected) to learn new methods of self-reflection, self-assessment and insight; for instance, the use of tools that promote self-scrutiny, such as questionnaires, mood diaries to chart thoughts, feelings, and behaviour, which constitute "regimes of the self that stress self-fulfilment, authenticity, and self-determination" (Rose, 2007 p.101).

Consistent with current trends aimed at self-improvement, notions regarding brain plasticity have also gained popularity, particularly exemplified by discourses encouraging brain 'training' (O'Connor, Rees, & Joffe, 2012; Pitts-Taylor, 2010), which depict the brain as a resource whose efficacy is dependent upon the way in which it is maintained; individuals are encouraged to enhance their brain function through diet, mental exercise, the use of pharmaceutics, and through the avoidance of risky activities or substances. Notions of neuroplasticity have become an influential trope, inspiring discourses of self-change, self-improvement, and by implication, responsibility (Papadopoulos, 2011; Pitts-Taylor, 2010). Such concerns echo the central ethos of neoliberal health discourse, which emphasises individual responsibility and lifestyle choices (Blaxter, 1997; Crawford, 2006; Petersen & Lupton, 1996; Rose, 2007).

Rose (2007) has written about the ways in which notions of genetic risk produce new ways of relating to the self and one's future, generating new forms of 'genetic responsibility', locating actual and potentially affected individuals within new communities of obligation and identification. He argued that not only are individuals considered to be responsible for their own mental and physical health, but now 'somatic individuals' must also understand and manage the implications of their own genome (Rose, 2007). In such a context, conceptualising illness in genetic terms does not result in fatalism, but instead obligates individuals to act in relation to potential futures. Such individuals may be marked by this risk status, leading to stigma and imposed self-surveillance strategies - "*in the emergent form of life, susceptible individuals are obliged to engage in responsible self-management, to justify choices….*" (Rose, 2007, p.94). For instance, he alluded to the way in which psychosocial genetic counselling has developed to focus upon the modification of lifestyle (Marteau, 1999, p. 426, cited in Rose, 2007), and the promotion of autonomy and self-directedness in clients (Elwyn et al. 2000, cited in Rose, 2007). Such growing expectations regarding self-governance and self-management generate new types of ideal and problematic subjects and in so doing, they carry important moral implications for patients.

Summary

This section sought to illustrate some aspects of the complexity involved in the relationship between neuroscientific knowledge and various aspects of selfhood. As has been noted, neuroscience is not a uniform body of knowledge, but incorporates diverse ideas and understandings with potentially different social effects (O'Connor & Joffe, 2013). Biogenetic explanations form a heterogeneous group of explanation types, including hereditary, neurochemical, and other biological mechanisms, which will likely hold different connotations, meanings, and implications for patienthood. The implications of knowledge regarding the brain for notions of selfhood (e.g., beliefs about free will and responsibility) are also dependent upon the precise mode of representation; for instance, whether neurological structures and functions are depicted as genetically pre-determined, or as 'plastic' and amenable to modification. Similarly, different diagnostic categories will generate different meanings, rendering

it largely unproductive to explore this topic in relation to a generic 'mental illness' category. The majority of studies included in the above literature review relate to 'mental illness' in general, schizophrenia, or depression. The diagnosis of bipolar disorder has been particularly poorly represented within this body of literature.

Although some of the reviewed studies have attempted to explore variations across different social groups (e.g., lay, professionals, patients, students, etc.), they tend not to account for variations in social context. The methods often involve population-based 'representative' studies, where participants are responding to abstract concepts, such as a generic 'person with mental illness', rather than to real people in real life situations, in which familiarity may play a significant role in the reactions to individuals with mental distress and disorder. It is also likely that many people endorse a diverse range of explanatory beliefs, and that the artificial dichotomy between 'psychosocial' and biomedical' factors masks this complexity. 'Biopsychosocial' models supposedly dominate psychiatry (Tyrer, 2013), and public opinion reflects the fact that there are multiple causal factors that combine to cause mental disorders (Griffiths & Christensen, 2004). The results from studies using multiple regression models may therefore be unduly influenced by small minorities who hold simplistic biological or psychosocial causal beliefs (Griffiths & Christensen, 2004). Such crude dichotomies are poor reflections of real-world explanatory frameworks, which are likely to be considerably more complicated and nuanced.

Beyond biomedical /psychosocial binaries

As the previous section suggests, the body of literature addressing stigma and the models of mental disorder overwhelmingly approaches the topic by adopting a biomedical/psychosocial binary; however, there are a variety of different conceptualisations and models that are not encompassed by these overarching categories. For instance, Zachar and Kendler (2007) suggested six conceptual dimensions which underlie the assumptions regarding the nature and categorisation of mental disorders (see *Figure 1*): 1) Causalism-Descriptivism refers to whether psychiatric disorders should be categorised according to their aetiology or their clinical

characteristics (descriptivism); 2) Essentialism-Nominalism refers to definitions of disorders that are either defined by their 'true' underlying nature (i.e., natural kinds) or as practical categories constructed by humans for particular purposes (nominalism); 3) Objectivism-Evaluativism refers to whether a problem can be defined as a disorder in an objective, value-free manner (objectivism), or whether these decisions invariably involve value-laden judgements (evaluativism); 4) Internalism-Externalism relates to whether psychiatric disorders should be defined by processes within the body (internalism) or whether events outside the body also play a defining role (externalism); 5) Entities-Agents refers to whether psychiatric disorders should be perceived as 'things' that people 'have', or whether they are in fact inseparable from the individual's subjective makeup (Agents); 6) the Categories-Continua dimension refers to whether psychiatric disorders are best viewed as categories with discrete boundaries, or whether they are the pathological extremes of functional dimensions (continua).

Zachar and Kendler (2007) describe four possible medical models according to their variation with respect to these six dimensions: the 'Biopsychosocial' model; the altered function model; the Organic model; and the 'harmful dysfunction' model. All four medical models are described as essentialist that view psychiatric disorders as things to be discovered, whereas alternate (non-medical models) are described as nominalist. All apart from the altered function model also endorse a categorical (as opposed to a continua) conception of mental disorder (see Figure 1). The authors also suggest alternatives to the medical models – the 'practical kinds' model (e.g. Zachar, 2000; Ghaemi, 2003), dimensional models, and two models that are in particular opposition to the medical models: the narrative approach and the interpersonal model. This article underscores the potential number of ways in which mental disorders can be conceptualised.

Only a limited amount of research has explored the implications of any of the above models for stigma, with some research suggesting that dimensional or continuum models can reduce the perceived differentness between the mentally ill and the mentally well (Corrigan et al., 2016; Schomerus, Angermeyer, & Matschinger, 2013). Since the tendency towards the separation of "us" and "them" is central to the

processes of stigmatisation (Link & Phelan, 2001), it may be the case that adopting a categorical approach to mental disorder could increase tendencies towards 'them' and 'us' thinking, thereby increasing stigma.

Figure 1: Medical Models and the Dimensions of Categorisation (Zachar & Kendler, 2007)
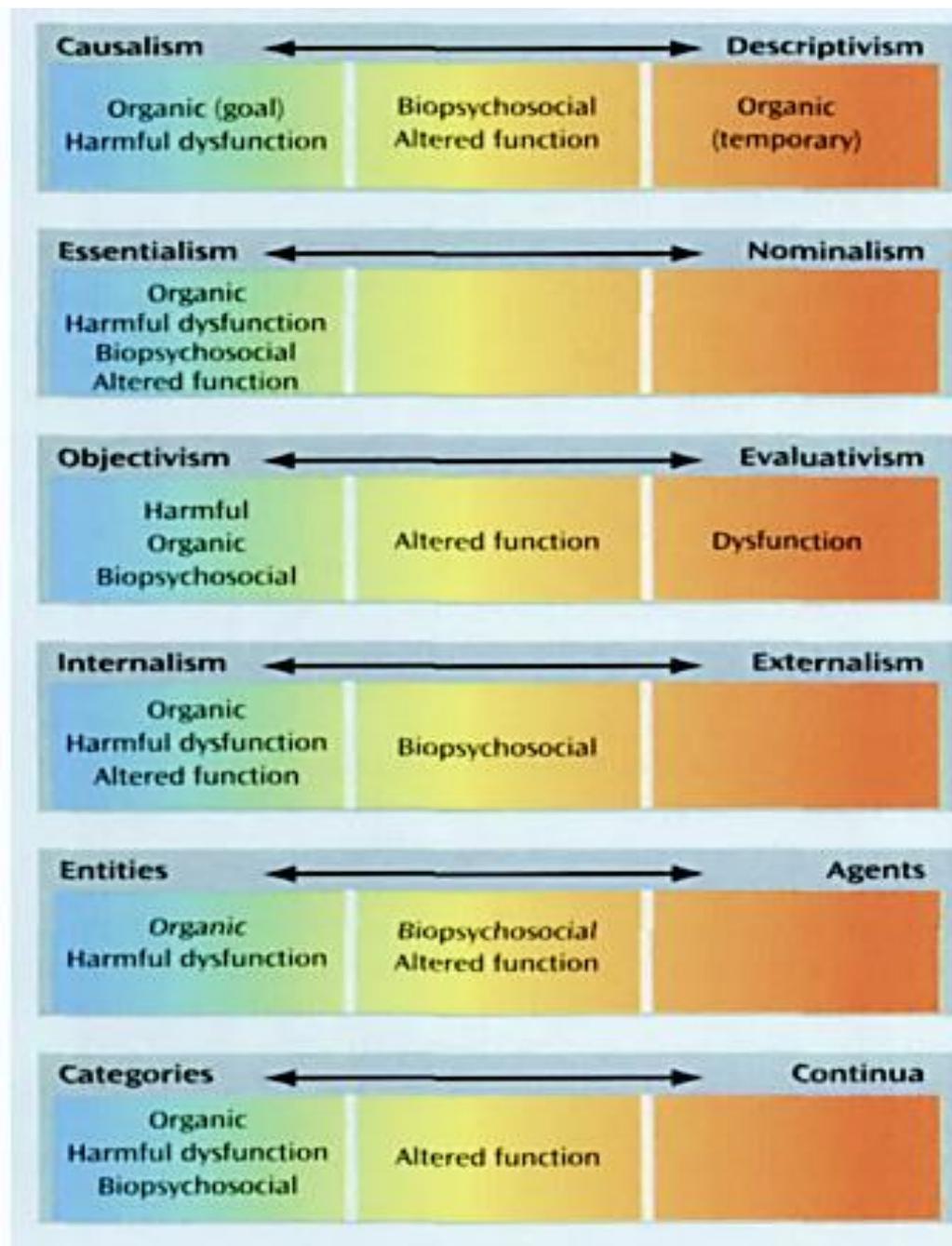
From static causal models to context-specific explanatory discourses

Not only are there multiple and complex models of mental illness causality, but qualitative research has shown that everyday explanatory accounts for mental health may consist of a variety of explanations that can be held simultaneously, or taken up and dismissed; they do not necessarily represent a coherent or consistent set of beliefs (Callard et al., 2012; McCabe & Priebe, 2004; Williams & Healy, 2001). This inconsistency makes it challenging to define a single set of causal explanations that might relate to attitudes, behaviour, or adherence to medication treatment. As such, Williams & Healy (2001) recommended the term 'explanatory map' rather than 'model', reflecting the diversity and complexity found within systems of health beliefs. The complexity, variation, and action-orientation of accounts provides a rationale for adopting an ethnographic approach to explanatory styles and models, which can account for the contradictory and fluid nature of explanations, as they are used to perform particular types of interactional 'work' within specific contexts. The framing and format of theories and models is also vital in considering the implications of explanatory models for identity (e.g. see Dar-Nimrod & Heine, 2011 on genetics and determinism, and Keehner, Mayberry, & Fischer, 2011, on the format of neuroimaging), as is individual understanding and interpretation (Condit, 1999; Laegsgaard et al., 2010). For instance, there are variations in the styles of genetic accounts, and there has also arguably been a shift within contemporary genetic accounts of mental illness from deterministic to complex susceptibility models *(Rose, 2007).* This highlights the importance of exploring the communication, interpretation and incorporation of causal ideas by different agents within context-specific encounters.

Similarly, just as explanatory styles are complex and context specific, identity is also a complex, multi-faceted and fluid concept. The notion of identity in this thesis is influenced by the social-interactionist work of Erving Goffman (1959; 1963), who described identity as a performance that is formed during social micro-interactions in order to achieve particular social effects – defined as 'identity-work' (Goffman, 1959). Within this tradition, identity is not a static or consistent state of being, but a flexible,

changeable, and at times contradictory way of doing and performing. As such, there is a need for studying stigma within the real world of everyday interaction in which the 'spoiling' of identity occurs (Goffman, 1963). Within a health context, it is within such subtle everyday interactions that patients are configured and constituted in order to accomplish organisational and ordering work (e.g. Latimer, 1997, 2000). One particularly appropriate place for exploring the implications of diagnostic and explanatory accounts would arguably be the clinical mental health setting, where psychiatric diagnosis and formulation occur, and where diagnostic identities are particularly salient.

Within mental health settings, explanatory models may fulfil particular functions, such as shaping clients' understandings of their own problems, allocating blame and responsibility, and guiding clinical decision making. Several survey-based studies have examined professional beliefs regarding causality and their corresponding attitudes towards patients within mental health contexts; for instance, Colombo et al. (2003) found that different implicit models held by professionals in a Community Mental Health Team (CMHT) informed professional understandings of schizophrenia, the appropriateness of different care options, as well as patient rights and obligations. Another study determined that beliefs in the controllability of patient behaviour was linked to critical staff attitudes towards patients on psychiatric wards (Barrowclough et al., 2001), suggesting that causal attributions could influence staff attitudes and staff-patient interactions. Research has also found evidence of mind/body dualisms within psychiatric thinking (e.g. Harland et al., 2009; Miresco & Kirmayer, 2006). As suggested by Miresco & Kirmayer (2006), such dualistic clinical reasoning reflects implicit attributions of patients' responsibility for their symptoms; they found that psychological causation (and to a certain extent, social causation) was associated with illness controllability and blameworthiness, whereas the opposite was found for behaviours with a biological aetiology. The authors suggested that further research should aim to understand how causal explanations are used for particular purposes by professionals, functioning as a means to alleviate blame, to encourage responsibility, or - as some research has indicated - to justify treatment coercion by using biomedical discourses (Cutliffe & Happell, 2009). Harland et al. (2009) also

highlighted the need for qualitative exploration of attitudes and decision making in actual clinical situations, since the use of questionnaires may capture idealised attitudes that do not represent those expressed in real world clinical contexts.

Nonetheless, previous research on the clinical implications of explanatory models has been predominantly quantitative, thus decontextualising and ignoring the often-subtle social actions performed by explanations. 'Artificial' methods such as experiments and survey interviews cannot adequately capture the meaning of everyday social activities and processes, a task that is better suited to qualitative and particularly ethnographic methods (Hammersley & Atkinson, 2007); such an approach is arguably necessary in order to grasp the personal and social meanings attached to neuroscientific ideas. Since medicine (and psychiatry) are arguably central to current understandings of the self, there is a need to further explore the "transactions between expertise and subjectivity" (Rose, 2007), in which patients are encouraged to reform themselves by working upon their own minds and bodies. Mental health professionals are key providers of dominant health narratives, and professional-patient interactions are conceivably key sites whereby professional 'knowledge' shapes and transforms patient identities (White & Epston, 1990). Patients come to mental health settings with pre-conceived ideas on causal factors, which may reflect social and cultural differences, and may also influence professional-patient relations (Mcabe & Priebe, 2004). Differing or contradictory understandings of patient illness, disease frameworks or cultural context can effect therapeutic relationships (Kleinman, Eisenberg, & Good, 1978), preventing the shared ownership of explanatory narratives. Hunter (1991) argued that this has been a central point of contention between doctors and patients, often revolving around factors such as language style and the prioritisation of one version over another.

The limited number of qualitative studies that have been conducted have also indicated an implicit mind-brain dualism within psychiatric thinking (Luhrman, 2000; Dobranski, 2009; Kirmayer, 1988, 1994). For instance, Luhrmann's (2000) ethnographic research on the psychodynamic – biomedical divide within US Psychiatry suggested that biomedical explanations can reduce responsibility by seeming to situate illness and its aetiology outside of identity and personal volition, whereas

psychodynamic models tend to locate responsibility within individuals themselves. There have also been a number of ethnographic studies on diagnostic cultures, such as Emily Martin's (2007) study of mania in US culture, and Sven Brinkmann's (2016) study of adult ADHD in Danish support groups. However, there has been a notable deficiency in such research within a UK context, which may be significantly different to that of other countries[16]; the current thesis seeks to address this gap by exploring the role of diagnostic and explanatory concepts and practices in categorising patients, and in shaping patient identities and self-practices within UK mental health settings.

Conclusions and research aims

As this chapter has emphasised, the implications of neuroscientific and biogenetic knowledge for identity and selfhood cannot be easily typified as either wholly positive or negative. The empirical research suggests that neuroscientific explanations are unlikely to eliminate the stigma surrounding mental disorder and that in some cases, they may in fact increase prejudice by reinforcing the boundaries that separate different categories of people. As the complex picture emerging from this body of research suggests, the effects of neurobiological understandings seem to vary across different social groups, contexts, and diagnosis; for example, biogenetic explanations appear to be most harmful in relation to schizophrenia, a diagnosis that is particularly afflicted by stereotypes of violence and dangerousness (Schnittker, 2008). Few of the studies reviewed have focused on bipolar disorder specifically, with the majority focusing upon schizophrenia and unipolar depression. In fact, as others have indicated (e.g., Bonnington & Rose, 2014; Ellison, Mason, & Scior, 2013), much of the research on stigma has focused more generally upon schizophrenia and depression, with bipolar disorder largely absent from the literature.

Much of the research conducted has also assumed the homogeneity of 'biogenetic' and 'psychosocial' explanations, although those studies that have considered

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[16] In the US for instance, diagnosis is important for reimbursement purposes; additionally, direct to consumer marketing of pharmaceuticals is allowed.

variations within these larger categories have indicated that different sub-types of explanation (e.g. brain disease, chemical imbalance, genetics, etc.) may produce substantially different effects. Much may also depend upon the mode in which illness concepts are framed and understood by different stakeholders. As O'Connor and Joffe (2013) argued, neuroscience does not impose a single narrative of personhood onto the public, and individuals do not passively receive this knowledge in a straightforward manner, but actively use, build upon and assimilate scientific information into pre-existing narratives and belief systems. As such, they suggest that the priority for social researchers should revolve around the investigation of contexts within and the means by which neuroscientific understandings of selfhood exert their impacts. This thesis aims to achieve this by exploring the deployment and assimilation of the diagnostic and somatic notions of selfhood within the specific context of different mental health settings. The following research questions have been considered:

1) What function do psychiatric diagnoses play in the everyday ordering and configuring work of patients by professionals in mental health settings?

2) How are biological and molecular/somatic visions of personhood mobilised and prioritised by mental health professionals and patients, and what are the implications for identity and expectations regarding self-management?

3) How is bipolar disorder in particular conceptualised by professionals and patients?

Chapter 3: Methodology

This chapter will begin by providing an account of the methodological approach taken within this thesis, locating the research within the context of an ethnographic framework, which draws upon critical traditions within the social sciences. I will then outline the research process, beginning with the selection of research sites and case sampling within settings, followed by a description of the main research sites in which observations were conducted: Community Mental Health Teams (CMHTs), the second opinion clinic, and the psychoeducation programme for bipolar disorder (BPC). The difficulties in obtaining NHS ethical approval for the study and its consequences for the research will then be considered, and I will reflect upon some of the disparities that emerged between the institutional ethical principles guiding my research conduct and procedures, and my own personal ethical concerns experienced during fieldwork. I then describe the process of data gathering; this will begin with a reflection upon the difficulties and successes encountered during attempts to establish and maintain access to the different research settings, and a consideration of the quality of access achieved and its implications in shaping the study. I will then move on to describe the procedures and practicalities involved in recruiting, observing and interviewing participants, and will outline the approach taken to data analysis. Lastly, some of the potential drawbacks of using ethnography will be considered, along with the potential limitations of the current study.

Research Methodology: Ethnography

Observations constituted the main method of data 'collection' within this project. In using observational and ethnographic approaches to psychiatric encounters, this study builds upon a considerable body of ethnographic work already conducted in medical settings (e.g. Allen, 2000, Atkinson, 1995; Bosk, 1979; Dodier & Camus, 1998; Dingwall & Murray, 1983; Jeffery, 1979; Latimer, 2000; Hillman, 2014, Hughes, 1988), and mental health settings (e.g. Dobranski, 2009; Lakoff, 2006; Luhrman, 2000; Martin, 2009, Brinkmann, 2016; Ware et al., 2000 etc.).

While its meaning has been somewhat contested (Hammersley & Atkinson, 2007), in practical terms ethnography usually involves the researcher participating, overtly or covertly, in people's daily lives for an extended period of time, watching what happens, listening to what is said, asking questions through informal and formal interviews, collecting documents and artefacts, and gathering any available data which may pertain to the emerging focus of inquiry (Hammersley & Atkinson, 2007). This mostly involves studying individual and group behaviour within everyday contexts (as opposed to experimental conditions set up by the researcher), and data collection is normally flexible and unstructured to avoid pre-fixed arrangements that impose categories on people's behaviour. Participant observation – the primary method associated with ethnography - is a deep investigation of social life and experience, which requires becoming involved in social life in order to see and experience how daily life activities are practised (Lofland, Snow, Anderson, & Lofland, 2006). Through participating in a studied community, culture, or organisation, the researcher becomes able to interpret the meanings, functions, and consequences of specific human actions, events and institutional practices, whilst attempting to consider how these are implicated in both local and wider contexts (Hammersley & Atkinson, 2007).

As has been previously mentioned, previous research relating to psychiatric models, diagnosis, and identity, has tended to use quantitative methods – often focusing on the relative merits of 'biomedical' vs. 'psychosocial' models of disorder. This type of research tends to remove diagnostic models and explanations from the language of relationships and everyday interaction in which stigma is grounded (Goffman, 1963), overlooking the complex ways in which explanatory discourses can be combined, framed, and used for specific purposes by different groups. Even previous research on the clinical implications of explanatory models has been predominantly quantitative, thus decontextualizing and ignoring the often-subtle social actions carried out by explanations (e.g. Barrowclough et al., 2001; Bhui & Bugra, 2002; Colombo et al., 2003; Harland et al., 2009; Miresco & Kirmayer, 2006).

Ethnography - in contrast to 'artificial' methods such as experiments and survey interviews - facilitates the understanding of the meanings that give form and content to everyday social processes (Hammersley & Atkinson, 2007). This methodology takes

a detailed and context-sensitive approach to interaction, enabling the consideration of the implicit and unspoken, whilst also providing a more holistic overview of processes and interactions, locating accounts within their socio-historic context, e.g. wider discourses that are often associated with institutions, such as government policy (Riley, Thompson, and Griffin, 2010). Ethnographic accounts - which are complex, situated and practise relevant, attending to "particular actions judged in particular circumstances" – are arguably ideal for studying the meanings associated with mental health problems, which are also complex, context-dependent, and multi-faceted (Pilgrim, 2009, p.477). Therefore, the current study sought to explore the complexities of (formal and informal) categorisation, decision making and diagnostic work, by observing their unfolding and enactment within mental health settings.

The ethnographic approach taken within this work is also somewhat influenced by recent linguistic/discursive and critical traditions within the social sciences (Hammersley & Atkinson, 2007). While an ethnographic approach generally involves a broad focus on different aspects of social life (e.g. space, time, material objects, concrete actions and events etc.), and while I did not conduct a discourse analysis of the data, my foremost concern during fieldwork was with the talk and language use in observed interactions. Through looking at how people talk about mental states and psychological concepts - such as emotions, minds, and identity - I was interested in studying the criteria and practices through which psychological life becomes constituted and recognised by specific communities.

Similarly, to linguistic ethnography - and other broadly discursive traditions – this research takes a post-structuralist orientation by critiquing essentialist accounts of social life (Creese, 2008). The view of language taken throughout this thesis, is that language is not a mirror by which we can perfectly reflect the world, but is active in constituting versions of reality: Language is not able to merely describe reality, since describing is a complex social process and a form of situated activity, and discourse is always rhetorical and action orientated (Potter & Edwards, 1990). This thesis takes an interest in the discursive patterns and practices found in everyday interactions - such as the management of facts, interest, and accountability (e.g. avoiding blame) - and in situating these within the dynamics of wider cultural settings and broader socio-

historical contexts (Wetherell, 2007). In a similar way to discourse analysis, the analysis also attends to the subtle, implicit and tacit aspects of conversation (Madill, 2015). This is vital for studying interactions, because much of the rhetorical work accomplished is likely to be on an implicit level; for instance, within psychiatric interactions, the use or recommendation of a particular intervention *in itself* can imply that a disorder has a specific cause, which is being targeted by the treatment.

This research has also been informed by critical social theory, in that it concerns the structures and policies that create the conditions in which dominant understandings and narratives about mental disorder are formed and maintained. Critical social theory is concerned with the power dynamics which shape decisions about what knowledge is relevant, what questions are worth asking, and whose voices are considered; language is seen as having a key role in constructing knowledge and common-sense accounts, and thus attention to discourse is a vital part of critical enquiry (Browne, 2000). In this sense, this work takes a similar approach to critical ethnographic enquiry, which aims to illuminate the seemingly neutral and taken for granted assumptions which underlie processes of unfairness or injustice within particular cultures and environments (Madison, 2012, p. 5). Particular influences on this study derive from the work of critical historical scholars such as Michel Foucault (e.g. Foucault, 1967; 1977), and more specifically the work of Nikolas Rose concerning the making up of subjects under the influence of the "psy-disciplines" (e.g. Rose, 1996, 1998, 2007; Rose & Abi-Rached, 2013).

Choice of Research Settings

Observations were conducted within three community mental health teams (CMHTs), and a second opinion clinic within the local health board, as well as a psychoeducation programme for individuals with a bipolar diagnosis. CMHTs include staff from social care, nursing, psychiatry, psychology and occupational therapy. These are therefore ideal settings in which to examine how explanatory accounts might be involved in diagnosis and decision-making regarding patient care, and in reinforcing professional

identities and power structures. The initial appointments observed within the CMHTs – lasting around an hour - all involved a fairly thorough exploration of personal history and social/psychological factors with patients. Similarly, the second opinion consultations often last over an hour, providing ample time to explore client background and biography. The psycho-education programmed provided a context whereby diagnosis was explained, interpreted and co-constructed by participants and facilitators; of particular interest were sessions on the nature and causes of bipolar disorder, which meant that current etiological theories and their implications for those with a bipolar diagnosis, could also be considered.

Mental health professionals are key providers of dominant health narratives, and the chosen sites - which broadly involve professional-patient interactions of some kind - are arguably key sites whereby professional 'knowledge' shapes and transforms patient identities (White & Epston, 1990). A relative emphasis on particular types of explanations for deterioration or non-improvement (e.g. personality based, explanations involving neuro-transmitters etc.) are likely to be involved in performing or shaping identities. I was interested in how accounts regarding mental ill health would perform particular rhetorical functions, such as shaping clients' understandings of their own problems, guiding behaviour, allocating blame and responsibility, and decision making within a multi-disciplinary context. Witnessing professional-patient interactions also allowed a consideration of the role played by diagnosis and explanatory styles in maintaining particular types of relationships, both between professionals, and between professionals and clients.

The interactions observed within this study are defined as 'naturalistic' in the sense that they have not been generated primarily through interaction with the researcher (with the exception of formal interviews), but would have been generated irrespective of the researcher's activities (Potter, 2002). The commitment to observing such 'naturalistic' interactions, does not amount to a naïve form of naturalism however; a clinical consultation is admittedly no more 'natural' than an arranged interview between a researcher and a participant. Rather, studying the phenomenon of diagnosis in 'real-world' settings (especially in settings where diagnostic identities are

salient) was deemed to be important, because these are arguably sites where particularly significant identity work takes place for patients.

Case sampling within & beyond 'settings'

Hammersley and Atkinson (2007) suggest that to talk of 'studying a setting' can be misleading, since it is impossible to give an exhaustive account of any locale; we are always somewhat selective in our descriptions; when sampling within broad cases (e.g. psychiatric diagnosis), decisions must be made about where to observe and when, who to talk to and what to ask, as well as about what to record and how. Additionally, they argue that the naturalistic preoccupation of 'studying fields' and 'settings' discourages the explicit selection of aspects of a setting for study, as well as movement outside of it to follow up promising theoretical leads. Since a case may not be contained within the boundaries of a setting, it may be necessary to go outside to collect information on important aspects of it (Hammersley & Atkinson, 2007). Correspondingly, in the current research, I chose to study a variety of different settings – partly due to convenience and potential access – but also partly in order to explore diagnostic talk across the boundaries of settings.

The broad emphasis within this study was on diagnostic talk and conceptualisation within professional-patient interaction; as such, several settings were selected which would capture this type of interaction - diagnostic and screening interactions within mental health services, and educational courses for bipolar disorder. Following the case across different settings meant that different facets of the diagnostic journey could be explored, extending beyond the initial point of diagnosis: Observing initial screening and consultations provided insight into the process of diagnosis, including the types of negotiation and identity work involved in making diagnosis relevant for particular purposes; observing education courses and conducting interviews with service users meant that aspects of diagnostic performativity and conceptualisation following diagnosis could be considered. Gathering a corpus of materials across multiple contexts has been cited as one of the advantages of using ethnographic

methods (Silverman, 1993). Examining talk and interaction within different contexts can allow comparisons to be drawn across difference types of data, and can also help illuminate the occasioned nature of talk, highlighting the variability of narratives in different contexts and points in time. It was also thought that sampling across multiple settings would increase the chances of capturing a broader range of discourses relating to diverse aetiological factors, e.g. genetic, social, personality etc.

Since it was interactions of a broadly diagnostic nature which were of interest, as opposed to the institutions in themselves, many of the diverse range of activities occurring within CMHTs, were not observed (e.g. therapy sessions with psychologists, home visits, depot injections etc.). Interactions were selected according to whether they were considered likely to involve conversations regarding diagnosis and causality. For instance, diagnostic consultations ideally involve taking detailed family and personal histories from patients, since such details can provide clues as to the nature of the disorder; a diagnostic formulation should also be provided at the end of an assessment, which will often contain a hypothesis regarding potential causes or triggers (Tyrer, 2013). Observing such encounters therefore seemed a suitable means of exploring how professionals might communicate with patients regarding the causes of their difficulties, how this might be involved in the processes of clinical decision making, and in shaping patient identities and professional-patient relationships in particular ways.

Although the initial aim was to 'sample' interactions where diagnosis would be discussed between professionals and patients, it is also likely that relevant insights would also have been derived from observing almost any of the professional/patient encounters within the CMTHs; diagnosis may be potentially discussed in almost any encounter (both within mental health settings and outside of mental health settings). However, choices had to be made regarding which activities would be most appropriate to observe; in addition, as is often the case with ethnographic studies, choice was limited to what was accessible at the time of conducting the research (Hammersley & Atkinson, 2007) (see section on 'gaining & maintaining access'); sampling was therefore partly convenience and partly purposive.

Description of Research Settings

The role & structure of Community Mental Health Teams

This section will provide a brief description of the nature and function of community mental health teams (CMHTs) within UK mental health services; in particular, the role of CMHTs as gatekeepers for secondary mental health services will be outlined. The implications of trends towards the prioritisation of those considered to be 'severely mentally ill' within UK mental health policy (e.g. Department of Health (DoH), 1995, 1999 a, b), for CMHT referral and assessment processes will also be considered. This will provide insight into the wider social and structural contexts shaping the interactions and processes within these settings.

CMHTs are specialist, multi-disciplinary, multi-agency teams which provide expert mental health assessments and interventions to individuals accessing services (Welsh Assembly Government (WAG), 2010). They form a central role in secondary mental health care service delivery, by screening people referred to secondary services, and delivering a range of medical, social care and psychological interventions. CMHTs bring together specialist medical, nursing, occupational therapy, psychology, social work, support workers and administrative staff within a team and a single integrated management structure (WAG, 2010). The Integrated Team Manager (ITM), who may be from a health or social background, is responsible for the day to day operation of the CMHT, for the delivery of the services provided, and for ensuring the delivery of effective clinical care for individual service users through coordination of the team (Cardiff and Vale University Health Board (CVUHB), 2012). In addition, a social work lead and a nurse lead oversee workers based within social care and nursing professions.

Referral and assessment in Community Mental Health Teams

CMHTs undertake screening assessments of patients, and where allocation within the team is viewed to be appropriate, provide a range of more specialist assessments and

interventions. Referrals are mostly received from primary care, but also from a range of agencies, such as: Other secondary care services; police and criminal justice agencies; housing officers; social services; and non-statutory partner agencies such as Mind, Gofal and Hafal (CVUHB, 2012). Additionally, under the Mental Health (Wales) act (2010), people who have been in receipt of support from secondary care services (CMHTs) and have been discharged within the last three years are able to self-refer directly for assessment, without referral from a GP. During fieldwork, however, the vast majority of referrals appeared to have come from GPs.

CMHT services are offered mostly - although not exclusively - to adults of working age (18-65), who require assessment by a specialist mental health professional (CVUHB, 2012). Following screening, patients may be referred on to specialist services (such as eating disorder services, or crisis resolution & home treatment teams (CRHTT), be taken on by the CMHT or referred back to Primary Care (CVUHB, 2012). Appropriate CMHT services are offered if needs for mental health or social care services are identified (CVUHB, 2012). Following assessments, assessors discuss individual cases with colleagues at MDT meetings, where an agreed decision is made regarding the appropriate course of action; previous research however, suggests that assessors' views are rarely challenged directly in MDT meetings, which often function to reinforce accepted norms, and strengthen the assessors' inclination to direct less 'appropriate' patients towards other services (McEvoy & Richards, 2007).

Guidance from the Cardiff & Vale operational policy (CVUHB, 2012), suggests that referral for CMHT assessment should be made under the following conditions: Severe mental disorder; complex mental disorder or mental disorder associated with significant risk to self or others, e.g. violent behaviour, clear suicidal intent, severe self-harming, or in cases where there are vulnerable dependents – such as children; where there is diagnostic uncertainty; where there are symptoms of psychosis or elevated mood associated with behavioural disturbance and/or lack of judgement (CVUHB 2012). The guidance therefore prioritises patients on the basis of severity, complexity, and risk.

Although this list seems fairly all-encompassing and inclusive, a privileging of those with a diagnosis of schizophrenia and bipolar disorder appears to be built into policy

guidance, since they are labelled as '*severe, difficult to manage and persistent mental illness*', which should be prioritised by services. For example: -

> "*Decisions on whether someone should be accepted for services should always be based on their health and social care needs as a whole and not on diagnosis alone. However, following an assessment of need, **priority for services will be given as shown below***:

> • *Service users with **severe, difficult to manage and persistent mental illness**, such as schizophrenia, severe depression, or **bipolar disorder.***

> • *Longer term disorders of lesser severity but which are characterised by poor treatment adherence requiring proactive follow up.*

> • *Any disorder where there is significant risk of self-harm or harm to others (e.g. acute depression, anorexia, high levels of anxiety) where the level of support exceeds that which the primary care team can offer.*

> • *Pregnant mothers suffering any type of mental disorder.*" (CVUHB, 2012, p. 7).

Those with Schizophrenia spectrum disorders, bipolar disorder and severe depression are therefore likely to make up a large proportion of those treated under CMHTs, since these disorders are prioritised for CMHT service provision (CVUHB, 2012). The Department of Health (DoH, 1995, 1999 a, b; 2002) has consistently recommended that CMHTs are meant to target services towards those in the greatest need, and prioritise interventions based on an assessment of need, risk and vulnerability for individuals whose complexity of care cannot be met within primary care. This is consistent with findings suggesting that gatekeeping clinicians within CMHTs now appear to be more tightly constrained and are targeting patients with severe mental illness (SMI) (Barr, 2000; Keown, Holloway, & Kuipers, 2002; McEvoy et al., 2000; McEvoy & Richards, 2007). There have been some difficulties in agreeing upon definitions of severe mental illness (SMI), a term which can involve considerable interpretation by individual decision makers (e.g. see McEvoy & Richards, 2007). Once again however, there is evidence to suggest that CMHT professionals may consider

both Schizophrenia and Bipolar Disorder as particularly representative of SMI (McEvoy & Richards, 2007; King, 2001).

Further difficulties arise from the incapacity of primary care to support those experiencing 'common mental health problems', the lack of alternative provision, and managerial reluctance to challenge clinical decisions (Peck, 2004; Colombo et al., 2003; Onyett, Standen, & Peck, 1997; Peck & Hills, 2000; Simpson et al., 2003). Additionally, although the focus on provision of CMHT services should be on those with a severe and/or enduring mental disorder, the Welsh Assembly Government (2010) also include the following as coming under the remit of CMHTs: *'Individuals with complex need which exceeds that which a primary care or tier one service could offer'* (WAG (2010). *G*iven the low intensity support provided by primary mental health services, a great many individuals could arguably fall into this category.

Within the observed teams, the screening process would begin with a small initial MDT meeting (overseen by the ITM, and usually including the consultant psychiatrist, nurse and social work lead), where referral letters would be screened, and decisions made regarding which referrals to invite for screening assessment. There was often talk regarding "inappropriate referrals" from GPs amongst team members (both inside and outside of these meetings), reflecting evidence of tensions between the views of referrers (usually GPs) and CMHT team leaders (Chew-Graham, Slade, Montana, Stewart & Gask, 2007; McEvoy & Richards, 2007; see also Shaw, Smith, Middleton & Woodward, 2005). The type of initial assessment would also be decided upon within this meeting, and patients would be accepted for GA (general assessment), or for MA (medical assessment with a Psychiatrist). Those allocated to MA usually concerned specific queries regarding diagnosis and/or medication, although a number of individuals attending GA also seemed to have specific queries regarding diagnosis.

Those invited for GA would be assessed by two team members (usually a combination of CPNs, Social workers, or Occupational Therapists); assessments would last around an hour, and would involve a comprehensive and holistic exploration of an individual's mental, physical and social health, taking into consideration a range of social and psychological contextual factors, e.g. family, friendships, work, education, interests/ hobbies, drug/alcohol use, lifestyle factors, accommodation, and involvement in the

CJS. Although, assessments styles were fairly flexible, an interview guide (used consistently across the health board) was used to ensure coverage of all appropriate topics. Usually, one professional would take the lead in questioning, while the other would write down patients' responses to questions, sometimes interjecting and asking a question themselves. At the beginning of assessments, patients signed a disclosure agreement allowing the sharing of confidential information gathered at assessment and during ongoing interventions with other team members and wider mental health/ social services.

Professionals would discuss individual cases in the general MDT meeting (in particular they would often seek advice from the consultant psychiatrist on whether any further psychiatric input might be appropriate, e.g. regarding medication or diagnosis); however, although official decisions regarding assessment outcomes were not made until following these meetings, patients would usually be given some idea about the outcome during assessments. At the end of assessments, professionals would normally provide a summary/formulation of patients' difficulties, along with suggestions regarding possible courses of action. There would be some indication here of whether or not they were considered to be appropriate recipients of CMHT care. This was often indicated explicitly, but could also be suggested implicitly through signposting to various PMH services (e.g. short CBT courses on stress reduction and mood management), or attempts to dissuade from any notions they might have regarding a diagnosis, etc. Patients would then be formally notified of the outcome by letter. All three ITMs estimated that around 70% of GAs were referred back to primary mental health services.

The following section will move on to provide a description of the specific research settings in which observations took place will also provide context for the study: the CMHTs; the second opinion psychiatric clinic, and the BPC psychoeducation course.

Community Mental Health Teams (CMHTs): Research Sites

Whilst the depth of access obtained in the CMHTs was not ideal for an ethnographic study, the accessing of three different clinics did allow for some comparisons to be

made. For instance, both CMHT B and C were based in areas of relative economic deprivation, whereas CMHT A was based in a more affluent area of the city; also, being nearby to local university halls of residences, it received large numbers of student referrals. As this was the setting in which most of the observations were conducted, it is likely that the high level of students assessed would have shaped the findings. It is possible, for instance, that students are not taken as seriously in encounters where professionals are looking for signs of severe and enduring mental illness, since they may be assumed to have a level of self-awareness and mental health literacy, factors which may seem to contraindicate mental illness.

In contrast to the second opinion clinic - which was situated in a modern building within a prominent University research centre - the three CMHTs were based in fairly old buildings (CMHTs A & C were both based in semi-detached houses, whilst CMHT B was located in an old infirmary). In addition, none were obviously signposted as mental health clinics. All had seated waiting areas, containing noticeboards covered with pamphlets advertising local mental health organisations and groups. Reception areas were all situated behind a glass screen, providing a view of the waiting area, but only accessible by staff members. Both CMHTs B & C had CCTV and intercoms positioned at the main entrances, so that reception staff could screen incomers, whereas CMHT A did not.

Assessment and treatment rooms were located in a secure part of the buildings (i.e. a key code was necessary to access these areas – patients were taken through to this part of the building from the waiting area for appointments etc.). Staff offices and working stations (the 'backstage' areas) tended to be located separately from assessment and treatment rooms (in CMHTs A & C, the main staff working spaces were located on the first floors, while the psychiatrists, reception staff, and treatment rooms were on the ground floors). In all three teams, the Psychiatrists occupied their own private offices (and often had access to their own secretaries), located separately to the more communal offices where the remainder of the team members were based. This (in addition to the deference shown towards them by other staff members) did seem to suggest that Psychiatrists retained a higher status within the teams; this is in spite of recent trends which have allegedly seen the "creeping

devaluation of medicine" (Craddock et al., 2008, p.6), following the move towards distributed responsibility and leadership within secondary mental health care, encouraged by the 'new ways of working'[17] model.

All three teams provided a range of different interventions, ranging from diagnostic and pharmacological intervention, intensive and longer-term psychotherapy (usually provided by clinical psychologists, but also by other staff members trained to deliver specialised therapies such as DBT, CBT etc.), group therapies, and one-to-one support from social workers, CPNs, and occupational therapists. Staff would therefore be involved in a range of activities, e.g. home visits, conducting routine and emergency assessments, attending MDT meetings, and running therapy groups etc. Apart from the Psychiatrists, Psychologists and the ITMs, most clinical staff took part in conducting general assessments on a rotation basis.

The psychiatric second opinion clinic

The main purpose of a second opinion consultation is to review a patient's primary diagnoses. In the UK, while patients do not have a legal right to a second opinion on their diagnosis, they are entitled to request one, and – according to NHS England - many trusts have arrangements in place for second opinion requests, although not all trusts offer *specialist* second opinion services[18] (i.e. where the consultant has a specialist expertise regarding a particular diagnostic area). For bipolar disorder, NICE guidelines recommend the accessibility of such specialist services (2014), although in the UK there has been a lack of research regarding the activities and outcomes of these services (Shepherd, Insole, Mcallister-Williams & Ferrier, 2009).

Medical sociologists have noted how the democratisation of health may have undermined the status and authority of medical professionals, altering their

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1. Royal College of Psychiatrists and National Institute for Mental Health in England. *New Ways of Working for Psychiatrists: Enhancing Effective, Person-centred Services through New Ways of Working in Multidisciplinary and Multi-agency Contexts. Final Report 'But Not the End of the Story'*. Department of Health, 2005.
   (http://www.newwaysofworking.org.uk/psychiatry/psychiatry_documents.aspx).
[18] https://www.nhs.uk/NHSEngland/AboutNHSservices/mental-health-services-explained/Pages/your-mental-health-assessment.aspx

relationship with service users. Wider access to health information (particularly from the internet), has made patients more willing to challenge their doctor, dispute findings, or seek advice outside the doctor-patient relationship (Lupton, 1997). It is perhaps in this context that second opinion clinics are particularly interesting, given their role in providing more specialised services to those who are questioning or disputing their diagnosis.

Most of these specialist psychiatric clinics in the UK are based within academic research centres (Shepherd, Insole, Mcallister-Williams & Ferrier, 2009). The second opinion clinic in the current study was located within the same local mental health research centre with which the BPC course was affiliated; the centre's research focuses heavily on the biological and genetic aspects of psychiatric, neurodevelopmental and neurodegenerative disorders, aiming to better understand the causes of these disorders, to develop new approaches to diagnosis, and to identify novel treatment targets. The six clinicians working in the clinic, were also employed as researchers at the institute, specialising in different areas of psychiatry, e.g. mood and psychotic disorders, peri-natal mental health, Post-Traumatic Stress Disorder, and childhood psychiatry. Each clinician tended to accept referrals relating to their specialist area of knowledge, and the clinician I observed specialised in bipolar disorder and peri-natal mental health. All five of the observed appointments involved female participants with mood disorders; three concerned a queried diagnosis of bipolar disorder; all five had potential gynaecological concerns, while three wanted (in addition to diagnostic advice) further guidance on family planning. Those patients with a potential/tentative diagnosis of bipolar disorder were asked to take part in the centre's research activity following appointments.

Unlike the BPC courses, where self-referral is possible, requests for a diagnostic second opinion at the clinic are only accepted from the secondary health care team with current primary clinical responsibility for the patient. The Second Opinion Clinic is a tertiary-referral service that provides one-off mental health assessments for patients, but is not involved in providing ongoing care. Patients are often referred

from different trusts across the UK, with some taking place via Skype[19]. Patients are encouraged to bring a close family member to the consultation, and in all five of the appointments observed, patients had opted to bring at least one family member with them (in all cases, either a parent or a spouse). Following assessments, the consultant may suggest an alternative diagnosis or confirm the pre-existing diagnosis, and may recommend alternative types of treatment, although they are not able to initiate new treatments, without first discussing this with the patient's senior clinician. Compared with initial appointments within CMHTs, which lasted around an hour, the second opinion appointments tended to be longer – with some lasting over two hours.

Psychoeducation courses & the BPC programme

Psychoeducation is an evidence-based therapeutic intervention, which provides information regarding a specific disorder and its management to patients and their families, in order to help them cope better with the disorder. These interventions can take place in a one-to-one, or group format, are normally led by qualified mental health professionals, and have had a tendency to privilege a more 'medical' view of bipolar disorder, emphasising the biological in addition to the psychosocial aspects of the condition (Smith, Jones & Simpson, 2010). The potential for psychoeducation in the treatment of bipolar disorder and schizophrenia has received increasing attention in recent years, and a number of studies have suggested its efficacy in lowering relapse rates and improving treatment adherence for these disorders (e.g. Castle et al., 2010; Colom et al., 2003; 2009; Miklowitz et al., 2009; Pekkala & Merinder, 2002; Pitschel-Walz et al., 2006)[20]. This form of therapy is recommended by NICE guidelines (2014) for the treatment of bipolar disorder, although a formal structured delivery of psychoeducation is rarely available within the NHS (Smith, Jones, & Simpson, 2010).

The course observed for the current study - the BPC - was developed by a group of researchers based in a local mental health research centre, with a strong focus on

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[19] I did not observe any of the consultations taking place via Skype.
[20] Although there remains some uncertainty as to the precise mechanisms producing these positive effects (Smith, Jones & Simpson, 2010).

psychiatric genetics[21]. The stated aim of the BPC programme is to help participants better understand bipolar disorder, identify early warning signs, and develop skills and strategies to help manage the condition. The programme consists of 10 weekly meetings; initially each session lasted for two hours, although this increased to 2.5 hours during the course of the research. The sessions consist of a combination of presentations, informal group discussions, and short exercises. Courses are held in different locations around Wales, and I attended courses in five different locations (although only four entire cohorts[22]).

The course is stated to be for those with a diagnosis of bipolar disorder; however, participants can self-refer onto the course – and while there is a telephone screening process, there is no requirement for people to *prove* their diagnosis. Screening interviews were carried out by the main facilitator to ascertain that individuals did have symptom patterns matching bipolar disorder, and also to gauge whether participants were currently well enough to attend courses. There tended, however, to be at least one individual in each cohort who was uncertain regarding their diagnostic status.

The main facilitator - James - was a psychiatric nurse (who also worked in a CMHT part time, whilst working for the research centre as BPC facilitator 2 days per week), who had been facilitating the BPC for many years (he had facilitated over 50 cohorts). Jess had very recently been employed as an administrator for the BPC course, and whilst not having a professional mental health background, helped co-facilitate the course. The third facilitator was Bridget – who had also recently joined the team as a service user facilitator after having attended a BPC course herself the previous year, and having suggested the need for a person with 'lived experience' to co-facilitate (she had previously been employed as a psychiatric geneticist, meaning she also had some specialist knowledge). Bridget's role differed to that of Jess and James – in that she would more often share her own personal experiences of managing the disorder,

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[21] Course attendees would always be invited to participate in the centre's research and encouraged to join mailing lists to hear about future opportunities.

[22] The REC recommended that I observe some BPC sessions prior to my re-application, in order to gain an understanding of the nature of sessions: several sessions were therefore observed prior to the start of data collection, and no notes were taken during these meetings.

(while James and Jess did not discuss their own mental health experiences with the group). Bridget also began co-facilitating at around the same time that I began observations, and many participants commented on the helpfulness of having someone with 'lived experience' running the course.

Despite being classed as an 'educational' course, the BPC was not delivered in lecture style for the most part; a number of slides would be displayed and delivered by facilitators throughout the 2-hour session, but much of the sessions were dedicated to group discussions (either prompted by material from the lecture slides or during group exercises). Such discussions were often lively and animated – but rarely heated or disrespectful. They often involved personal stories about illness experiences, psychotic/manic breaks, details about family life and relationships, and other such intimate details. This did mean that some sensitive 'material' would emerge during sessions, although arguably not to the same degree as in a more conventional form of psychotherapy. For example, although a few might have alluded to difficult childhood experiences – these were not generally discussed in detail on the course. A further example is that participants were also advised to complete a 'life chart', tracking the major mood shifts of their lives alongside relevant life events, in order to identify potential triggers and causes. James suggested that they do this at home as it could be upsetting due to its personal nature.

Participants were given some ground rules at the beginning of the course – one of which involved a respectful and tolerant attitude towards fellow participants, i.e. allowing others to speak, not interrupting or behaving disrespectfully etc. On the whole these rules were well adhered to by participants – although as in any group, certain individuals were more talkative than others, and the course facilitators attempted to minimise any such imbalances, by giving quieter individuals the opportunity to speak. In general, there was a relaxed and friendly atmosphere; conversation seemed to flow naturally, group members gave each other time to speak, and if one person was speaking the others listened respectfully, making helpful or thoughtful comments when appropriate. In all of the 5 groups observed, participants appeared to 'get on' well and to enjoy each other's company – with many vowing to stay in touch following the end of the course.

Although not technically a therapy or a peer-support group, it is in some ways treated as such by the group members, many of whom have not had the opportunity to share their experiences of their mental health difficulties with others with 'lived experience'. Indeed, the facilitators acknowledged a few times that they felt the main benefit of the course came more from the social aspect (i.e. meeting and socialising with others with the diagnosis) than from the 'educational' aspects of the sessions. The facilitators were also extremely sensitive in their approach to participants and in their delivery of course material. Although stigma was not a word frequently mentioned by them in discussions, it often seemed as though they would try to deliver information in as destigmatising a way as possible. For instance, whenever suggestions were given regarding lifestyle factors (e.g. going for a walk when depressed), this would often be with the addendum that this was obviously easier said than done and not always possible during periods of illness.

Obtaining Ethical Approval

In the UK, research using human subjects and NHS premises and facilities must be reviewed and approved by Research Ethics Committees (RECs). The functions of UK RECs are not only to protect patients and the public against harm from unethical research, but also to encourage research that will improve healthcare and health (Alberti, 2000). Both the local Trust (R & D) and the REC must approve the same protocol and accompanying paperwork before the research can proceed. There is a centralized system of application whereby researchers complete an online version of a research ethics application form – the IRAS system (Integrated Research Application System). Depending on whether the research is single-site or multi-site, on the type of research, and on whether the research involves clinical interventions or not, the process of application is slightly different (i.e. questions are included/eliminated according to relevance). Obtaining ethical approval for this project entailed the completion of a 10,000-word (approximately) research protocol, a 76-question IRAS form, and all research documentation (i.e. consent forms, information sheets,

recruitment letters etc.), which had to be scrutinised and approved by an NHS REC, and at a local level by an R & D committee. Additionally, under the Research Governance Framework for Health and Social Care in Wales, 2nd edition (2009), a sponsor organisation must be identified for all research studies. Prior to submission the protocol and all study documents therefore had to be approved by the University research and innovation service, in order that the university could act as the study sponsor.

The IRAS form suggests an expectation that the research design stage will actively involve patients, carers, and/or members of the public, since one of the questions asks for details regarding this - and justification in the case of not involving service users etc. Therefore, whilst designing the study, I sought guidance from the McPin foundation, who employ panels of individuals with lived experience of mental health issues to review and make suggestions on proposed research projects; information sheets and consent forms have also been reviewed by a panel of mental health service users (FAST-R), to ensure that they make sense. From the McPin foundation, two individuals provided reviews of the study; these seemed largely positive (see Appendix I), although some recommendations were made (e.g. interviewing people in a place of their choice e.g. at home, and providing remuneration to participants). One reviewer raised concerns that the study was excluding too many individuals (e.g. those who don't have a bipolar diagnosis, those who don't access services etc.).

Initial rejection & subsequent revision

The process of obtaining ethical approval involved having to make considerable amendments to the design of the project – which ultimately impacted upon the way data was collected. Following the submission of the IRAS forms, an appointment was made to attend a local REC meeting to discuss the research. This involved an interview style meeting with a panel of fifteen lay and (medical) professional committee members. In the initial meeting, concerns were raised regarding several factors (see Appendix II: *Letter of Unfavourable Opinion*), leading to an unfavourable opinion. In particular, there were concerns regarding the potential vulnerability and riskiness of

patients; there was some concern regarding issues of capacity (for instance, how would I be able to assess patient's capacity?), and the potential for patients to be harmed by taking part (presumably emotionally harmed). In addition, they appeared to assume that patients with bipolar disorder might be a potential risk to my safety, particularly as a lone researcher, suggesting:

"*that as patients have bipolar disorder, would it not be safer to conduct interviews on NHS premises or as standard have a second interviewer present if conducted at patient's home*" (Appendix II).

As a result of these concerns, it was decided that interviews would only be carried out within clinical settings, where access to support would be available if necessary. It was also clarified that capacity in patients is assumed and therefore it was not necessary for the researcher to assess for capacity. The Mental Capacity Act (MCA) (2005) stipulates that a person must be assumed to have capacity unless they are established not to have capacity, and an assessment of capacity should never be done because of the presence of a person's diagnosis alone. Since capacity to make informed decisions is situation specific, it was explained that time would be spent prior to interviews ensuring that participants understood what was involved in the study, in order to ensure that no misunderstandings have occurred. Furthermore, I would be relying on professional guidance with regards to the suitability of patients for the study.

The committee were also unhappy about the language use within the information sheets and consent forms, suggesting that I "*ask a service user and friend/colleague to read the information sheet for ease of use and clarity*" (Appendix II). Advice was sought on the wording of information sheets (from colleagues and FAST-R), and an attempt was made to make the information sheets as straightforward as possible. The information sheets had also originally made explicit reference to the study's intention to focus on those with a potential diagnosis of bipolar disorder, and the committee rightly pointed out that this would mean potentially alerting individuals to their potential diagnosis before any professional had spoken to them regarding this. It was decided that the study should be widened to include general mental health diagnosis,

rather than bipolar disorder specifically; this was partly in order to avoid alerting individuals to their potential diagnosis via the information sheet, but also because I had been advised by one of the IMs (CMHT A), that it would be difficult finding sufficient participants if I only observed those participants being assessed for bipolar disorder. With hindsight, this also would have been logistically more difficult to arrange and would have required more work on behalf of staff sending out my information sheets, since they would have been required to single out patients with a prospective diagnosis of bipolar disorder, whilst excluding all others from the study.

Following resubmission, a further REC meeting was attended, a few further clarifications were made, and approval was provided for the study. The next stage of the process was to obtain local R & D (Research & Development) approval from Cardiff & Vale University Health Board; this involved an independent scientific review by the Health board's CaRRS (Cardiff & Vale Research Review Service) committee, a joint UHB and Cardiff University research review Panel consisting of expert reviewers who assess research proposals to ensure they are of sound scientific or methodological quality and value, also considering any ethical problems which may arise from the study. The CaRRS committee also requested changes to be made to study documentation and protocol; although these were mostly less significant than the changes made for the REC.

Furthermore, approval had to be sought from the clinical lead of the intended research speciality (i.e. in my case both the lead for psychology and psychiatry had to be sought); they consider what directorate resources are involved, how costs will be met e.g. R & D set-up fee, locations, staff time, the appropriateness of clinical / management supervision arrangements, and whether the study is feasible. The clinical leads also recommended that the study be registered with the NISCHR Clinical Research Portfolio. The Clinical Research Portfolio is a register of high quality health and social care research studies active in Wales that meet specific eligibility criteria. Registration onto the Clinical Research Portfolio is central to the allocation of Activity Based Funding, obtaining NHS support costs for studies, and accessing Health and Care Research Wales resources. It also requires that all recruitment data is uploaded on to the online portfolio on a monthly basis.

Following further changes to the study documentation, R & D approval for the project was granted in April 2016, and fieldwork commenced.

RECs & qualitative Research with 'vulnerable' participants

Several social researchers have noted the fact that the application form for NHS REC review seems to have been designed for clinical trials rather than other types of research designs, with some also arguing that REC members often lack an understanding of qualitative and ethnographic social research (e.g. Angrosino & Mays de Perez, 2000; Hannigan & Allen, 2003; Richardson & McMullen, 2007). Hannigan & Allen (2003) suggest that qualitative researchers must often engage in a process of 'translation' when presenting their work to bodies - like RECs - which are more familiar with experimental and other quantitative approaches. Although for my own project, the REC in question did not seem to have any issues regarding the qualitative nature of the study, the expectations and the language used on the IRAS forms *did* seem to be designed with quantitative/experimental research in mind. For instance, questions asked for exact details regarding participant numbers, precise amounts of time required from professionals and patients (e.g. length of time it would take to read information sheets etc.), detailed recruitment procedures and inclusion/exclusion criteria, and possible benefits and 'harms' to participants.

Systems (such as RECs) which rely on formulaic guidelines can create difficulties for qualitative researchers (Dingwall, 1980); for example, once approval has been given, no changes can be made to the protocol or to any of the associated documents, without going back to the REC and R & D to gain permission for the change. However, when conducting iterative qualitative research, much of the information required by RECs before the start of the research may be difficult to know with any certainty until the research has begun and some data has been analysed (Richardson & McMullen, 2007). The unfolding and emerging nature of qualitative research can also make it difficult to fully inform participants about all the potential consequences of the research, since, often, ethical issues, may not become apparent until after the research has begun (Cieurzo & Keitel, 1999; Ramcharan & Cutliffe, 2001, p. 358).

Richardsen and McMullen (2007) argue that this creation of standardized review procedures has led to standardized research procedures, which "is one part of what has become a rather prescriptive, bureaucratic and rigid process in the NHS", involving a 'ritualistic adherence to ethical procedures' (Sin, 2005, p.279).

Such formulaic guidelines regarding procedures might also extend to formulaic notions of vulnerability in particular participant groups, such as those with psychiatric diagnoses. People experiencing mental health problems have often been viewed as especially vulnerable research subjects, due to assumptions of incompetence and non-autonomy (DuVal, 2004; Eichelman, Wikler, & Hartwig, 1984; Hewitt, 2007; Koivisto et al., 2001; see also Oeye, Bjelland & Skorpen, 2007); there is also evidence to suggest that RECs may be particularly concerned regarding research which involves this group (e.g. Hannigan & Allen, 2003; Osborn & Fulford, 2003). Oeye, Bjelland & Skorpen (2007) point out that traditionally, medical research ethics has relied upon the assumption that research participants are autonomous, self-determining, and free of any kind of coercion; they argue that psychiatric patients will rarely fulfil this ideal, due to the influence of illness, but also due to social factors such as stigma, poverty, and dependence. However, such apprehensiveness runs counter to guidance from the Royal College of Psychiatrists (RCP, 2011, p.1), which states that "the vast majority of people with a mental illness have the right to decide for themselves whether or not they wish to take part in a study", and that work must be done to challenge "erroneous and stigmatising" assumptions regarding the risks associated with psychiatric research, and to foster a positive research culture in mental health services.

With regards to my own application, both the REC and R & D did seem to have particular concerns regarding the vulnerability and risk associated with individuals who had mental health difficulties (e.g. the statement in the REC letter (Appendix II), implying that it could be unsafe for me to interview individuals with bipolar disorder in their homes, as a lone researcher). It was planned that anyone considered by professionals to be unable to provide informed consent, or as vulnerable and at-risk of being harmed by the study, would be excluded e.g. those currently or having very recently experienced psychosis or severe distress. Despite this precaution, both the REC and R & D still expressed concerns regarding the risks associated with the

research; therefore, all interviews had to be completed within a clinical setting, in order that professionals were on hand to provide support (presumably for both my own safety and also for participants' wellbeing). This factor did substantially shape the research, since it turned out to be difficult to interview patients within the clinical settings, and this led to the decision to interview service users recruited through 3rd sector organisations.

Institutional vs. personal ethics

Richardsen & McMullen (2007), argue that rather than relying only on mechanistic codes of ethical conduct and the involvement of institutional ethics committees to oversee research, researchers should be supported to become more morally active in their research activities. They suggest that there should be a greater emphasis on 'virtue ethics' - a style of ethical thinking that is less preoccupied with prescriptive codes and rules, and more concerned with the development of particular virtues and dispositions in researchers (e.g. honesty, sensitivity, respectfulness, reflexivity etc.) (Richardsen & McMullen, 2007). In qualitative research, the researcher is the research instrument, meaning that 'confronting ethical issues in qualitative research is a confrontation with the self' (Soobrayan, 2003, p. 107).

Often, the concerns highlighted by the REC turned out to be different to those everyday concerns – or 'ethics in practise' (Guillemin and Gillam, 2004, p. 261) - which troubled me most during data collection. For instance, taking notes during what were often private and personal meetings between patients and professionals could feel invasive and insensitive. Although (out of respect) I avoided making fieldnotes at any point where patients appeared to be distressed or emotional, this also seemed dishonest – since I would attempt to capture these moments at the earliest possible opportunity (e.g. immediately after the appointment or at another convenient time during the appointment).

Similarly, while the ethics committee had a concern regarding patients' capacity to consent, I did not have any significant doubts regarding any participant's ability to give

consent; rather, I was concerned about the extent to which participants could really be said to be giving *well-informed* consent, since ethnographic research which focuses upon the mundane and routine aspects of interaction is often difficult to explain in layman's terms. Research into informed consent suggests that it is a problematic process both in theory and in practice (e.g. Corrigan, 2003; Sin, 2005; Wiles et al., 2005). Malone (2003, p. 813), for instance, argues that research designs are often too complex and specialised for most people (even those 'with capacity') to fully understand, rendering many attempts to obtain informed consent 'a pretence' (O'Neill, 2006).

For instance, despite spending large amounts of time with the three BPC facilitators - and despite their knowledge of research and my attempts to answer any questions they had - I never felt certain that they fully understood the research; in particular, the more critical approach involved. Relating to this was a discomfort with the way in which participants (in particular, service users who are already subject to considerable stigma and discrimination) were being represented within the research. In agreeing and volunteering to be interviewed, participants are trusting the researcher to represent them accurately and with sensitivity – the latter at times difficult with critical research. As Bosk (2001) argues, ethnographic research is often morally problematic, since ethnographers allow (and even encourage) participants to make disclosures which might be unflattering or incriminating, without disclosing completely the potential harms that can emerge from such research, in order to further their own research agendas.

It was also concerning that the study seemed to have a presumed trustworthiness, perhaps deriving from the official documentation and the support of the organisations in which the research was taking place. Whilst taking consent from participants, there were rarely many questions about the research – (particularly at clinical assessments, since participants seemed much more concerned with moving on to the actual assessment itself). One concern that participants did at times voice surrounded issues of confidentiality and anonymity, although most were reassured that anonymity would be maintained through the use of pseudonyms; however, simply allocating pseudonyms and changing smaller details can be insufficient to maintain anonymity

(Bosk, 2001). Since this presumed trustworthiness - suggested by institutional approval (in this case, support by the institution providing participants with mental health care) - has the ability to influence a potential subject's decision to participate in research, it may constitute a threat to voluntariness (Nelson & Mertz, 2002).

Ethics & representation

An additional ethical issue concerned the representation of participants 'data', which - although often based upon personal and emotionally charged experiences - was interpreted through a critical lens. In drawing attention to some of the potentially negative identity practices of an already stigmatised group, there is the risk of further perpetuating harmful stereotypes (e.g. see Willig, 2012, for a discussion of 'suspicious' vs. 'empathic' interpretations). There can also be a potential conflict between participants' self-understanding and their representation by a researcher (Josselson, 2007), and approaching this data from a social constructionist stance which focuses on the performance of identity within accounts, and remains largely oblivious to the lived 'reality' of participants' experiences, seemed demeaning and disrespectful towards participants. There is evidence to suggest that participants can significantly 'misunderstand' the purpose and nature of research (e.g. Dixon-Woods et al., 2017; Snowden, Garcia & Elbourne, 1997), and this is arguably more likely to be the case with constructionist research, which asks people to provide narratives about their experiences, without being interested in participant's feelings or experiences in their own right. This led me to feel what Lofland and Lofland (1995, p. 28) refer to as an 'ethical hangover': A "feeling of persistent guilt or unease over what is viewed as a betrayal of the people under study". Despite these concerns, this type of research remains important to conduct; whilst it may involve challenging (and in some cases undermining) the assumptions and understandings of participants, this is a vital part of identifying and challenging dominant and potentially harmful assumptions and stereotypes.

Data Collection / Fieldwork

Gaining and maintaining access to research sites

The initial aim of the research was to explore the nature of diagnostic and explanatory talk within diagnostic encounters. The project proposal for the REC and R & D applications stated the intention to conduct research within various settings where diagnosis would occur or would likely be discussed: Psychiatric diagnostic assessments in CMHTs (a site where psychiatric diagnosis commonly occurs), a psychiatric second opinion clinic based within a local university research centre, and a psychoeducation course for bipolar disorder run by the same centre. An additional reason for suggesting these different sites initially, however, stemmed from the knowledge that obtaining access to these different sites could be potentially very difficult, particularly given that I did not have any pre-made contacts within the settings. Therefore, it was decided that options should be kept open initially, since this would allow a greater amount of flexibility if one or more settings proved to be inaccessible. As predicted, access to these settings did prove difficult and messy - particularly within the clinical settings, and this heavily shaped the research, as did the ethical restrictions imposed upon the project. This section will outline the journey to access within the various research settings, highlighting some of the difficulties encountered.

During the initial project phase – I was advised to explore options and make tentative contacts with relevant individuals in order to discuss and plan the research. I initially spoke with several mental health professionals (mostly psychiatrists and clinical psychologists), and service users – all of whom were helpful and advised me on my project proposal, which was difficult to explain to individuals who mostly had experience in quantitative research. One clinical psychologist – who I had contacted due to his specified interest in using psychological approaches in psychotic disorders – took an interest in the project, putting me in contact with other professionals who he thought I would benefit from discussing the research with. After a few meetings, he also agreed to act as a clinical supervisor for the project, and although no longer

based within a CMHT himself, helped initiate contact with the integrated managers (IMs) of two local CMHTs, who were both initially happy to discuss the project.

However, the relationship between seeking REC approval and negotiating access to study sites has been previously noted as a difficulty (Hannigan & Allen, 2007). In retrospect, one difficulty in approaching unknown settings as an outsider is that an understanding of the setting can be difficult to obtain prior to gaining ethical approval (since individuals within the setting are less inclined to 'waste' time on a project which may not obtain approval); as has been noted, the achievement of formal ethical approval is often one of the first questions gatekeepers will ask (Hannigan & Allen, 2007). Conversely, ethical approval can be difficult to obtain without a good understanding of the setting, since it is more difficult to plan recruitment methods, and anticipate ethical difficulties etc. With hindsight, therefore, it may have been easier to have a clinical supervisor within one of the research settings.

CMHT A was the easier of the CMHTs in which to establish access. This was partly due to the laidback nature of the manager (although this also made him difficult to contact during the research), who invited me to speak at an MDT meeting and was happy for the research to go ahead, providing his team agreed to this. Having given a 5-minute presentation to the team about the research (about 20-30 individuals were present), there was a mixed response. A few individuals seemed resistant towards participating, with one recommending that I consider conducting the research at a local MH research centre, where he suggested they would be more accustomed to research; one of the consultant psychiatrists explained that the research would be difficult because diagnosis is often not achieved within the first meeting, but can take considerable time. Whilst the resistance towards the research may have been partly explained by the difficulties in explaining qualitative/ethnographic research to those more familiar with quantitative designs, it is also possible that the research could have been perceived as threatening due to its critical focus on professional-patient interaction and stigma (although having the low status of a PhD 'Student', may have appeared less threatening than a professional researcher or clinician (e.g. see Richards and Emslie, 2000). Participant observation in itself can be an intrusive method (Angrosino & Mays de Perez, 2000), which may appear as a form of professional

surveillance and scrutiny (e.g. see Oye, Bjelland & Skorpen, 2007). Additionally, there can be a resistance regarding the value of academic research (Laurila, 1997), and even a few of those professionals who willingly participated in the study made sceptical comments regarding academia.

However, a few of the CPNs suggested that it might be interesting to observe general assessments (GAs), since diagnosis would often be discussed within these settings, even though a formal diagnosis would not be given. Following the meeting, and receiving R & D approval for the study, I commenced data collection in April 2016. I began by observing GAs, having been told by the manager to write my name on the weekly rota whenever I intended turning up (I also checked with the professionals listed on the rota before turning up to ensure they were ok with me being there). The GAs– which were held twice weekly in sessions of 3 - turned out to be very interesting, since diagnosis was frequently discussed, often by patients who came in with a desire to know what was 'wrong' with them. I attempted to discuss the research again with the consultant psychiatrist, who again expressed doubts, since diagnosis was not something she would usually do within the first meeting with someone (although during the one appointment that I attended of hers, she did offer a diagnosis in the first meeting with a patient). For three months, I observed GAs – most patients seemed willing to be observed, and in between observations (it was rare for all three scheduled appointments to attend), I sat in the staff offices of the CMHT - a 'backstage' area (Goffman, 1959). Here, I could engage in more informal discussion with professionals, and there would be conversations between staff regarding patients following and prior to assessments, providing an opportunity to gain insight into tacit professional knowledge and understandings (Taylor & White, 2000).

After 3 months, I was told that I would be unable to observe GAs for the next few months, due to the CMHT taking on several trainee placement students, who would need to observe assessments. At this point the IM was on sick leave – and he remained off work for several months; I was unable to contact him when he returned and was unable to plan further observations. After many weeks of attempting to make contact (by telephone and by email), I was told that the IM was receiving my messages but was very busy and would contact me in due course. This difficulty contacting

professionals within CMHTs (e.g. secretaries, admin assistants or IMs) turned out to be a major obstacle whilst conducting fieldwork; in asking for considerable help with the research (i.e. asking staff members to remember to send out information sheets to service users with appointment letters, informing me about appointments etc.) from very busy individuals with no personal investment in the research, it was difficult to strike a balance between making requests heard and being overly demanding. This problem in gaining access to settings is often problematic for ethnographers, since – as Hammersley and Atkinson note - "one is operating in settings where the researcher generally has little power, and people have pressing concerns of their own which often give them little reason to cooperate" (2007, p.40).

In addition, while a few professionals appeared resistant towards the research, they tended not to *explicitly* refuse to take part; refusal tended to be enacted in more subtle ways, and this could be in the form of ignoring contact attempts. As such, it was difficult to know how persistent to be in making contact attempts, since this may have constituted a form of coercion. Staff sickness and absences were also common, e.g. the IM in CMHT B was on sabbatical leave throughout the research period, the IM in CMHT A was on sick leave for several months during the research period, and several admin staff were also on long term sick leave at various points throughout the research process.

I later returned to CMHT A in December 2016, to observe psychiatric appointments for a further 3/4-month period. Meanwhile, in April 2016, I had also attempted to access CMHT B. The IM had read my information sheet and (subject to some corrections and further meetings), said he would put me in touch with one of the team's psychiatrists (he explained that the two consultant psychiatrists within the CMHT were very different in their manner and approaches to diagnosis, and felt this one would be more approachable). However, this initial attempt was unsuccessful; the IM placed me in email contact with the psychiatrist - with the caveat that he had seemed sceptical about the project - prior to going on a 9-month sabbatical leave. Despite repeated attempts, I was unable to arrange to speak with this particular psychiatrist.

A month or so later I was put in contact with the temporary IM for this CMHT, who arranged for me to speak at one of their MDT meetings. Again, around 20-30 individuals were present during this meeting. After a short talk about the research, one of the staff grade psychiatrists said she would be happy to be observed, and there were a few questions, e.g. regarding my methods of obtaining consent from patients. The IM suggested I also attend some general assessments (GAs) and liaise with the administrator about sending information sheets out to those due to attend assessment clinics. After the meeting, the team's other consultant psychiatrist (the one that the initial IM had thought would be *less* approachable) agreed to me observing her assessments. GAs at this clinic ran once a week only, in sessions of five, and they took place on the same day as one of the BPC courses (which I prioritised due to the good level of access), so I did not attend many GA assessments here.

In December 2016, I approached a 3rd CMHT, having requested R & D permission, and having been put in touch with the IM of the team. Access with this team ensued differently to CMHTs A and B, since it did not involve speaking at the MDT meeting; I met and spoke with the manager about the project, who introduced me to some of the team members in the office, and to the consultant psychiatrist, who agreed for me to observe appointments. Although I did not manage to observe many appointments there (mainly due to high patient nonattendance rates), during the time spent waiting in CMHT C, I interviewed some of the professionals who worked there.

Difficulties observing 'initial' psychiatric appointments

While the original plan had been to observe initial psychiatric appointments (due to the likelihood of their focusing on both causal factors and diagnosis), these turned out to be difficult to observe in large numbers. In all three CMHTs, DNA rates seemed to be high for these appointments in particular: For example, in CMHT A, only one initial psychiatric patient attended over the second period of observation (who was unwilling to be observed); in CMHT C, only 1 of 6 patients attended the appointments that I attempted to observe. Although this was partly due to bad luck, research has indicated

that DNA rates for Psychiatry are particularly high (compared with other medical specialities), with initial adult psychiatric community appointments showing especially high rates of non-attendance (Mitchell & Selmes, 2007a; 2007b). A number of reasons have been suggested for non-attendance, including levels of illness, disagreement with referral decisions, and long waiting times between referral and appointments (Grunebaum et al., 1996; Kruse, Rohland & Wu, 2002).

This problem with non-attendance led to the decision to observe follow-up psychiatric appointments in addition. The Psychiatrists observed tended to hold only one initial appointment per clinic (meaning that they might see 1 initial patients per week; sometimes none at all), with follow-ups making up the bulk of their appointments. This meant that attending only for the purpose of initial appointments was an unproductive use of time; Although DNAs also occurred with follow up appointments, usually at least one patient would turn up – meaning that attendance was productive to some extent. It was also more difficult logistically to organise observations of initial appointments due to their inconsistency, and in having to ask secretaries and admin support staff to specifically identify initial appointments and send out information sheets only to those patients.

Additionally, several of the 'initial' appointments that I attended, were in fact re-referrals of patients who had been previously discharged; since these patients were known to services, these encounters were less diagnostic in nature (since often the patient had already received a diagnosis). Furthermore, since the process of diagnosis within psychiatry is often complex, extending beyond the initial encounter, follow-up appointments seemed worth observing. In November 2016, I was put in touch with a new locum psychiatrist working at CMHT A, who agreed to my observing his clinics (although it was necessary to work around the trainees attending his appointments). All of these were follow-up appointments, since the initial appointments did not turn up (with the exception of one, who was not happy to be observed).

Follow-up appointments tended to be fairly different to initial appointments; lasting around 30 minutes (initial appointments usually last an hour), there was generally less preoccupation with confirming a diagnosis (or finding out 'what was wrong'), and a tendency to focus more on medication (i.e. effectiveness, dosage, side effects,

alternate possibilities etc.) and patient functioning and symptomatology. Observing these appointments was particularly useful, in that they elucidated the 'de-stigmatising' aspect of more 'medical' approaches to mental disorder; within follow up sessions, patients were often oriented to as a group of symptoms, which could be targeted and fixed by appropriate medications. As such, patients were not held accountable within these meetings in the way that they were in GAs. While social factors (i.e. family, friends, social activities, work etc.) were considered, they were generally a peripheral concern. Another useful feature of the appointments was that discussions of diagnosis did emerge to an extent (although most of those observed had already received a diagnosis)- at times explanatory work involving diagnosis occurred, patients asked about or challenged their diagnosis, or at times simply used diagnostic terminology to explain their behaviour. It was also informative to discuss patients with the psychiatrist before and following appointments, where an extra layer of formulation would be added to those provided to the patient.

Within the second opinion clinics, appointments with the observed consultant were fairly infrequent and inconsistent, which partly explains why not many observations where conducted. One patient appeared unsure about whether to take part in the study, and so I did not observe her session; there were also two participants who did not attend. In addition, this clinician did some of his appointments via skype (as he frequently worked from outside of the clinic), which I was unable to observe. Two further clinicians agreed to having their appointments observed during the last few months of fieldwork, but their appointments were infrequent and inconsistent, and I did not manage to observe them.

Access and achieving theoretical saturation

The superficial levels of access achieved in the clinical settings may not meet the standards of traditional/classic ethnography, with the fieldwork conducted resembling what has been termed a "smash and grab" ethnography (Kovack, 2009; Martin & Frost, 1996). Although there is no predetermined optimum length for

fieldwork, Atkinson & Pugsley (2005) suggest that research should continue until the analyst is no longer acquiring significant new information about the setting. Due to practical constraints however, it is likely that the observations conducted allowed a fairly good understanding of the nature of GAs (within CMHT A at least), although not regarding the culture of CMHTs more generally. However, the length of fieldwork and level of saturation required is also dependent on the breadth of the researcher's interest (Atkinson & Pugsley, 2005), and since the research was concerned not with the general culture of CMHTs, but with professional and patient talk regarding diagnosis and causality, focusing on key interactions within the research sites constituted a form of purposive or theoretical sampling (Denzin & Lincoln, 2000). Arguably, enough of these interactions were observed to gain an understanding of their nature and function, and to build up an adequate representation of the nature of the observed assessments.

I also argue that a level of what Gummesson (2000) refers to as 'mental access' was reached, whereby the researcher is able to understand what is happening and why in the investigated settings. Despite not spending an extended period of time within one particular CMHT, I became largely able to understand what staff were discussing with each other, e.g. when they used professional terminology or abbreviations. One illustration of this was during a conversation which occurred prior to a GA; a CPN was reading the GP referral letter for the subsequent patient, which described a young female university student with recurrent depression, who was proving difficult for the GP to treat successfully. She warned me that this patient sounded difficult and might not want me to observe, muttering "it sounds like a bit of *'dare I say it….'*", at which point she trailed off. I had become familiar enough by this point with professionals' ways of discussing 'difficult' female patients to guess what she meant, and clarified "do you mean personality disorder?", which she confirmed.

However, it is unlikely that theoretical saturation - when all of the main variations of the studied phenomenon have been identified and incorporated into the emerging theory (Glaser and Strauss, 1967) – was achieved; in part, this was because CMHTs handle a large variety of potential cases, diagnoses and problems, many of which would not have been captured within the limited number of assessments observed.

Additionally, there were certain categories which were insufficiently elaborated within the data for the purpose of theory development; for instance, although broader concepts such as social class and gender emerged as potentially important categories within the data, it was difficult to make any claims regarding the role of these categories in shaping the interactions observed, due to the limited number of observations conducted.

Recruiting participants & taking fieldnotes

The main corpus of clinical observations consisted of twenty-one CMHT general assessments, six initial-psychiatric CMHT appointments, 24 follow-up CMHT appointments, five second opinion assessments (n = 56). In addition, two initial MDT screening meetings was observed. Patients within these settings were originally approached to participate by letter; information sheets were sent out along with appointment letters (and the course confirmation letter in the case of the BPC programme). This meant that potential participants always had sufficient time to consider participating[23] – they could contact myself or their team if they had any concerns or did not wish to participate. On attending appointments, the professionals in question would check with participants to make sure they had received the study documentation, and to ask if they were ok with me observing. The professionals would then let me know whether to not it was ok for me to sit and observe the session. If patients were ok with this, I would then introduce myself, and briefly explain the study, giving them a chance to ask any questions or raise any concerns. Most participants appeared content for me to observe and take notes, with only a few refusing.

I would then sit and make notes – trying to capture as much detail as possible regarding the dialogue (capturing quotes where possible), whilst also attending to

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[23] This did mean that I was unable to observe 'emergency' or urgent appointments within CMHTs, since I would not have been able to give participants the required 24 hours in which to read information sheets and consider participating. Only 'routine' appointments were observed therefore.

details regarding body language, spatial positioning, demeanour, tone of voice etc. I had been advised by several professionals not to audio-record interactions, as this might be off-putting or threatening to patients and professionals alike; this was something which – after having observed a few appointments, I agreed with.

One advantage within mental health assessments generally, is that note taking is common practice – psychiatrists would take notes during their consultations, and during GAs, one of the professionals would generally take (thorough) notes, whilst the other would tend to ask questions. This meant that my own note-taking was partly camouflaged during these encounters, and so may have been seemingly unobtrusive and ordinary. Patients in initial assessments would also be required to sign a disclosure form, allowing the team to share relevant information with other relevant agencies (e.g. GPs, criminal justice services etc.); this meant that my consent forms could be signed at this point in a less conspicuous way (although my own consent forms were considerably more complicated and always required some explaining due to the number of different points which participants had to agree to). Furthermore, professionals themselves were also used to having appointments observed; the psychiatrists tended to be regularly observed by medical students/trainees, and similarly the teams would often take placement social work and nursing students, who would also observe assessments for training purposes.

In addition to observing the appointments themselves, I also observed conversations between staff both prior to and following observations; these could take place either in the assessment rooms (sometimes, after seeing the patient out, professionals would then shut the door and have a discussion regarding the patient – particularly if they disapproved in some way of the patient), but more often took place in the staff offices, where professionals would return to write up their notes and/or wait for the next appointment. This 'backstage' (Goffman, 1959) behaviour – occurring when patients were not present – was useful in that I could observe how professionals were categorising patients, in ways that might not have been directly communicated to the patients themselves. In this sense, it was possible to test my interpretations of professionals' subtle and implicit behaviour during the assessment, by triangulating with their more explicit talk following appointments. Additionally, since these

conversations directly followed assessments, they also allowed me an insight into professionals' decision-making processes, which might be further explained and debated immediately after the appointment. Therefore, although only fourteen formal interviews were carried out with professionals, the many informal conversations with staff were often very insightful, since they directly followed decision making processes, rather than being removed from their clinical context, as with formal interviews. Listening to (and participating in) these conversations could also feel very uncomfortable at times, particularly when staff were expressing negative views regarding patients.

The potential for the researcher's presence to fundamentally change the nature of observed interactions and processes has been one criticisms levelled at ethnographers. However, gathering 'pure' data that is completely free from 'bias' or external influence is arguably impossible; all that can be attempted is to consider accounts in the light of the context in which they were produced, and to collect further data that allow us to develop and check interpretations (Hammersley & Atkinson, 2007). Furthermore, while to an extent this reactivity can be minimised or at least taken into account, it can also be usefully deployed as an analytical tool, since the way in which subjects respond to a researcher's presence can in itself provide important insights (Hammersley & Atkinson, 2007). I found this particularly to be the case when observing professionals 'behind the scenes', since they might explain themselves or justify their decisions to me, in ways that would provide some insight into their own concerns, but also their perceptions regarding me and my research. An outsider's presence may force insiders to engage in making taken for granted knowledge explicit, which would not occur in situations where participants are unaware of the researcher's presence.

Obtaining access and consent in BPC courses

In contrast to the difficulties with accessing the CMHTs, access in the BPC was considerably more straightforward; the main facilitator – James - supported the research from an early point, despite being more familiar with quantitative research and my difficulties in explaining the purpose of observing sessions. He would mention the study to participants during their screening phone-calls, giving them an initial opportunity to express any concerns regarding participation. Letters and information sheets about the study would then be sent out along with course confirmation letters, enabling participants to further familiarise themselves with the study before making a decision. In addition to this, at the beginning of the first session of each cohort, I would give a brief talk about the study, emphasising that they could take the next week to decide on whether or not they were happy for me to attend sessions and take notes. If unhappy about the study, they would be able to contact myself or any of the course facilitators to raise any concerns, although nobody did this.

I travelled to the course with the facilitators– helping to set up the room, distribute materials to participants, and with clearing up at the end of sessions. In addition, I began to deliver small parts of the course (e.g. talking about CBT therapy, or facilitating group exercises etc.), which meant that I had more of an active 'role' within this setting. Although this was helpful in establishing and maintaining access, this also posed an ethical dilemma, since it is possible that I became indistinguishable from the course team (despite making it clear that I was a researcher), potentially making it more difficult for people to express any discomfort they might have had at my presence.

Nobody openly expressed any dissatisfaction with my presence (either to myself nor to the facilitators), and I did not sense any hostility from course participants, although in the first course attended it took some time before I learnt how to take notes appropriately. For instance, having obtained participants consent to be there and make notes, I began by attempting to capture *every word* spoken by both facilitators and participants, before detecting a slight discomfort in participants; I then amended my note taking behaviour – only taking notes when it seemed appropriate (i.e. ensuring not to take notes during times when participants were discussing sensitive

issues or during displays of emotion). This seemed ethically problematic, however, since I would usually attempt to note down such events at some point after their occurrence – e.g. during the break or following the course.

For the most part, I did not get the feeling that my presence as a researcher making fieldnotes was inhibiting participants - at least not to the degree that individuals avoided speaking about personal matters; the latter four courses did not seem any different or any less comfortable than the initial sessions attended where I did not make any notes and was not yet officially conducting the research. In addition, if my presence was having an adverse effect on group dynamics, it seems likely that the facilitators would have picked up on this and would have been less supportive of my presence. However, it is impossible to know this with any certainty – and the possibility that there may have been individual's there who would have participated to a greater degree had I not been there must be acknowledged.

Interviews

Although participant observation and informal interviewing are the primary means of data generation in ethnography, this is often supplemented by semi-structured interviewing, both to obtain information about activities that cannot be directly observed and to check inferences made from observations (Hammersley & Atkinson, 2007). Interviewing patients following their appointments would have been useful in allowing me to check my own interpretations with them, and to reinterpret through triangulation. However, there were difficulties in finding space within the clinical settings to interview patients following appointments, meaning that - although several participants were willing to be interviewed following appointments - only one participant *was* interviewed following observation. The reason for this was that interviewing these patients within a clinical environment was a condition of ethical approval, and it was difficult to book rooms out within the CMHTs, since they were in use much of the time. In addition, a few interviews were arranged, but cancelled by participants shortly before they were due to take place due to ill-health. It might have

antagonised staff had I regularly booked out rooms and not used them, so I decided to interview individuals from 3rd sector organisations, instead of those from CMHTs.

In interviewing service users from BPC programme and from the 3rd sector, I sought to elicit narratives regarding subjects' experiences of the diagnostic process (as well as experiences of mental health services in general), and to hear their own accounts of how they came to experience mental health problems. I was interested in subjects' own understandings and conceptualisations of their mental health difficulties; the theories, labels and explanations they had derived from encounters with professionals; and how they felt about these labels and explanations. Although I was interested in how these experiences had shaped subjects' sense of self, I usually attempted to glean this from the narratives and accounts told during the interviews; such details would usually emerge naturally in stories regarding mental health experiences, diagnostic journeys, and contact with mental health services.

Separate ethical approval was obtained from the University departmental ethics committee in order to recruit from 3rd sector organisations. Individuals were recruited through BipolarUK (a recruitment email was sent out to local members of Bipolar UK) and through Sefyll – a local mental health project which involves service users in the running, planning and development of local mental health services (an advert for the study was in the monthly newsletter). Interviews were conducted with twenty-six service users in total; eleven from BPC courses; twelve from BipolarUK, and three from Sefyll. Interviews mostly took place in participants' homes, or in the University graduate centre, where rooms could be booked out for this purpose. A few also took place in cafés when participants had a strong preference for this. BPC participants were interviewed either prior to or following the sessions, in the course venues.

Formal interviews were also conducted with fourteen mental health professionals in total, including three integrated managers, two consultant psychiatrists, two social workers, three community psychiatric nurses, one social work assistant, one occupational therapists, (all from the CMHTs; one of the BPC facilitators was also a CPN in CMHT C). In addition, one rehabilitation ward manager, and one occupational therapist working within personality disorder services were interviewed. The other two BPC facilitators, although not trained mental health professionals were

interviewed in addition. Again, a flexible interview guide was used, including questions regarding professional roles and duties, perceptions regarding the usefulness of diagnosis, both within their own professional role as well as perceived usefulness for service users, questions regarding them causal models for mental disorder, and questions regarding the perceived purpose and nature of general /or diagnostic assessments (depending on relevance to the professional) (see Appendix III for interview schedule). These interviews lasted between 30 – 90 minutes, with the majority lasting around 60 minutes. These interviews took place in a variety of settings – some within clinical settings, some within a room booked out in local libraries and leisure centres.

Interviews with service users were conducted throughout the research process; in particular, with BPC participants, several interviews were carried out during each cohort. However, many of the interviews (especially with professionals) were carried out later in the research process. This was partly due to practical issues, such as being largely unable to interview patients within clinical settings, and having to separately recruit through 3rd sector organisations (which meant gaining ethical approval from a separate ethics committee). However, conducting the interviews later in the process also meant that the interviews could be used in part to test the theories emerging from the observations. Ideally, ethnographic research should become increasingly focused as the research problem develops and becomes increasingly clarified; this progressive focusing can involve a shift from describing the social world towards the attempt to develop and test explanations and theories (Hammersley & Atkinson, 2007). In the case of interviews with professionals, for instance, I was able to explore the topic of general assessments with CMHT staff (something which I had not originally intended to study, but emerged as a focal point in the study); I was able to ask them their views on the nature and purpose of general assessments, and to explore any problems or difficulties they might articulate regarding this process.

Establishing rapport, making disclosures & researcher positionality

For qualitative research conducted from a realist standpoint (i.e. trying to access people's 'real' beliefs, experiences and emotional responses etc.), developing a rapport with participants is vital in order to access a person's 'true' story (e.g. Liamputtong & Ezzy, 2005; Goodwin et al., 2003). However, the constructionist stance taken by the current research meant that the relative 'truthfulness' of participants' accounts was not of primary concern; although some rapport was needed to prompt some level of disclosure, a high level of intimacy with participants was not deemed necessary.

In order to establish rapport and lessen the hierarchical nature of researcher-participant relationships, researchers may share of their own personal stories (Liamputtong & Ezzy, 2005). The intensity and frequency of such disclosures may also be greater in research on sensitive topics (Lee and Renzetti, 1990), since qualitative research on sensitive topics creates a space for self-disclosure by researchers (Dickinson-Swift, James, Kippen & Liamputtong, 2007). This was not something I routinely engaged in, although during the BPC sessions on talking therapies I was asked by the facilitators to discuss my experiences of Cognitive Behaviour Therapy, which constituted a form of disclosure (one participant later mentioned that he had appreciated this, since it lessened the feeling of a 'them vs. us' gap on the course).

However, participants did not often ask me about my own mental health experiences, and I made disclosures only when asked or thought it to be relevant. It is possible therefore that participants' might have assumed that I had not experienced mental health difficulties. One interviewee, for instance, remarked that he could tell simply by looking at someone whether they had mental health problems or not; when I asked him how, he responded pointedly that if a person looked like they had washed their hair - as I clearly had - then it was obvious that they did not have mental health problems. Although he still spoke at length about his experiences, this assumption is likely to have shaped the nature of his and other participants' disclosures during interviews.

Interviewing 'vulnerable' participants

Although interviews have been advocated as being particularly well suited to the collection of data on sensitive topics (e.g. Richards & Schwartz, 2002), conducting qualitative research into sensitive health matters, can involve asking people to relive distressing experiences at times of stress or crisis (Liamputtong & Ezzy, 2005; Morse & Field, 1995; Stone, 2004). Many researchers have expressed concern about the potential harm arising from qualitative and unstructured interviewing (Davis, 1990; Hewitt, 2007; Smith, 1992), particularly those that delve deeply into personal lives and histories (Kylmä et al., 1999; Lee & Renzitti, 1990), suggesting that interviews can revictimize individuals through the reliving of their stories. According to Stone (2004), obtaining first person narratives regarding mental illness is risky, since it encourages a 'willed passage into and through the same spaces of self – thought, memory and emotion – in which the illness has been (p. 20).

One positive aspect of interviewing those from the BPC course and 3rd sector organisations, rather than recently assessed clinical patients, was that there were potentially less ethical difficulties involved with interviewing these service users. Both the REC and the R & D committees had expressed concerns regarding the risks of interviewing patients who were potentially vulnerable (the R & D committee asked for reassurances that professionals would be available in case of any problems during or following interviews with clinical patients). The cancellations by individuals who had initially agreed to being interviewed may have indicated that they were experiencing current periods of unwellness or crisis and interviewing them may have been an added source of stress. While I did not interview anyone who *appeared* to be in significant distress at the time of interview, many of those observed in assessment appeared to be going through a period of emotional stress or crisis in their lives, and interviewing them may have carried a greater risk of causing harm.

By contrast, individuals recruited from the 3rd sector were to a greater extent self-selecting since they had responded to written recruitment advertisements (which are arguably more easy to ignore than a face to face request); while this increased the potential for recruitment bias (in that certain types of individual are more likely to respond to written research requests – e.g. those who actively identify with their

bipolar diagnosis, and those who are interest in research and telling their stories). In addition, most of those interviewed appeared to be relatively socially 'high functioning'; although I did not deliberately 'collect' data regarding participants' occupational status etc., such details tended to emerge during interviews, and it seemed that most participants were actively involved in their local bipolar 'community', with a disproportionate number engaged in facilitating local peer-support groups and in volunteering as mentors for bipolarUK. As such, these participants tended to be both knowledgeable about bipolar disorder, have high levels of mental health 'literacy' and awareness, and to be advocates of self-management etc. Similarly, those attending BPC courses also were arguably more likely to be in a position of stability than someone attending a CMHT assessment, since they were well enough to attend weekly sessions, and had 'passed' the course screening.

Nonetheless, interviewing still carried the risk of causing distress, since participants were being asked personal questions regarding their experiences of illness and diagnoses, questions regarding illness causality etc. which had the potential to prompt sensitive and personal narratives. One suggested way of minimising the risk of emotional harm to interview participants, is through using ethnographic immersion within the field to build trust and rapport with potential participants (Douglas and Carless, 2008). With those individuals recruited through 3rd sector organisations, I felt less confident about my ability to gauge the impact of the interview upon them, and in general these interviews tended to be less personal and sensitive in nature. Given that these were one off interviews I could not be certain that these interviews were not causing distress to participants after the event, whereas this was easier with those recruited through BPC courses, since my familiarity with participants meant that I was better able to gauge their emotional responses, and I would also see them again during subsequent sessions. Only on one occasion did an interviewee become tearful during an interview, but when this occurred it seemed a natural reaction to an emotional memory, and although I checked to make sure that the participant was ok, and offered to stop the interview or have a break, she insisted that she was fine. Although this was a concern, there is some research suggesting that emotional

responses such as crying during interviews, do not seem to translate into long terms negative effects for participants (Lipson, 1994).

There was a 'phase of emergence' (Corbin & Morse, 2003) at the end of interviews, where discussion would lead away from sensitive and emotional matters into more mundane conversation, e.g. discussing a personal hobby or interest of the participant (unrelated to the topic of mental health)– raised but not explored during the interview. This meant that contact was not ended directly following any emotional discussion, and there was also an opportunity for interviewees to ask further questions about the research, thus removing the focus from them. While I tried to remain sensitive to participants responses, emphasising that they could stop at any time, it is impossible to fully know the impact of a research interview on a person. Many of the participants interviewed were currently under the care of secondary mental health services, meaning that in theory they should have been able to access support from their CMHT if they should need to; but in reality, a few participants stated that they did not feel supported by their team, and may not have felt able to reach out to them in a crisis. Similarly, providing participants with a list of possible contacts in case of distress following the interview (e.g. Samaritans, local MH organisations etc.) seemed both patronising and inadequate; many participants laughed when I attempted to provide these details, brushing off the idea that they would need any support following the interview.

Some researchers have actually claimed that interviews on sensitive topics can benefit participants, particularly when handled appropriately by interviewers (e.g. Corbin & Morse, 2003). Hutchinson et al. (1994) suggested that interviews can offer the following possible benefits to participants: (a) act as a catharsis, (b) provide self-acknowledgement and validation, (c) contribute to a sense of purpose, (d) increase self-awareness, (e) grant a sense of empowerment, (f) promote healing, and (g) give voice to the voiceless and marginalised. Since illness can be demoralizing, people may use storytelling as a way of "re-moralizing", enabling them to gain some distance from what is threatening to their sense of self (Frank, 2000; see also Williams, 1984). Corbin and Morse (2003) argue that interviews on sensitive topics should not be considered as a greater risk than a similar interaction with relatives or friends and that any distress

caused can be counterbalanced by the opportunity to talk with someone who is interested and can listen non-judgementally; they also argue that emotionally vulnerable individuals who don't feel able to talk about an issue will not volunteer to participate.

However, this overlooks the fact that participants may have particular expectations regarding interviews, which may be unfulfilled by the reality. The kind of 'emotion work' (Hochschild, 1983) involved in sensitive qualitative interviewing (Dickinson-Swift, James, Kippen & Liamputtong, 2007), also means that traditional boundaries between research and friendship can become blurred. Such research seems to transcend conventional conversational boundaries, prompting admissions that would usually be reserved for intimate relationships. Unlike interactions with relatives and friends – research interviews on sensitive topics can imitate the intimacy of such relationships – without providing the follow up support, e.g. Larossa et al., (1981) suggest that the stance of "interviewer as friend" which emerges from sensitive but less structured interviewing, can entice individuals into divulging information that they later regret. Patai (1991, p. 142) suggests that as researchers:

> *… we ask of the people we interview the kind of revelation of their inner life that normally occurs in situations of great familiarity and within the private realm. Yet we invite these revelations to be made in the context of the public sphere, which is where, in an obvious sense, we situate ourselves when we appear with tape recorders and note pads eager to promote our 'projects' for which other people are to provide the living matter.*

Some participants may associate interviews with therapy (e.g. Coyle & Wright, 1996; Dickson-Swift et al., 2006; Hewitt, 2007; Moyle, 2002), since semi-or unstructured interviews can mimic counselling sessions (Hutchinson, Wilson, & Wilson, 1994), but again without proving the follow up support that would be involved. This is particularly concerning since some have argued that those who opt to participate in research interviews are more likely to be individuals who do not feel that they have enough people in their lives who listen to them (Patai, 1991; see also Ely et al, 1991). The term 'tin-opener effect' (Etherington, 1996), describes how in qualitative interviews people are often asked to talk about aspects of their lives that they may not have previously

discussed. Although my interviews were focused on aspects of experience that were less likely to constitute 'untold stories' - since many of the issues would likely have been discussed with MH professionals in some capacity - there were certainly times when participants told emotionally charged stories about their experiences. One way of resolving some of these issues is to provide as much information regarding the purpose of the interview as possible. In addition to information sheets describing the study, participants were offered a copy of the interview schedule in advance, an offer which some participants took up.

The schedule questions (Appendix III) were however intended as a flexible guide, and the interviews took the form of guided conversations (Rubin & Rubin, 1995), at times taking unexpected directions. However, the following areas were consistently covered: narratives of diagnosis and illness; understandings/conceptualisations of diagnosis; usefulness of diagnosis; experiences of stigma; beliefs regarding causality of illness (either in theory or for the individual); experiences of mental health services. Despite the schedule, participants had some control over the exchange – I attempted to allow them to steer the direction of the interview to an extent, by not closing down avenues of conversation, and by asking follow-up questions on matters of interest to them. As Corbin and Morse (2003) point out, individuals agreeing to interviews are motivated in some way to participate – meaning that they will have expectations from the interview, e.g. being able to tell their story, being sympathised with, or being able to contribute and help others by providing information etc. It is difficult to say whether or not their expectations were met; a few participants appeared to view the interview as an opportunity to highlight the inadequacy of mental health services (one participant even asked me to access his notes to find out why his team had failed to contact him). It was often more difficult to get participants to discuss more abstract issues surrounding causality and the models of mental disorder, but easier to elicit personal narratives, through which models and theories of illness could be implicitly inferred.

Data Analysis

In ethnographic research, there is no single point at which analysis can be said to be 'done'; analysis is a continual process, beginning with the planning of the research, continuing throughout the research process, and extending into the writing up of the research (Hammersley & Atkinson 2007, p.158). On beginning the process, I had initial questions and 'foreshadowed problems' (Hammersley & Atkinson, 2007), concerning the role of explanatory discourses in shaping patient identities within professional-patient interactions. Having decided to focus upon diagnostic screening and educational sites, where such discourses would likely occur, what emerged during fieldwork related more to the role of diagnosis in itself as an explanatory framework. It became apparent that there was a tendency for patients to actively seek out diagnoses, and also conversely for professionals to withhold or resist giving diagnoses; this then became one of the main focuses of the analysis.

Formal analysis began following the transcription of both recorded data and fieldnotes; NVivo 10 QAQDAS (Computer Aided Qualitative Data Analysis Software), was used to facilitate the generation of codes (or 'nodes') and descriptions. The software allows codes to be adapted as analysis progresses, meaning that they can be organised and reorganised into major categories and sub-categories (i.e. 'parent' and 'child nodes'). It also enables easy data retrieval and storage; for instance, the ability to track the frequency counts of particular codes (i.e. how many times each code has been applied to the dataset), the ability to search and retrieve extracts coded to a particular node, and to search for key terms and phrases in the data (Saldana, 2009). Additionally, Hammersley & Atkinson (2007) have argued that code-and-retrieve software enables more complex forms of analysis, due to the ability to attach several codes to particular stretches of data, with segments overlapping one another, and codes nested within one another.

Initial coding

Formal data analysis began with the development of initial concepts through a process of 'open coding' (Strauss & Corbin, 1990), consistent with a grounded theorising approach (Hammersley & Atkinson, 2007)[24]. Coding refers to the categorisation of segments of data with short labels that defines what is happening in each segment, and its meaning; it involves selecting, separating and sorting data into analytically meaningful categories (Charmaz, 2006). The approach taken loosely followed the two phases associated with grounded theory coding: Firstly, an initial phase involving the naming of each word, line, or segment of data, followed by a focused, selective phase that used the most significant or frequent initial codes to sort, synthesize, and organize large amounts of data (Charmaz, 2006). This did not involve following an exact formula or procedure for analysis, however. As Hammersley and Atkinson (2007, p.158) point out, the iterative approach to grounded theorising is very comparable to that of ethnographic research which aims to generate theory, descriptions or explanations; nevertheless, there is no prespecified "formula or recipe for the analysis of ethnographic data" (p.158).

From the beginning, a detailed and dense form of coding was used, referred to by Saldana (2009) as 'splitting' (as opposed to 'lumping'), which produces a more nuanced form of analysis from an early stage, and encourages "the careful scrutiny of social action represented in the data" (Saldana, 2009, p. 20). This was similar to 'line by line' coding - where each line of data is labelled - which according to Charmaz (2006), works especially well with "detailed observations of people, actions, and settings that reveal visibly telling and consequential scenes and actions" (Charmaz, 2006, p. 51). This variety of detailed coding is also helpful in identifying implicit meanings and tacit assumptions within the data, encourages flexibility in producing different and unexpected leads to be followed up, and helps in the process of making the familiar aspects of interaction unfamiliar (Charmaz, 2006). Since much of my data

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[24] Hammersley & Atkinson refer to the term '*grounded theorising*', as opposed to grounded theory, in order to emphasise that it constitutes an activity - rather than procedure – of generating ideas from data.

involved detailed observations, and I was interested in the implicit and subtle interactional work being performed by subjects, this detailed form of coding seemed appropriate.

While approaching the coding initially with some prior foreshadowed concepts in mind, I attempted to remain as open to all possible theoretical directions indicated by the data (Charmaz, 2006, p.46). Coding is not a neutral or objective process however, but an active process which inevitably reflects the analysts own views and values (Charmaz, 2006); although ethnographers tend to employ a relatively open and exploratory approach, they usually begin with an interest in some particular aspect of social life (Hammersley & Atkinson, 2007). While coding was approached in an open-minded way therefore, I kept in mind my initial research questions and aims, attending particularly to the way in which mental health difficulties were being conceptualised by participants at different times. I particularly focused on identity performance, paying attention to participant's subject positioning (e.g. Edley, 2001) and presentation of self (Goffman, 1959); talk was therefore examined for its speech-act (Austin, 1975) functions, focusing upon the types of 'accounts' (Scott & Lyman, 1968) participants were engaged in giving, e.g. offering justifications or excuses for themselves or others; providing explanations for events and actions; attributing motives to their own and others' actions, etc.

Consistent with suggestions from a number of social researcher (e.g. Hammersley & Atkinson, 2007; Coffey & Atkinson, 1996; Leech & Onwuegbuzie, 2007; Saldana, 2009), several initial coding approaches were used in order to capture the complex social processes within the data, and to enhance the depth and breadth of findings. A combination of labels broadly resembling 'descriptive', 'values', 'process', and 'In vivo' codes (Saldana, 2009) were applied to data. In particular, process coding, which often focuses on the consequences of social action and interaction, is especially appropriate for analysing the "ongoing action/interaction/emotion taken to situations, or problems, often with the purpose of reaching a goal or handling a problem" (Corbin & Strauss, 2008, pp. 96-7) - a description which arguably applies to mental health assessments. The following questions – suggested by Emerson, Fretz and Shaw (1995) - were also considered: What is going on here? What are people doing or trying to

accomplish? How do they do this and what specific strategies do they use? How do members talk about, characterise, and understand what is going on? What assumptions are being made? (1995, p. 146). Values coding was used to capture participants' values, attitudes, beliefs, and perspectives etc. (Saldana, 2009), and 'In vivo' codes were also applied to capture commonly used terms used by participants (e.g. references to "being bipolar" or "having bipolar").

Data was initially coded separately according to data type, i.e. clinical assessment fieldnotes, psychoeducation fieldnotes, and patient and professional interviews were all analysed separately. This was partly because many of the codes generated for clinical assessments were not applicable to those generated for the psychoeducation course or for the interviews. However, there were also many similarities between the codes and themes emerging from different sites, and the lists of codes facilitated comparisons between them.

Focused coding & developing themes

Following initial coding, the next stage involved reorganising and analysing the data, in order to develop a coherent synthesis of the material. Since the initial coding produced a large number of codes, as analysis progressed, the codes were refined and grouped together into categories which could capture larger themes in segments of texts. Codes which were conceptually related were merged together; infrequently used codes were assessed for their utility in the overall coding scheme, with some considered as 'marginal' or unimportant (Saldana, 2009). This entailed a form of focused coding, which involved selecting the most significant and/or common initial codes, and making decisions about which were most adequate for categorising the data in the most complete and incisive way (Charmaz, 2006). There was a focus on those categories which seemed likely to be central to my analysis, with a view to clarifying their meaning and exploring their relations with other categories; certain

thematic groups were therefore further developed, according to their prevalence, their relationship with other themes, and their relation to the original research aims.

The strategy used drew upon the 'constant comparative method' (Glaser and Strauss, 1967) – which involved examining each item of data coded in terms of a particular category, and noting its similarities with and differences from other data that had been categorized in the same way (comparisons were also made within and between individual interviews, and between interviews and observations etc.). This facilitates the differentiation of initial categories into more clearly defined ones, leading to the development of new categories and subcategories, and to the reassignment of data among categories (Hammersley & Atkinson, 2007). Concepts from literature and theory were also drawn on in an iterative process to make sense of what is going on in the data (Charmaz, 2006). Grounded theorising involves a constant interplay between data and theory throughout the research process; ideas are drawn upon and developed to try and explain the data, and the data is then returned to in order to test the fit of these ideas and theories (Hammersley & Atkinson, 2007).

Although initially, data from each setting had been coded separately, I sought relationships across the corpus of materials, with the aim of comparing and relating what was happening at different places and times, in order to identify stable features that transcended immediate contexts (Hammersley & Atkinson, 2007). Since most of the interviews took place during the later stages of fieldwork - meaning that some of the questions were informed by the earlier observations - they were also coded last, and thus were approached with prior knowledge regarding the themes from clinical and educational settings; this undoubtedly influenced the themes that were developed from the interviews.

Exploring the relationships between themes led to the reorganisation and sorting of themes and concepts into larger groups, which then led to the development of higher-level theoretical constructs. For example, categories representing 'diagnosis seeking' (found both in interview narratives and in clinical encounters), and 'diagnostic scepticism and denial' (i.e. denying another's claim to a diagnosis – also found across the datasets), and 'impact of diagnostic uncertainty', were linked together. The

concept of strategic essentialism was drawn upon to explain the benefits of belonging clearly to a specific diagnostic group, which – due to the identity benefits conferred by group membership (for instance, being able to offset certain types of stigma) – could also encourage tendencies towards diagnostic possessiveness. These themes appeared to span across the different datasets, and the conceptual framework applied could be used to explain and group together large amounts of data into a coherent narrative.

Selecting illustrative examples

During analysis, both the importance of diagnosis and it's contested nature emerged as particularly strong themes; as such, in choosing cases to use as illustrative examples, it made sense to focus more on those cases where there was some doubt concerning diagnosis (i.e. marginal or contested cases). Examples from the observational (clinical) data tended to involve extended interactional exchanges, as opposed to brief data extracts, to avoid removing data from its interactional context. This was particularly the case with the assessments, whereby several detailed cases were used to illustrate the complex interactional processes occurring within these encounters. Since diagnosis is in itself an activity which involves considering the person and their narrative in its entirety, I felt that the entirety and complexity of the process itself also had to be preserved (to some extent) during the analysis; fragmenting these activities would arguably have led to a decontextualised representation. With interviews and BPC fieldnotes, shorter extracts were often chosen which illustrated themes particularly well, although when context was deemed to be important - extended sequences of conversation were also selected.

Research Limitations

Post-structuralist theorists have stressed that research findings are constructed in a social, cultural and historical context rather than discovered and revealed in isolation from circumstantial factors. This has induced doubts regarding the ability of ethnographic research (and research in general) to produce universally valid knowledge by accurately representing the social world (see Atkinson 1990; Hammersley 1992; Atkinson & Hammersley 1998; Richardson, 1998), referred to as the crisis of representation. However, while it is vital to be aware that any account of the social world is inevitably selective, partial and interpretative, and important to be mindful of the factors shaping different aspects of our research (from the questions we ask to our analytic interpretations and representations of research participants), this does not indicate that our data and 'findings' cannot in any way offer a useful and informative representation of the social world (Hammersley & Atkinson, 2007).

Additionally, the specific, local and selective nature of ethnographic research (which usually involves a detailed focus upon only one or a few settings or cases), has made the application of traditional criteria for evaluating social research (such as 'validity', 'reliability' and 'generalizability') problematic (Brewer, 2000). Although, I make no assumptions regarding the generality of my own findings across diverse mental health settings, the clinical interactions (general, diagnostic and follow-up assessments) are likely to retain some consistency across CMHT settings, in part due to the standardisation of screening instruments (assessment forms, diagnostic questionnaires and checklists etc.) and professional training across NHS services, but also due to the consistent policy guidelines and structures under which mental health service operate, within a national context.

However, it must be noted that most of the participants tended to be fairly well functioning at the time I observed or interviewed them; this was largely due to ethical restrictions (e.g. I could not observe emergency or urgent patients being assessed and was not interviewing patients who were severely unwell). In addition, my interview participants were individuals who actively identified with their diagnosis, since they had responded to advertisements recruiting those with a bipolar diagnosis, or were

actively participating in a course for those with this diagnosis. Similarly, those observed in clinics were people who had actively turned up to appointments; the study thereby excluded those who did not identify with their diagnosis, and who did not wish to engage with mental health services or obtain a diagnosis (which according to the high DNA rates at psychiatry appointments seemed to be fairly common).

Conclusion

In this chapter, I have outlined the methodological approach taken, and have described the various procedures involved in carrying out the research. In particular, I have explained some of the challenges and difficulties faced whilst planning and carrying out fieldwork, and have considered how these difficulties may have shaped the research; for example, limitations imposed by the ethics committee, and challenges faced whilst attempting to gain access to research settings both had strong roles in influencing the nature of the research conducted, and thus in shaping the kinds of claims that can be made from the study. In the CMHTs in particular, I suggest that the data collected was sufficient to gain a level of familiarity with certain types of interaction within the setting, but insufficient to reach levels of theoretical saturation with regards to particular themes. In addition, I acknowledge that the types of participants recruited (for interviews particularly) within this study were generally well functioning at the time of participating, and tended to be those who related to their diagnosis, and who were often positively disposed to practices of self-care and self-monitoring. In focusing on those using broadly diagnostic services, it is likely that this study inadvertently excluded those individuals who actively reject their diagnosis, or their status as recipients of mental health care.

Chapter 4
Diagnosis-seeking & delegitimisation within secondary mental health assessments

Introduction

This chapter presents the analysis of observational material drawn from 'diagnostic' assessments within CMHTs and a psychiatric second opinion clinic, in addition to relevant patient interview extracts. Findings suggest that patients use various strategies to emphasise the severity of their problems, whereas staff tend to downplay the seriousness of patients' problems, emphasising the potential for self-management strategies (e.g. stress and anxiety management, lifestyle factors, self-education etc.). I argue that this downgrading justifies the categorisation and dismissal of individuals in certain ways (e.g. referring to less intensive/specialised services, such as primary mental health services etc.) and that one aspect of this conflict can be seen in the active diagnosis-seeking behaviour of patients, and the corresponding withholding of diagnosis by professionals. There is also a moral element to the process of screening, meaning that patients must often work to perform moral worthiness in order to avoid downgrading or chastising responses.

The following analysis will examine four diagnostic assessments (Bethan, Hannah, Joyce, and Kate[25]), and will also draw upon patient interview extracts (Eleri, Laura and Roxanne), with the aim of illustrating: a) the tendency of professionals to trivialise, normalise, and delegitimise patient's problems during diagnostic and screening interactions, and the moral work involved in this process; b) the way that this justifies both the responsibilisation (O'Malley, 1996) of patients for their own mental health management, and also the downgrading and dismissal of patients (i.e. guiding them towards less intensive – and arguably less helpful treatment options); c) the way in which patients can display diagnosis seeking behaviour partly as a means to avoid this downgrading, and also as a way of avoiding moralising reactions from the mental health system i.e. as a way of offsetting "volitional stigma" whereby mental disorder

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[25] in order to protect the anonymity of those participating in the research, all names referring to participants throughout the thesis are pseudonyms.

is viewed "as an ongoing voluntary behavioral choice rather than as a mental illness" (Easter, 2012, p. 3); and d) the strategies used by patients to align themselves with particular diagnostic categories.

Gatekeeping assessments in secondary mental health

Decisions not to allocate resources to referred patients, or to channel them towards less-intensive interventions, constitute an important aspect of CMHT work (Griffiths, 2001). Initial assessments (referred to as general assessments – 'GA') are an important part of gatekeeping practices within CMHTs, since decisions as to who is 'taken on' by the team are based on their outcome. One of the purposes of assessment is to decide whether a person's condition is serious/complex enough to require CMHT intervention, with the majority (approximately 70%) of those screened referred back to primary mental health services.

Previous research on CMHT case talk in MDT meetings (another important site for gatekeeping decisions), demonstrates the importance of both implicit and explicit categorisation in determining gatekeeping decisions (Griffiths, 2001); patient selection and rationing were intimately linked to these processes of categorisation. Two particularly significant categories - largely because of their recurrent use in CMHT official documents at the time - were the `seriously mentally ill' and `the worried well'; CMHT staff could deny individuals access to services by successfully reframing a case as a person experiencing life problems but not seriously mentally ill. Similarly, current policy guidance suggests that CMHT resources should be focused on those with 'severe and/or enduring mental disorder' (Welsh Assembly Government, 2010). The screening interaction provides insight into the implicit operationalisation of 'severe and complex' by professionals; i.e. how patients are sorted into categories of severity and appropriateness for the service.

As previous sociological research within health settings has found, triaging processes often involve both moral and medical evaluation (Gibson, 1978; Hillman, 2014), and the sorting of patients into categories of good, 'normal rubbish', and appropriate/inappropriate (Dingwall and Murray, 1983, Jeffery, 1979). Allocations can

thus be partly a means by which staff reward or punish patients based on their perceived appropriateness to the service. Patients (and family members) must legitimise claims to treatment by performing and presenting a responsible and authentically ill self (Hillman, 2014), in order to influence their categorisation by staff and their access to resources. Similarly, the following analysis will suggest that certain patients are oriented to as problematic within CMHT assessments, either in moral terms or by representing categories which fall outside of the perceived organizational responsibilities of a CMHT.

Access to secondary mental health is not a simple either-or matter however; while many are assessed and redirected back towards primary MH, some may be seen again for further assessment in order to further consider diagnosis or medication (by a psychiatrist), and those taken on by a CMHT will receive varying levels and modes of support (e.g. allocation of a CPN, access to group psychotherapy, occasional meetings with a psychiatrist for medication monitoring etc.). Therefore, there are numerous ways in which a patient can be downgraded within the system. Furthermore, both the obtaining of a diagnosis and the role of diagnosis in accessing mental health services is also complex and nuanced; nevertheless, this chapter makes the case that certain diagnostic categories operate as a form of currency in these settings, offsetting the potential for trivialisation, downgrading and delegitimisation. Four examples will be used to illustrate attempts by patients to upgrade their mental health problems and to avoid relegation to a deviant (as opposed to a disordered) category, and the corresponding resistance from professionals. The first example (Bethan) will illustrate the 'disposal' of an assessed patient (i.e. an assessment which appears to result in the rejection of a patient from secondary mental health); the second two examples (Hannah and Joyce) will consider a more subtle form of patient downgrading which can occur within diagnostic assessments (one within a CMHT and one in the second opinion clinic); a final short example (Kate) will illustrate the successful avoidance of downgrading and moralising reactions in an assessment which results in a clear (and preferred) diagnosis.

Downgrading & normalising patients' problems

There were consistent tendencies within assessments to responsibilise (O'Malley, 1996) patients by asking about their mental health 'coping' and 'management strategies'. This often involved questions regarding diet, alcohol /drug use, exercise habits, and sleep 'hygiene'; professionals would also suggest common self-help strategies, such as breathing exercises, brain training, mobile phone relaxation apps, mindfulness, 'bibliotherapy'[26], and techniques for self-soothing (e.g. the rubber-band technique for self-harmers). Clients demonstrating responsible attitudes were subtly rewarded with positive affirmations and body language (e.g. enthusiastic nodding, affirmative verbal responses etc.), whilst those indicating a less proactive stance were more likely to be oriented to as difficult patients (through chastisement, dismissal etc.). Furthermore, those who were unable to present a convincingly authentically ill self were more vulnerable to being downgraded and responsibilised in this way. In such cases professionals tended to reframe an individual's problems as difficulties managing stress/ emotion, depression, or anxiety etc. thus assigning the patient's problems to the category of 'common' mental health problems (thereby not fulfilling CMHT criteria). The following example concerns a 20-year old female university student – 'Bethan' - attending the CMHT for general assessment, having experienced low mood and anxiety. The analysis will illustrate the way in which Bethan's problems are dismissed as 'mental health' which 'most people learn to live with', despite her attempts to upgrade the severity of her condition.

Bethan is assessed by a CPN and a trainee social worker (TSW), who comments prior to the assessment, from having read the GP referral letter that he is expecting her to be 'difficult', since the GP 'does not know what to do with her'.

> *After being asked her to explain her difficulties and about her previous overdoses, Bethan then explains that she has already had contact with primary mental health and student counselling which she has found unhelpful. The professionals ask, 'what would help?' and Bethan responds,*

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[26] Bibliotherapy refers to the 'prescribing' of psychoeducational books to patients as a form of treatment

'I don't know what's wrong with me'. The TSW extrapolates 'so you want a diagnosis?' to which she affirms 'yeah'. The TSW seems to warn her about the potential for disappointment here, pointing out that 'it's not clear cut with mental health …you can't do a blood test …it's all symptom based'; this is followed by a pause in which Bethan does not respond, and the TSW follows up with 'but that's something we can look at today'. They then continue to ask her about her symptoms, and during this questioning Bethan comments: 'it's strange - I go through phases of being down then weeks where I want to go out and have lots of energy… doing stupid things, sleeping around – things that are out of character'.

This description of an abnormally elevated mood lasting for several weeks seems to imply the potential presence of mania/hypomania - which is alluded to again by Bethan further on in the assessment. Following this description, the professionals question her more closely on the nature and implication of these energetic phases: -

'so, these elated periods – how long do they usually last'? Bethan responds, 'a few weeks at a time' and that she goes to extremes – she will be on top of the world spending money that she doesn't have. They ask, 'so are you into debt then?' she replies 'no – not into debt' but says that she buys impulsively.

They ask whether she gets into any trouble because of the impulsivity? She replies 'no – just going home with people' (presumably to sleep with) - that this is mostly under the influence of alcohol but not always. The focus turns then to her drinking, and they ask about smoking and the use of illicit drugs, which she admits to having used, and though currently not using – says she would if she knew a dealer locally.

Having established that these elated moods do not result in debt or in her getting 'into any trouble', they move on quickly from focusing on her elated mood, apparently signaling that it is not of significant concern to them.

The TSW asks about her family and whether they get on, to which Bethan responds 'yeah' but does not elaborate any further, potentially signaling that

she is not happy with the rapid direction change. Following this minimal response, they ask 'so what problems do you need help with? **She replies, 'just mood stuff...there are no particular triggers ...it just happens' then 'my mental health advisor says the things I do when happy aren't normal...that they are above and beyond normal.' The professionals** *do not really respond to this however. She says that she previously saw a professional (she thinks a psychiatrist) - who wasn't very nice and told her 'you're wasting our time' and then that she was 'referred to you'.* **Bethan follows this with 'until they tell me what's wrong I don't want medication'.**

The last statement can be heard as a demand for a diagnostic label, and the previous comments appear to suggest once again a form of elevated mood, which surpasses normal happiness. Bethan's reference to a third party (her University mental health advisor) appears to have been unpersuasive here, judging by the lack of response from the professionals. However, drawing on a third person as evidence for extremity of mood and behaviour was a common strategy deployed by patients during assessments – functioning to both strengthen their diagnostic case and to minimize their own apparent stake in obtaining a particular diagnosis (implying that it is not the patient themselves who believes that they have a particular diagnosis – but another person who knows them well).

The TSW then asks 'do you get voices? **Bethan says no, but that she is quite paranoid** *and pessimistic, to which he replies, 'so you're quite negative in your thought patterns?' and then* **'I think that's reasonably normal .... would you say that's normal?'** *(addressing both Bethan and the CPN here). Bethan then goes on to emphasize how it is NOT normal – e.g. that her friends comment on her behaviour etc. (despite previously saying that she puts on a good front), and that she worries about the police if she throws a cigarette on the floor, and has always been paranoid – giving examples from her childhood.*

Despite Bethan's apparent attempts to upgrade her problems, the professionals pay minimal attention to her reported euphoric moods, suggesting at the end of the interviews that *'it sounds to me like reactive depression which comes and goes, but we*

aren't qualified to give a diagnosis'; and then 'we'll speak to the psychiatrist abut medication for you'. It is clear therefore that diagnosis is not an important issue in their opinion, since they do not suggest her seeing the psychiatrist for further diagnostic assessment (which is what happens in cases where diagnostic queries are taken seriously).

> *They end (as in many general assessments) by suggesting PMH groups (i.e. 6-week CBT groups), and bibliotherapy, both of which are rejected by Bethan who says that she can't see how books would help. They respond that they could 'help pull yourself back up instead of going down the hole again.' They talk to her about accessing CBT online and about 'common sense things' like not drinking, eating, exercise etc. especially when her mood is low – to avoid drinking. Then 'I know it's not what you want to hear but most people learn to live with mental health'.*

This assessment arguably constitutes a 'delegitimising encounter' (Ware, 1992), whereby problems are normalised and trivialised due to their commonality. Bethan's complaints are categorised as a normal aspect of life, as opposed to 'symptoms' of a more serious illness (Ware, 1992). It is also consistent with 'volitional stigma', which involves judging individuals by 'normal behavioural standards', as opposed to categorising them in terms of mental illness (Easter, 2012, p.3). While this tendency to encourage an autonomous and self-managing form of patient may seem 'therapeutic' to staff (the GA was referred to by several professionals as a therapeutic interaction), it also functions as a downgrading strategy which justifies the withholding of more complex (and potentially helpful) interventions. The emphasis on self-governing strategies in CMHT assessments reflects the tendency for patients to be positioned as individualised consumers under neoliberalism, responsible for managing their social and biological risk factors through the exercising of lifestyle 'choices' (Ferguson, 2007; Petersen and Lupton, 1996; Rose, 2007); health problems have become the individual's moral sin (Cederstrom & Spicer, 2015), downplaying the relationship between mental distress and social structural factors (Rogers and Pilgrim, 2010).

As in the diagnostic encounters, interviews often involved the building up of diagnosis validating narratives; for instance, participants would emphasise the extreme nature of their behaviour, citing the efficacy of medication as an indicator of underlying pathology and by citing evidence from others, such as family, friends and colleagues etc. (this will be discussed further in chapters 6 and 7). Such narratives could be interpreted as a way of offsetting the trivialising responses which many reported experiencing during their journey to diagnosis, and some continued to experience due to their questioned and uncertain diagnostic status. The following interview extract illustrates the motivation to have a diagnosis of bipolar disorder explicitly acknowledged by a professional (and to know the specific subtype); it also suggests the importance of an individual's positioning within a hierarchy of severity, and the potential trivialisation associated with a diagnosis of 'not so severe' bipolar (in this case, bipolar type 2 disorder).

> *E: Yes, so it wasn't until I asked her a few weeks ago, it was like okay so what type of bipolar do I have?*
>
> *I: this was a few weeks ago?*
>
> *E: Yes, yes, I mean it kind of, it was like you know I had to ask her to get my diagnosis basically and I had to ask her before. It was like so **what do you think I have**? She was like oh you know **I think it's bipolar.** It's like **yes, thank you, eventually**, and then yes, the last time I saw her ... I said okay so what kind of bipolar do you think I have? She goes **well it's not so severe**. So I'd say it is bipolar 2. But I don't know, thinking back I think I was pretty close to being hospitalised.* (Eleri, BipolarUK, Interview).

Those with an affirmed bipolar diagnosis could therefore also be subjected to delegitimization because of the perceived lack of seriousness of their condition. In cases such as these – individuals at times described feeling as thought they were being punished for self-managing and avoiding hospitalisation, since this led to their experiences being trivialised. For instance, in the above extract Eleri emphasises the fact that she was close to being hospitalised, thus countering the suggestion that her bipolar was not so severe. This risk of delegitimization compels individuals to convince

others of the authenticity and seriousness of their disorder (e.g. through citing evidence form other people, through describing extreme behaviour etc.). In order to avoid these downgrading and moralising responses, patients must build up representations of a morally accountable but authentically unwell self. Such efforts can often be characterised by attempts to build up patterns of symptomatology that correspond to a specific diagnosis, which Bethan's account seemed to attempt (unsuccessfully) in the previous example. The following section illustrates some of the techniques deployed by patients in negotiating diagnosis and access to resources, whilst drawing attention to forms of resistance from professionals.

Negotiating a diagnosis

Several patients displayed explicit diagnosis-seeking behaviour at assessment; this could be partly understood as a way of preventing the moralising and downgrading of their problems by professionals, who frequently reframed problems as low-grade or common mental health issues (as in the previous example). As Parsons (1951) argued, achieving a medical diagnosis and gaining access to healthcare can function to authenticate suffering by re-conceptualising human problems as medical entities, which can promote more humane and flexible treatment. The social legitimacy of suffering requires the successful enacting of the sick role, compelling sufferers to convince their social networks of the legitimacy and authenticity of their illness (Glenton, 2002). The denial of diagnosis can equate to the denial of the sick role and its related access to services, status, and resources, leaving individuals open to accusations of malingering (Clarke & James, 2003; Jackson, 2000; Lillrank, 2003; Ware & Kleinman, 1992). However, some diagnoses appear to be viewed as more valid than others, and those perceived as psychological/psychosomatic (as opposed to biological/organic) can be seen as weakening the legitimacy of suffering (Glenton, 2002).

Research has shown how sufferers of uncertain and contested diagnoses must actively fight to obtain their diagnoses and legitimate their suffering (e.g. Dumit, 2006; Werner

& Malterud, 2003), necessitating the use of rhetorical strategies to 'prove' suffering. This diagnosis seeking and validating can be seen in the proliferation of online communities organised around particular diagnoses, which demand recognition of conditions as physical diseases, and amongst other forms of support, exchange advice on the acquiring of diagnosis, offering strategies on the way in which to credibly present symptoms to a professional (Conrad & Stults, 2010; Dumit, 2006). Dumit's (2006) analysis of online CFS (Chronic Fatigue Syndrome) & MCS (Multiple Chemical Sensitivity) discussion boards found common discussions regarding how one should approach doctors when seeking a diagnosis, with explicit instructions on what to say and what not to say, what to bring, wear etc. as well as advice on how doctors will see the sufferer.

Similarly, in the current study, patients appeared to use various strategies to persuade professionals of their compatibility with a diagnostic category, actively emphasising the characteristics and traits associated with a particular disorder. Other strategies involved citing evidence from relatives and friends to verify diagnostically salient traits, and the recounting of family histories of mental health problems. Patients frequently came to assessments (particularly those where a diagnosis was being sought) with family members, who were then called upon to lend validity to patient accounts, acting as apparently objective witnesses to the patient's behaviour patterns and character.

Psychiatric professionals appear to be well aware of patients' motivations to obtain a diagnosis (e.g. see Chian & Sireling, 2010, p.104): Most of the professionals interviewed in the present study mentioned the need for a diagnosis in claiming state benefits and/or accessing other services. When patients attended seeking a diagnosis, professionals would often display a sceptical stance towards patient narratives, at times even accusing patients (although not to their faces) of malingering behaviour, i.e. of not having anything 'really wrong' with them but wanting a diagnosis for the purpose of claiming benefits.

The following example concerns 'Hannah', a female patient in her thirties, who attends the clinic with her partner, and is actively seeking a diagnosis of Autism (her partner mentions before the appointment about how long it has taken them to get to

the point of being assessed for this). However, even before the appointment begins, doubt is cast over the authenticity of Hannah's problems, as she has previously been accused of faking unwellness in order to access support:

> *Before the patient is invited in Dr. A. reads aloud from the patient's referral letter. She has had a history of anxiety, depression, attempted suicide and 'historic abuse' by her stepfather's brother. The letter mentions that Hannah thinks she has ASD and that her brother has a diagnosis of ASD, which she wants to be assessed for. There are some notes regarding previous assessments which Dr A. reads out, noting how the patient **presented as not making eye contact and suicidal – whereas she was spotted 15 minutes before outside the clinic laughing and eating lunch with her girlfriend. She also reads that Hannah had claimed to self-harm by carving names on her skin, although 'there was no evidence of this'**.*

The notes read prior to the assessment cast Hannah as dishonest and attention seeking, already casting doubt over the legitimacy of her problems. Although this is the first time that Dr. A has encountered Hannah, this description appears to colour the entire assessment, which is characterised by professional scepticism regarding her account.

> *Dr. A begins by exploring Hannah's experience of depression and anxiety – when asked what kind of thing makes her anxious, she replies that **noises disturb her and overwhelm her, also socialising and going out - e.g. making small talk and interacting with people** as opposed to crowds per se. She also finds talking on the phone difficult. **Dr. A asks if she had phoned up to cancel todays appointment would Hannah have answered – she says no she would let it go to voicemail.** Dr. A says it is important to answer these types of calls – she would never leave a message for a patient as you don't know who might hear it – **so it is important to answer phone calls as you don't know what opportunities you might miss.***

These 'symptoms' emphasized by Hannah match closely to common symptoms of autism, such as difficulties with social interaction, and unusual sensitivity to sensory

stimuli (APA, 2013), also noted by Hacking (2009a) to be a common feature of autism autobiographies. Dr. A appears to be testing the severity of the anxiety when asking whether Hannah would answer the phone – Hannah confirms the seriousness of her problems by indicating that she would not answer; however, this is used to admonish her and emphasise her responsibility to self-manage, i.e. this behaviour is being treated less as a symptom of disorder here, and more as a harmful choice requiring change.

Later, when asked what she enjoys doing Hannah says only that she really loves playing with Lego, which she collects. She also tells how when she was a child she needed to collect toys as opposed to wanting them to play with, suggesting another feature consistent with Autism: 'restricted, fixated patterns of interests that are abnormal in intensity or focus' (APA, 2013).

When asked about childhood and family background, she provides further evidence to indicate her compatibility with ASD by emphasizing her resemblance to her brother, who has been diagnosed with ASD:

> *Dr. A explores Hannah's family history, and Hannah discusses childhood difficulties – her mother had severe postnatal depression and lacked maternal feelings for her, and her parents' divorce, although these are not explored in detail. Dr. A asks about Hannah's brother and Hannah mentions how **he has a diagnosis of ASD and that they get along really well because they both think in the same way and are really similar**.*

When asked about family history of mental health issues, Hannah draws upon understandings of the genetic inheritance of mental disorders as further evidence for her diagnosis.

> *Dr. A briefly asks about Hannah's stepfather and his brother (who abused Hannah) drawing them onto a family tree. Dr. A then asks about family history of mental health issues – apart from Hannah's brother, she says her father definitely had **something wrong with him – although undiagnosed because he is a manly man who does not talk about emotions etc. Dr. A asks about her mother – and she says her mother also thinks she herself***

has autism – *and she also has had problems with depression (also quite severe postnatal depression).* **It was her mum who suggested that Hannah might have autism. Hannah also refers to a cousin on her father's side who has a diagnosis of ASD**, *establishing that there is some kind of family link.*

Patients were consistently asked about family histories of mental health problems in both general and medical assessments. This appeared to be an attempt to establish possible genetic links to mental illness, since questions relating to family history were often asked separately from questions relating to childhood experiences[27], and patients were rarely asked to elaborate on the experience of having grown up with a parent suffering from mental health problems. Patients often demonstrated awareness of the diagnostic importance of genetics, by readily divulging details of family members' mental health issues; whilst this often involved details about specific diagnoses, at times people drew upon an array of vague notions about family members' having 'something wrong with them', being somewhat odd, having made suicide attempts or having 'mild' cases of autism for instance. Often, accounts would involve family members with various disorders as opposed to the diagnosis being currently considered. In the above example, Hannah suggests that her dad had something undiagnosed, which in addition to implying a genetic predisposition to mental health problems, also serves to underline the uncertain relationship between formal psychiatric diagnosis and psychiatric symptomatology, i.e. implying that people can have symptoms which warrant a diagnosis, without obtaining an actual diagnosis.

Despite Hannah's attempts to establish a family link to autism, she possesses characteristics which undermine her compatibility with ASD (e.g. she has managed to hold down a job and interact successfully with other people, her autism wasn't picked up as a child etc.). Hannah must therefore justify her lack of visible traits by emphasizing internal (non-visible) symptoms and her ability to develop coping strategies which allowed her to hide her symptoms. Dr. A tells Hannah that one of the

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[27] Whilst mostly this knowledge of family history seemed to be a factor which could *implicitly* be used to upgrade a patient's severity status, this was at times made explicit. In one example, for instance, family history (which the patient offered in some detail) was used by a psychiatrist to emphasise the risk of a patient who had just been diagnosed with bipolar disorder, in order to persuade him to try medication.

criteria for an autism diagnosis is that the associated symptoms must have been present prior to the age of three; she would therefore need Hannah's mother to be present in order to do a formal diagnostic assessment for ASD. She appears to begin the assessment in the session however, asking Hannah if she has always been the way she is now?

> *Hannah replies yes straightaway – **she has always felt different - like an alien,** and struggled to fit in, saying **that she thinks differently to other people and struggles to see from other people's point of view**…. She describes how even in pre-school teachers would tell her to make friends but she was never able to relate to other children and would just be doing her own thing (making water fit into different shapes etc.) – that she always got on better with adults as a child, and that **probably teachers just thought she was shy at the time, but it was that she was different.** She also claims that at some point **she learnt to cope with this by putting on characters – she would play a game called 'let's try to be normal' where she would pretend to be a normal person, and that this is how she has coped in life and managed to fit in.** She says school reports would always mention how she needed to make more friends etc. and Dr. A asks if she still has these reports (presumably to bring to the official diagnostic interview), and she explains that a lot of stuff at her nans would have been thrown out after her death, but that she would see what she could find.*

In using the alien metaphor to describe her feelings of difference, Hannah is drawing upon a common trope found in some autism communities (Hacking, 2009b). By stressing her active use of coping skills in hiding her difference, she is explaining the lack of obvious ASD traits; she is also claiming that those traits which were visible (i.e. lack of social interactions) were misinterpreted as signifying more common difficulties (i.e. shyness). She once again emphasizes this proactive use of coping skills in the following extract:

> *Dr. A asks about secondary school and if Hannah had friends there, and whether these were friends who you would listen to talking about*

themselves or just friends with the same interests. Hannah answers yes –
she knew she would need to find a group to belong to ('pack mentality')
in order to have protection and to not be targeted by bullies *as she knew*
she was a geek; although she doesn't directly answer Dr. A's second
question she indicates that these were friends who she made out of
necessity as opposed to 'real' friends with whom she was genuinely close.

Again, Hannah is Having to justify her success, through building up a picture of her
own resourcefulness - her apparent normality is explained by her self-preservation
instinct. Further on in the appointment, Dr. A expresses further surprise at Hannah's
success in her career and ability to do jobs which involve social interaction, given her
anxiety and interpersonal issues:

At some point, Dr. A asks why Hannah is not able to make eye contact today
– approaching this carefully so as not to seem judgmental (joking about the
centre not being very nice to look at and about herself being 'scary') - she
wonders why Hannah can't make eye contact with her even though she has
done all these different jobs where working with the public, where making
eye contact and body language etc., are all very important. Hannah nods
as if she understands what Dr. A is getting at. She explains **that this is due**
to her 'characters' that she puts on – while in work situations she adopts
these characters as she knows this is appropriate, *whereas in this*
situation she thinks it is better for the doctor to see her **as she really is –**
that she is not putting on any act – she is acting naturally. *She also says*
that her colleagues might look at me now (if they could see me) and say
that's not the real Hannah – the way she acts in work is the real Hannah –
but that's not true.

Hannah is having to fight to establish that she is not faking or putting on her displays
of body language (i.e. not making eye contact). Her 'normal' behavior is presented as
reflecting an inauthentic version of herself; her inner self is presented as the more
truthful and authentic version of H, and it is this which gives her grounds for a
diagnosis of autism. The use of the term 'characters' emphasizes the artificiality of her
attempts to adopt normal mannerisms. These different inauthentic versions of herself

which Hannah brings to attention, imply that the external self is an unreliable diagnostic measure (since it does not accurately reflect the inner authentic self on which diagnosis should be based). This contrast between an authentic and inauthentic self is further described in the following extract, where the 'real self' is described as 'spilling out':

> *Dr. A asks if she finds it tiring putting on the act – Hannah replies emphatically that she finds it totally exhausting. Dr. A asks what is happening now with her current job – is she still off sick? Hannah replies yes – that she finds her current job really stressful as she is in an office environment where there is so much noise and you have to make pointless conversation and small talk with people which she finds really difficult. She has gotten to the point where it is just too much putting on the act and that her real self is just spilling out. It emerges later that she has actually handed her notice in and she describes how she couldn't carry on making herself miserable anymore by working in this kind of environment. She mentions she had an appointment with occ. health and requested that she work from home some of the time to make things easier, but they refused this request so she has handed her notice in.*

It is possible that Hannah's unemployed status and problems with occupational health may detract from the apparent authenticity of her suffering, since it implies that she has a stake in obtaining her diagnosis (and thus a cause to be untruthful). This stake is morally problematic since she risks being cast as a malingerer (i.e. someone who is faking the sick role in order to avoid work and obtain benefits). In the following extract, Dr. A. addresses this by asking Hannah explicitly what she hopes to gain by obtaining a diagnosis, compelling her to provide a more morally acceptable motivation, drawing on notions of identity fit, self-awareness and self-management:

> *Dr. A again discusses the possibility of an ASD diagnosis – saying that there is a limit to how much they can help and that she is unsure about it – she asks what Hannah is hoping to get from the diagnosis – why is it important…. because having the diagnosis might not make things much better, as there is not much help available for this etc. Hannah says that she would find it helpful just in*

*understanding herself, because if she knows what's wrong with her she can research it and understand it better and know what strategies to put in place to help herself ….. she describes how she knows she has depression and anxiety etc. but that with ASD it just fits – she has felt for a long time that she has it and when her brother was diagnosed she read about it and just thought **'that's me- that describes me exactly'** even though acknowledging that different people have different symptoms etc. **She also says how she feels at the moment like she is wearing clothes that don't fit and that the jigsaw pieces don't fit together – that she wants clothes that fit** (i.e. appropriate diagnosis). Dr. A nods understandingly here.*

Hannah is using the notion of identity fit to justify her desire for a diagnosis (which is less morally problematic than requiring a diagnosis in order to receive benefits). The issue at stake in the above extract appears to be not only the patient's problematic fit with the diagnostic category, but also the utility of receiving a diagnosis. However, further on, when Dr. A. explains that she will see Hannah for a formal diagnostic interview, ASD is described less as a practical category, and more as an objective entity - an essentialist as opposed to a nominalist approach to psychiatric diagnosis (Zachar & Kendler, 2007). It is therefore not sufficient to demonstrate the presence of certain symptoms/ traits which might require professional attention and increase vulnerability to other mental health problems (e.g. difficulties adapting to change, social interaction and abnormal repetitive behaviour); in order to receive a diagnosis and its associated benefits, there is a requirement to achieve full category status (by drawing on 'objective' evidence from parents and teachers about the presence of traits prior to the age of three).

*At the end of the session Dr. A explains that she will see Hannah for a proper diagnostic session with her mother (a 'DISCO' – diagnostic interview for social and communication disorders), although she expresses some doubt as to whether Hannah has ASD or not. She says that it is a **bit of a 'mixed bag'** – Hannah has some of the traits but some she doesn't have and that she has also had to deal with many traumatic and difficult situations and has had to come up with strategies for dealing with these…Hannah nods understandingly here, and it seems to be implied that reaction to these*

*traumas may be a better way of explaining how she is now. **A also mentions
that Hannah doesn't fit typical ASD in some ways – e.g. she is not good at
maths but is good at English and poetry** – she describes how typically
people with ASD do not understand metaphor or poetry – they may like the
rules of grammar etc., and they tend to like maths because it is a matter of
following the rules etc.*

Here it seems as though the incidence of childhood trauma is taken as evidence
against the presence of ASD, consistent with the dominant view of ASDs as being
biological in nature. It also represents an 'entity' perspective – emphasising uniformity
(dominant in psychiatry since DSM 3), as opposed to unique individual expressions of
disorder (advocated by DSM 1) (Zachar & Kendler, 2007).

Consistent with Ian Hacking's 'looping effect' (1995), it is possible that people's
attempts to match their own symptomatology to a particular diagnosis might result in
the broadening of the categories in question, e.g. Hannah presenting the argument
that she has learnt to disguise her symptoms from a young age encourages the
consideration of non-visible and internal symptoms in diagnostic decision making,
which could lead to the widening of the diagnostic category to include those with less
clear symptomatology. Because of individuals like Hannah fighting for a diagnosis,
more of those who are 'a mixed bag' and less 'typical' diagnostically, may end up
widening and changing the diagnostic category in question.[28]

Finally, after Hannah has justified both her lack of obvious autism symptoms and her
desire for a diagnosis, Dr. A ends by downplaying the importance of obtaining a
diagnosis, and by stressing the primacy of Hannah's anxiety issues in her future self-
management:

*At the end of the session Dr. A also states that even if Hannah receives an
ASD diagnosis – she still thinks that the **major thing for Hannah will be in
learning how to manage her anxiety, and to not be hard on herself** etc. -
we cannot all be the same – it is just about doing what you have already*

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[28] This broadening of a diagnostic category has also occurred with bipolar spectrum disorders (Angst
et al. 2003).

*been doing – **trying to act in the appropriate ways even if you feel different
and accepting that you are different etc.** She **recommends the PMH CBT
course on managing anxiety** and 'living life to the full', which Hannah has
already been on and found somewhat helpful (Dr. A told me before the
appointment that this course is brilliant). She also recommends an **anxiety
management app** from Bristol university and shows her how to use this –
talking about how helpful breathing exercises can be etc.*

The conclusion of this encounter is that the patient has achieved a provisional
diagnostic status – i.e. her strategies have been successful in obliging Dr. A to
investigate further, with a view to diagnosing her. She has successfully avoided
dismissal; however, Hannah's difficulties here are still subject to reframing and
downgrading as problems managing anxiety, which as per the advice on breathing
techniques and CBT, is something that she must learn to self-manage. The anxiety is
given primacy above the ASD associated traits. This downgrading to emphasize
anxiety/stress issues was a common feature of general CMHT assessments, and
functioned to allow professionals to highlight patients' own agency in managing their
mental health, and to steer them towards less intensive services and self-
management, e.g. primary mental health courses, online 'apps', mindfulness, and
'bibliotherapy'.

Explanations that 'bypass the self': Diagnosis, agency & responsibility

According to Rosenberg (2002), the persistent use of mechanism-defined disease
entities (e.g. bipolar disorder, schizophrenia etc.) as explanatory categories have
functioned to naturalize and legitimate conceptions of difference and deviance.
Psychiatric disease entities therefore play a central role in negotiating the 'ever-
shifting boundary between disease and deviance' (Rosenberg, 2006). Several
professionals in this study spoke about the perception that a diagnosis could seem to
absolve people of blame and responsibility for their problems, as in the following
example:

*Prior to Hannah's appointment, I ask Dr. A whether it is common for patients to come in with an idea of what diagnosis they might have – she says yes, very common because nowadays it is so easy to get information from the internet etc. and that apparently, you can download diagnostic interviews from I-tunes (she seems horrified by this). She also comments that **people would rather believe they have something to explain their behaviour rather than take responsibility for it themselves.***

Certain diagnoses also appear to minimize agency and moral accountability to a greater extent than others; for instance, those seen as drug dependent are held by the public to be more responsible for their problems than those with depression or schizophrenia, with drug dependence not widely considered to be mental 'illnesses' (Link, Phelan, Bresnahan, Stueve, and Pescosolido, 1999; Crisp, Gelder, Rix, Meltzer, & Rowlands, 2000). Diagnoses with a perceived biological cause in particular may appear to influence psychological experience directly, downplaying the role of individual agency in the causation of disorder; for instance, Williams and Healy (2001) found that - unlike with other types of depression - pre-menstrual syndrome (PMS), post-natal depression (PND), and the menopause were perceived as conditions which 'bypassed the self' and not therefore a reflection on an individual's personal ''strength'' (Williams & Healy, 2001, p. 473). Those deemed to have personality disorders appear to be particularly vulnerable to blaming responses from professionals, who are also more likely to contest its validity (Kendall et al., 2009). As a group of disorders which sit on the boundary between deviance and medical disorder, personality disorders may tend to be less medicalised than other mental health disorders.

In an ethnography of US CMHTs Dobransky found that clients informally labelled as 'not severely mentally ill' (particularly those with personality disorders) elicited moralising responses from professionals, and were held more accountable for their actions than those labelled as 'severely mentally ill' (those with psychotic and severe mood disorders), which prompted medicalizing responses from staff. In the present study, staff in diagnostic encounters appeared similarly to distinguish between individuals they held to be accountable for their actions, who elicited more self-

managing guidance and chastising responses from professionals, compared with those who's behaviour was attributed to their illnesses, rather than personality/personal choice. A biological/psychological, deviance/disorder binary was apparent in the way in which professionals would explicitly and implicitly contrast those with genuine 'illnesses' and those with lifestyle/personality/behavioural problems.

Patients tended to downplay their blameworthiness in various ways, e.g. contrasting their usual behaviour with the behavioural manifestations of their condition, emphasising the unpredictability and lack of control over their 'symptoms', and at times working to upgrade their diagnostic status; for instance, there were instances where patients with more morally stigmatising diagnoses (e.g. personality disorders), would actively seek an alternative diagnosis (such as bipolar disorder). Psychiatrists have noted the increase in individuals actively seeking a diagnosis of bipolar disorder in particular (Chan & Sireling, 2010), and this was a theme encountered in the present study, with one psychiatrist commenting (after diagnosing an individual) that this was *'the first person to not want to hear they have bipolar'* (fieldnotes). As mentioned, an important aspect of obtaining a diagnosis involves being able to successfully position the disorder in relation to the self; with bipolar disorder, it was necessary to be able to differentiate clearly between an individual's well and unwell self. The act of diagnosing (which clearly divides those with the disorder from those who don't have it), and its need to separate the self from the disorder could arguably perpetuate the tendency to distinguish between those who's difficulties are attributed to the individual, or to a disorder which can be seen as separate to but acting upon the self (and beyond individual agency).

In the following case, a woman in her 40s with a diagnosis of borderline personality disorder attends the second opinion clinic (by her own request) accompanied by her father, with the belief that in addition to personality disorder there is also '*something else going on alongside it'* (i.e. another condition). She initially suggests '*being somewhere on the autistic spectrum'*, and elements of premenstrual syndrome as possibilities, although she then goes on to describe symptoms consistent with mania and psychosis:

*When asked at the beginning to describe how long her issues had been going for Joyce proceeds to describe a point in her late 20s where she was working as a deputy ward manager and '**became more and more elated….** 'I became **convinced** I could commune with Marilyn Manson', describing how she was spending a lot of money, buying cars, buying everyone food, working massive hours – 17-hour shifts…she describes how she was **convinced that Marilyn Manson was giving her money**. Professor R asks her if she was working beyond her allocated hours (she says yes) and did she get into debt? (she replies yes although I do not catch the exact amount – somewhere in the thousands). Interestingly her father interrupts her narrative here and says, 'but when you were a teen – you had a traumatic experience - your friend was murdered…' presumably he is suggesting a possible trigger/cause of her problems here – implying that they go back to a trauma in her teens. DR. R acknowledges this, saying that we'll come back to that later.*

*Dr. R – going back to the previous topic asks – 'what happened – did that settle (the high mood) or did it lead to a crisis point'? She describes how she crashed and went low and thought people were talking to me…' then 'I felt my stomach was blocked and describes how she ended up presenting to A & E about this. Dr. R asks, 'what was it with the stomach then?' - she describes 'I can't put anything in my mouth – he clarifies 'so you couldn't swallow?'…she then clarifies that she could swallow but that she couldn't put any food into her mouth – she could drink but not eat. It's not really clear here – but it sounds as though this was 'psychological'. He asks, 'what happened then?' she describes how she was sectioned in A & E, she was frightened that the police were after her – then she says, 'which they weren't ……but then they were…' (presumably initially this was a delusion which then became a reality as she had run away?') Dr. R doesn't clarify with her. He asks, 'so did you think 'people are out to get me?' she says she was **convinced** of it.*

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Dr. R asks, 'so were you low in mood then?' (Joyce: 'yeah'). Dr. R asks what other symptoms she experienced? She describes how she felt like someone was going to shoot her …then says which makes sense with what happened to Emma (her friend who was shot).

*Dr. R – did you hear voices?' (Joyce: yeah) ''tell me…' She describes how she would hear Marilyn Manson - with others talking in the background. R tries to explore the voice hearing further asking, **'was it real like me speaking now**?' she describes how Marilyn Manson was real – the others weren't. He asks 'could you hear them inside your head…or outside? She replies that it was both.*

*She then describes how when she was 'little' – 14 or 15 she would go down to the field and was **convinced** people were talking to her and would have conversations with people – then '**I was convinced** I was a Norwegian princess…'*

Joyce gives descriptions consistent with mania (elated mood, unusual spending behaviour, grandiose beliefs and extreme over-activity) and psychosis (beliefs in being persecuted, hearing voices etc.), using extreme case formulation to emphasise the excessive nature of her behaviour. By stressing the fact that she is '*convinced*' about her communications with Marilyn Manson and being chased by the police, her description aligns itself with the concept of psychosis, as does her description of Marilyn Manson's voice as *real* sounding. The perceived 'reality' of voices is considered an indicator of 'real' as opposed to 'pseudo hallucinations', consistent with the notion of insight i.e. patients who do not believe in the reality of voices presumably retain 'insight' (Hamilton, 1978).

However, the picture is confused by the fact that some of the voices weren't 'real', and some were reported as coming from within her own mind. Historically, externally located voices have been considered as more pathological than internal voices within psychiatry, with external voices being considered to represent true hallucinations, and internal voices being dubbed 'pseudo hallucinations' (Jaspers, 1962). Several studies have found evidence to the contrary however (Copolov, Trauer, & Mackinnon, 2004;

Junginger and Frame, 1985; Nayani and David, 1996; Oulis et al., 1997), and 'pseudo hallucinations' have been described as a 'joker in the diagnostic game', allowing clinicians to question the genuineness of hallucinatory experiences that do not fit into a preconceived psychiatric diagnosis (Berrios & Denning, 1996).

In recent years, there has been an increasing awareness of the prevalence of hallucinations amongst those diagnosed with BPD, with voice hearing amongst this group often dismissed as 'pseudo' or 'quasi'-hallucinations (Yee et al, 2005). Hallucinations in this group have also been considered as reactions to stress (APA, 1994). This was reflected in the current research; the few examples of patients presenting with voice hearing or otherwise unusual sensory experiences, who had a formal/informal label of BPD, had their hallucinations subsequently dismissed as 'pseudo-hallucinations'[29]. In the present case, for example, Joyce's hallucinations are framed as reactions to stress, not 'genuine' psychotic experiences (both during and following the appointment).

In the following extract, Joyce appears unhappy about attempts to responsibilise her, using the passive tense to emphasise the involuntary nature of the voices, and her own lack of agency in responding to this experience ('the voices come…'). This passivity that she emphasises in her voice hearing experience could be viewed as a means of minimising the 'volitional stigma' (Easter, 2012) which can be attached to mental disorder.

> *Dr. R. asks whether she returned to 100% following this episode, and she reveals that she has never gone back to 100%, but has since then struggled with 'more of the same…'Her dad adds that she has 'been up and down since then' and has been sectioned 5 or 6 times. She adds here **that 'the voices always come...then 'when I'm ill it's like a helmet and the voices all around me ...I can't concentrate on anything…' She complains how people tell her to 'distract yourself from the voices…but I can't'.***

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[29] Such dismissals were normally voiced following appointments (i.e. not to the patient's face)

Following this however, her dad implicitly stresses the role of her agency in bringing on the voices, linking the voices to stress which she is depicted as actively bringing about herself:

> *Her dad argues 'but me and your mum put it down to stress …**you get worked up about something …then get voices and there's no going back from there'**. He adds 'she doesn't take her meds (she intervenes 'I do!') because the voices tell her not to.'*

Whereas Joyce's account suggests that the voices simply 'come' and then lead to further problems, her father's account suggests that it is her 'getting worked up' that brings on the voices, thus emphasising her agency. Additionally, he accuses her of non-compliant behaviour (not taking medication) which could be taken to imply an irresponsible attitude towards self-management.

> *Professor R continues to explore her voice hearing in further detail asking if the voices are there all the time? (she replies yes). He asks if it is still Marilyn Manson, to which she replies not so much now but a new person – a man from Manchester. He verifies – talking to you? – she replies, 'no talking to others about me'. He once again tries to verify where these voices appear to come from, asking '**where do you hear the voice? She gestures to her right saying, 'just here' and saying 'more to the right than the left'. He asks again if it is real sounding, which she confirms, and he asks if she can hear the voice now – she replies yes and he asks what is it saying?** She pauses and says it is more like crowd jostling at the moment.*

Again, although Joyce asserts that the voices arise from outside of her (offering specific details about where the voices arise from) and are real sounding (features which distinguish real from 'pseudo hallucinations'), her answers are also vague and lacking in the detail which would make them convincing.

In addition, in the above extract Joyce reports hearing the voices all of the time as opposed to during periods of unwellness. Similarly, Joyce's description of delusions as a teenager, where she was also 'convinced' of being a Norwegian princess, may undermine her claim to an illness which is separate from her personality. Whilst her

initial description of illness appears to indicate a clear 'episode' involving unusual symptoms within a discrete time period, the description of teenage delusions blurs the boundaries between a previous 'normal' self and the subsequent episode of illness. For 'illness' categories (e.g. schizophrenia, bipolar disorder, depression etc.), there is a tendency (and a requirement) for patients to emphasise the difference between their character when well and behaviour when under the influence of illness. This contrasts with assessments for developmental diagnoses such as ASD (autistic spectrum disorder), where there was a requirement to demonstrate that difficulties arose from lifelong personal characteristics, in the absence of mental health problems such as anxiety and depression. The is picked up by professor R, who then attempts to establish the difference between Joyce when well and when unwell:

> *Professor R asks, **'what's the difference between when you were sectioned and when not (presumably symptom wise)?'** and then 'if you were ill what would it look like?'.*

> *Joyce describes feeling 'agitated, low, no concentration' then states '**I haven't read a book since 2004'**. Professor R responds by asking **'but is that you all the time?'**, and despite having indicated that there was some kind of change after 2004, she replies yes. Her dad adds that she also doesn't sleep (presumably in response to the question of what illness looks like for her). Again, Professor R. asks, **'but is that you all the time**?' to which she responds yes – she doesn't sleep unless she uses quetiapine. R comments **'so it sounds like these things are all the time' 'what is different when you are unwell?'***

> Joyce does not provide an answer here and her father at this point comments that everything was fine before her friend got killed (when Joyce was 18) and they move on to discussing this experience. They then explore her self-harming tendencies. Joyce states *''**when I self-harm its more to do with voices – I don't get any relief about it'** (presumably voices telling her to self-harm?).*

Here Joyce appears to be distancing herself from the type of self-harm associated with BPD (i.e. it is not used to regulate her emotions), through emphasising her lack of agency and the role of the voices in causing this behaviour. Professor R however continues to ask her questions relating to the symptoms of BPD (e.g. anger, emotional intensity and fluctuations, feelings of boredom and emptiness).

> He asks about *'**the damaging things that you do ...e.g. spending – what else do you do?'** Her dad replies that she smokes, and then adds that she eats a lot of chocolate. He then asks about relationships, and her dad again replies for her saying 'you're very intense and then you hate them…' Professor R asks, '**do you idealise people and then…?'** Joyce attempts to defend herself here, explaining why she fell out with a couple of previous friends, but emphasising that she **has a long-term friend who she hasn't fallen out with. Further on, when questioned about her previous work as a nurse, she describes how she got on with everyone, and how she had friends at school, with whom she is still in touch with via Facebook.*

Joyce appears to be downplaying the role of her personality in having caused her problems, strengthening the argument that there is 'something else' going on alongside her personality disorder, although this becomes undermined by her father and Dr. R's questioning, which appears quite leading.

When asked about the relationship between her mood and her periods, Joyce emphasises the suddenness of symptoms ending, which appears to imply a direct causal link between hormonal changes and mood status, thereby not implicating Joyce's own agency.

> *Joyce describes every month having an episode when gets really angry, irritated and anxious, but on **the day of her period it ends suddenly**. Dr. R asks her if she has angry episodes at other times of the month, to which **she admits that she can get a bit shirty at times and can become really nasty**. Dr. R asks if she has done a mood diary to which she replies no.*

Once again Joyce's claim to a more biological understanding of her problems is undermined by the fact that, not only has she not produced evidence in the form of a

diary she also gets angry at other times of the month, implying that the problem is with her personality, since instances of anger cannot be located only in one discrete time-period. The importance of PMT as a cause of Joyce's problems appears then to be dismissed (not much further discussion is dedicated this).

At the end of the consultation, Dr. R seems to tentatively confirm the diagnosis of BPD, dismissing the possibility of ASD, due to Joyce's success in her job as a nurse and her childhood history. Joyce then complains that BPD is a 'red herring' as a diagnosis, and a term for someone who behaves in ways that others find uncomfortable. She also complains that it affects the way in which her mental health team treat her, describing how they are always telling her '*you need to do this and do that*'. The implication is that Joyce feels her personality disorder label is invoking responsibilising tendencies in professionals.

When I ask Dr. R following the consultation whether Joyce's hallucinations would be considered to be 'real' or 'pseudo' hallucinations, he does not clearly state which he considers hers to be, but comments that '*people with BPD can push themselves into these states*' (presumably through stress) and goes on to explain why her diagnosis fits into this category. His statement again seems to confirm the way in which agency is attributed to those with PD diagnoses.

Joyce's consultation represented a stark contrast to those assessments where individuals were diagnosed with bipolar disorder. As has been mentioned, in these cases patients were able to distinguish clearly between their usual selves, and themselves under the influence of illness. These individuals were usually responded to in a sympathetic and non-judgemental manner, with efforts from professionals to alleviate feelings of blame. For instance, in the following case, Kate, a woman in her 20s, has had her diagnosis of bipolar disorder confirmed in the second opinion clinic. At the beginning of the assessment one of the questions Kate wants answering is '*why it has happened to me?*' - she wants to '*make sense of it*'. They return to this question towards the end of the session and Kate's mother expresses concerns that her daughter views her problems as a personality disorder:

They move on to the second point Kate had asked about at the start of the interview – making sense of it and why has it happened to her. She says that she realises that there are a lot of factors and lots of theories etc. but……' she trails off here. Kate's mother says, **'it's very hard to understand because she's always been the placid one of all her friends', and 'she thinks it's a personality disorder…but she needs to understand that it's not.'** *Dr. R says that bipolar is* **'a lot like diabetes – there is genetic susceptibility – and it is just bad luck,** *e.g. like your sister might develop asthma for example'.*

The description of bipolar disorder as 'just bad luck' clearly excludes individual agency as a causative factor; emphasis on genetic causation, alongside comparisons with diabetes and asthma also work to establish bipolar disorder as a medical (as opposed to a moral) condition. Similarly, in the following interview extract, Laura considers why she finds the bipolar diagnosis less stigmatizing than potential diagnoses of personality disorder and Autism: -

L: Um – just um two years ago, I had a consultant who I really didn't get on with I found her controlling, dictatorial and she seemed to be making a lot of assumptions and she claimed that **I didn't suffer from psychosis and what I called psychosis was a paranoid thinking style in keeping with personality difficulties** *– which I strongly disagreed with… And because she kept saying things like this and because she was such a nightmare to deal with I requested a different consultant - so I've been seeing this [new] consultant for the past year. When I first met him he said having read my notes, which was something my previous consultant hadn't done and the few consultants before her* **– that he did not doubt that I have bipolar disorder** *– um but because of all this doubt I asked to go back to the CUPS [i.e. second opinion psychiatric service] service – I'd already seen him a few years before and for me it was kind of unusual because if I'm seen by them – I was seen by my first consultant.*

I: how did that make you feel about yourself - Did it change the way you saw yourself at all? The fact that it was suggested that you might have autism say?

L: It didn't change the way I saw myself but I felt frustrated - felt labelled – which is interesting because I don't feel that way about my bipolar diagnosis – uhm.

I: That's interesting

*L: And it was the same psychologist as well – it seems like anything that can be treated with a talking treatment is now labelled personality disorder. And I don't like that – I hate that I find it all really contentious. **And I feel really differently about that than I do about my bipolar diagnosis as well.***

.....

*Yeah. **So is that why I didn't find the bipolar diagnosis stigmatising because it was like nobody was saying you can't cope this happened to you because you can't cope – it wasn't at all presented like that**. And then also – I suppose I was lucky because around about the time I came out of the hospital the first time – there was a **psychologist called Kay Redfield Jamison who had just published her autobiography.** And she was bipolar – and so there was a lot of publicity around that, and I read it and she was kind of like on Richard and Judy and stuff and so that gave the whole positive spin on it – that **people can be really creative and successful and so…***

In this extract, the bipolar diagnosis seems to de-emphasise the role of the self in causing the disorder, and as a result is not taken to imply any kind of inadequacy in Laura as a person. Bipolar disorder is also described as appealing due to its association with celebrity (Kay Redfield Jamison), and positive attributes such as creativity and success, an association that will be explored in chapter 7. Another interesting aspect of the above extract, to be explored in chapter six, is the suggestion that individuals who can be treated with talking therapy are vulnerable to being labelled with personality disorder, suggesting a potential stigma associated with psychotherapy. This tendency to associate the psychological with personality disorder could also be seen in Joyce's consultation; the tendency to conceptualise her difficulties as personality driven appear to be accentuated by the fact that she has experienced a traumatic event. Similarly, the following extract from an interview with Roxanne, who

– having been diagnosed with bipolar disorder, then experiences a traumatic life event, finds that her psychiatrist then suggests that she also has traits of a personality disorder, following her reaction to the traumatic event:

> R: *It's almost a punitive thing that – something's happened to you so now I'm going to give you an extra mental health problem – diagnosis.*

> I: *So because of something that had happened to you – as opposed to anything you were doing?*

> R: *Yeah - so it was because I was struggling to deal with that and emotional – it was making my health worse and then obviously triggered off some stuff that had happened in the past that I hadn't really thought about – it then became part of this diagnosis and it's kind of – so then it just becomes a permanent question in your head about what your diagnosis is and then that general question of whether you are free to show emotion to your psychiatrist without it then becoming part of something else* (Roxanne, Interview, BipolarUK).

Roxanne describes her psychiatrist's suggestion of personality disorder traits as 'punitive', indicating the stigma attached to personality disorder; there is also the sense that this new label has altered the dynamic in her relationship with her psychiatrist, imposing restrictions on the way in which she can display emotion within this relationship. The extract also suggests the identity confusion which can result from an uncertain diagnostic status, and the tendency to seek out certainty (this tendency is also evident from the number of participants who had requested second opinion appointments regarding their diagnoses).

Conclusion

Findings from this chapter add to previous research which has demonstrated the moral nature of categorisation work within health settings (e.g. Dingwall and Murray, 1983; Jeffrey, 1979; Hillman, 2008, 2014). Findings also indicate the importance of effective performance in diagnostic settings. The downgrading of patients' problems

(which can happen through de-medicalisation) can leave patient's vulnerable to trivialising and blaming responses from professionals, whereas more medicalised diagnoses may counteract blaming tendencies, particularly when patients are able to clearly differentiate their 'unwell' selves from their 'normal' selves.

In addition, findings support previous research which has noted a deviance/disorder dichotomy within community mental health settings (Dobransky, 2009; Columbo et al., 2003). Despite the apparent holistic and 'biopsychosocial' nature of diagnostic assessments, the resulting categorisations tend to reflect a mind/body dichotomy whereby those considered to have more medicalised disorders (such as bipolar disorder, schizophrenia, and autism) were held to be less accountable for their actions than those with less medicalised conditions (PDs, and anxiety/stress). The medicalisation of certain diagnoses above others also has implications for those consigned to lesser categories (e.g. personality disorder), who may be more vulnerable to volitional stigma (Easter, 2012). Individuals like Joyce, with complex problems which do not neatly fit into a particular category, who are unable to clearly distinguish between their well and ill selves, or who are unable to articulate a coherent narrative regarding psychotic experiences, may also be more likely to encounter downgrading and responsibilising reactions from professionals.

Diagnosis in the settings of the current study tended to be entity based and essentialist (Zachar & Kendler, 2007), maintaining a dichotomy between those who have and those who do not have a disorder; this has strong implications for those on the boundaries of a diagnosis or who do not exactly match the criteria for a diagnosis - such as Hannah and Bethan - who may feel like their experiences are being 'delegitimised' (Ware, 1992). Despite Dr. A's assertions that obtaining a diagnosis would not make much difference, the benefits of receiving a diagnosis are well documented, and chapter 6 will consider some of the perceived advantages of receiving a bipolar diagnosis in particular. The following chapter – drawing upon data from the BPC courses and participants interviews – will consider the tendency for bipolar disorder to be depicted as a reified, biological entity, which gives rise to particularly somatic forms of self-governance in those with a diagnosis.

Chapter 5
Somatic forms of selfhood & self-management in bipolar disorder

This chapter focuses on the reification of bipolar disorder, and its conceptualisation as a distinct and naturally occurring ontological entity by participants. Drawing on interviews with individuals diagnosed with bipolar disorder and fieldnotes from the BPC courses I will illustrate some of the implications of these reifying and essentialising tendencies for service user identities and forms of self-management. Unlike with the clinical assessments (discussed in chapter 4), the courses are post-diagnostic encounters where the validity of diagnosis is not (generally) in question; the nature, management and monitoring of symptoms are the focus. Reification is achieved in the following ways: 1. The construction of bipolar disorder as a distinct ontological category, depicted as something a person either 'has' or does 'not have'; 2. Emphasising medicalised conceptualisations of the disorder, and explanations which emphasise endogenous factors help establish bipolar disorder as a 'natural kind', e.g. chemical imbalances, drug specificity theories (depicting medication as targeting specific chemical imbalances and underlying disease processes), brain functioning & genetics (although family history accounts also serve to strengthen a person's diagnostic claim and to emphasise levels of susceptibility); 3. Somaticisation (Ortega, 2014) – the construction of bipolar disorder as pertaining more to the body than the mind, achieved partly by comparing bipolar disorder to 'physical' illnesses, such as epilepsy and diabetes.

Reification also has a number of implications for identity: It separates the mental health problem from the person's identity – positioning the disorder as a force which comes from outside of the person's self; as such the diagnosis is perceived to have the ability to offset trivialising and blaming reactions – or 'volitional stigma' (Easter, 2012). Rather than being inevitably pessimistic, these constructions of an irrational disease entity which is reified and separable from the self, obligates the 'rational' self to manage the disorder (i.e. through trigger management, medication adherence, lifestyle choices, etc.). More specifically, I argue that the reified notion of bipolar

disorder gives rise to a particularly somatic form of illness management, emphasising interventions that target the body and brain on a molecular level. As such, there is a tendency to downplay the potential role of psychological (and particularly cognitive) therapies in the treatment and management of bipolar disorder.

The Reification of Bipolar Disorder

Bipolar disorder as a categorically distinct entity

Whether or not mental disorders should be classified as categorical or dimensional has been a controversial issue in recent years (e.g. Clark & Widiger, 2000); as Regier, Kuhl and Kupfer (2013) point out, the DSM has tended to imply that psychiatric disorders constitute unitary, discrete entities through the use of strict categorical boundaries, despite the statement in the DSM-IV that "*there is no assumption that each category of mental disorder is a completely discrete entity with absolute boundaries dividing it from other mental disorders*" (APA, 1994, p. xxxi). DSM-5 – while retaining the categorical system of classification, has however included dimensional aspects of diagnosis along with categories, through the addition of specifiers, subtypes, severity ratings, and cross-cutting symptoms; diagnosis still however largely remains dependent on a 'yes or no' decision (Regier, Kuhl, & Kupfer, 2013).

During interviews and the BPC courses participants often *discussed* bipolar disorder as if it were a real and immutable essence, consistent with previous findings that Bipolar 1 disorder was one of the mental health disorders judged to be closest to 'medical disorders' (i.e. a real and immutable essence) by professionals and laypeople (Ahn, Flanagan, Marsh, & Sanislow, 2006). Similarly, participants mostly depicted bipolar disorder as categorical rather than dimensional, i.e. as something people either have or don't have; it was not conceptualized as forming a continuum with normality.

One of the key messages from the BPC session 'what is bipolar disorder' emphasises the distinction between normal mood changes and the extreme fluctuations associated with bipolar disorder, implying that the states associated with bipolar

disorder move beyond 'mood swings' into the category of 'severe episodes of illness':

-

> *'Everyone experiences changes in mood from time to time. People with bipolar disorder do not just experience mood swings but can experience severe episodes of illness.'* (Course material, BPC).

The idea of the bipolar spectrum was introduced in the session 'what is bipolar disorder', with the example that some may have a less severe form that does not require medication. However, the spectrum is not described as relating bipolar with normal mood fluctuations as such – simply that there are less severe forms and different subtypes of 'bipolar'; the way in which mental disorders were most frequently described seemed to suggest a distinct categorical difference between 'normality' and 'abnormality', and between 'illness' and 'mood swings'.

> *In the first BEPC session, the usefulness of the diagnosis to individuals is spoken about, and although individuals have different stances towards this, the reality of bipolar disorder is not really questioned – it is reified as a permanent 'real' thing that people 'have'. For instance, some individuals talked about being in denial and not wanting to believe that they had 'it', but knowing deep down that they really did 'have it'. Jacob said he was relieved to discover that he 'had it' and that there was a name and an explanation for what was happening to him. Anne said that she still didn't believe that she 'had bipolar' – although she didn't challenge the ontological status of the diagnosis as such, it appeared that she just didn't believe that she 'had it' herself.*

In the following session, during a discussion regarding misdiagnosis, a few people (as in the first week) mention the uncertainty over whether they '*really have this thing'* (George). Although Jean says, '*that's because you don't want to have it'*. Again, bipolar is described as something a person can 'have'. During the session on 'the causes of bipolar disorder', James discusses the use and findings of twin studies and they discuss the shared genes of bipolar and schizophrenia (amongst others) and James wonders if that was why in the past more people were diagnosed as schizophrenia and now

increasingly with bipolar. Anne talks about how her father had schizophrenia – but suggests that perhaps **'it was bipolar really'.**

BPC participants also discuss the difficulty in getting others to accept the reality of the disorder:

> *Bev asks if anybody has a partner (or family member) who 'can't see it'? it isn't immediately clear what she means but she explains how her husband can't see it when she is down or high –even if she cries for almost no reason he says that this is 'just how she is' and that he doesn't recognise it as an illness and doesn't believe in 'it'. A few others relate to this and Jean tells how her mother has always hidden her as an embarrassment and won't tell people that she has bipolar as it is seen as shameful. Bridget also mentions how her mother wouldn't acknowledge her being ill (even though her mother herself has a diagnosis of bipolar).*

> *In another session, Rachel discusses her husband's dismissal of her bipolar as 'all in her head'; she laughs when she says this, commenting 'of course it's all in my head…but….'; everyone laughs at this, recognizing that it doesn't make it any less real for it to be 'all in the head'.*

Getting others to recognise the 'reality' of the disorder seemed to be important to many participants. They often told stories about experiences of trivializing and unsympathetic responses from others, particularly family members and work colleagues, which arguably made convincing others of the reality of their disorder important. It is also noteworthy that the BPC involves a specific session aimed at family members and friends, which aims to educate them about bipolar disorder, arguably also working to persuade them of its 'reality'.

The following section illustrates the way in which the genetic causes of bipolar disorder tended to be emphasised both on the course and by participants, and the way in which genetic theories of causation could serve to reify and medicalise the disorder, and to offset blame for individual sufferers.

Genetic causation & diathesis-stress models

As outlined in chapter 3, the BPC course privileges a medicalised and reified conceptualisation of bipolar disorder, i.e. a disease model with emphasis on the genetic and brain-based nature of mood instability. The third week of the BPC programme is dedicated to discussing 'the causes of bipolar disorder'. The disorder has already in the second week ('what is bipolar disorder?') been described as "a complex brain disorder in which people experience episodes of low and high mood", caused by "a faulty mood thermostat". In the third session, (the causes of bipolar disorder), genetics are particularly emphasized. On the genetics presentation slide, it is stated that 'most of the risk for bipolar is genetic' (this statement is changed in subsequent courses); James quickly corrects this and mentions that this is wrong. Bridget (who is an ex-geneticist) - perhaps overcompensating for the 'error' on the slide - says she thinks it is more environmental, but talks about everyone having a certain 'thresholds' for the disorder – with some lower than others.

> *The group are asked if they believe in a genetic link to bipolar – the majority agree with this (only Jacob – who was adopted - says that he is not sure; George says he doesn't know much about it but believes it probably does). Most of the group cite family members who have been mentally unwell in various ways – e.g. a mum with 'black moods', a dad with schizophrenia; previous family behavior is reinterpreted in a medical light – even when nothing was diagnosed.*

This reflects findings similar to those of Callard et al., (2012) and Laegsgaard, Stamp, Hall, & Mors (2010), which suggested that genetic theories allow individuals to reinterpret individual and family history, and can also help individuals to understand and accept their illness. The following extract, for instance, seems to demonstrate the comfort that could be derived from family history narratives:

> *I: So, what kind of explanations have you come across then through your reading and talking to people and what, …. what explanations do you find helpful?*

J: I find helpful that its genetic…. That makes me, that makes me think oh yes, there is…. Because I look back at my family and, on my, especially on my Dad's side, my mother, not so much. They were all very sort of highly strung, emotional people. (Jean, BPC course, interview).

Genetic explanations seem to be considered important by most on the course. For instance, during the BPC programme, participants take part in a small-group exercise where they must rank various explanatory factors according to their importance in having caused individuals' bipolar disorders. Genetics (and other biological factors) tended to be ranked consistently highly in these activities, although participants would also draw on a range of other explanations (mostly positioned as 'triggers' however):

In a group exercise where participants had to order a number of (pre-defined) causes from 1 – 11, Genetics were listed as high for two of the groups (in 1st or 2nd place) and 5th of 11 (although faulty brain thermostat was high and 'a problem with the way brain handles emotion' was 1st) for the third group. 'Lifestyle factors' seemed to be generally quite low for all groups. Parenting was also medium/high for most of them, but was not discussed in the group feedback. (Fieldnotes, BPC course).

At times, genetic explanations and tales of family heritability, also functioned to reify bipolar disorder; at the end of the following extract for example, genetic causation is related to the existence of a disease as a 'real' entity: -

D: Its definitely hereditary my grandmother – I mean my father's mother was very anxious, a very very anxious person – whereas my dadcy – his - the Cardiganshire side of the family – are very much the bipolar stroke schizophrenic um – lots I mean they all were like that. My grandfather was hilariously funny but also could be in such a bad mood where you couldn't even play near the window where he was sat. uhm cos he would just go nuts (just because he was in a bad mood) even when he was like 85. He'd be like that yeah. But he'd also do things like pull a peppermint from behind his ear and wink and just …

I: So, do you think that - so you see that as being a kind of genetic thing then?

> *D: Absolutely – I'm a hundred percent convinced it's genetic – **bipolar is – but depression isn't – if that exists but bipolar definitely is**.* (Dan, Sefyll, Interview).

As in the previous example, these family members are being retrospectively assumed to have these underlying disease entities, without necessarily having been formally diagnosed. At other points in the interview Dan dismissed both anxiety and depression as being 'reactive' as opposed to 'real' and endogenous illnesses – like bipolar disorder. In this extract, bipolar disorder and unipolar depression are contrasted in terms of genetic causation – and the 'existence' of depression as an entity is doubted at the same time as its genetic basis is questioned. This linking of the geneticisation of an illness to the reification of a diagnosis as a 'real' disease has also been shown in relation to eating disorder (Easter, 2013).

This linking of genetics to the medicalisation of a disorder, can also be seen on the BPC course. During session 3 of the courses, the video of a newsnight episode from 2011 is played.[30] The video concerns the way in which developments in psychiatric genetics and neuroimaging might change the landscape of psychiatric care, e.g. through improved drug treatments and predictive medicine etc. This type of research on mental illness is presented as a revolution in mental health treatment, transforming the field so that it become 'just like any other field of medicine'. Professor Nick Craddock foresees that mental health will be 'much like cardiology and other medical specialties', where there are a range of tests: 'imaging tests of the way the brain functions, blood tests to know about susceptibility factors and other sorts of psychological tests that will really help to direct us towards the diagnosis and crucially will help us to know much more accurately how to help people'. This kind of discourse is consistent with what Conrad (2001) has referred to as 'genetic optimism', whereby new knowledge about the genetic causes of illness are expected to lead to new advances in treatment and diagnosis.

The reporter finishes by noting that this new direction for psychiatry will involve viewing mental illness in a different way – not as a problem of the mind that "*people*

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[30] https://www.youtube.com/watch?v=sAF4SnLd8tA

can simply pull themselves back together from", reinforcing the way in which biomedical understandings of mental illness have become inextricably related to de-stigmatizing agendas, which attempt to absolve affected individuals of blame and responsibility.

Similarly, Callard et al. (2012) argue that the narrating of mental illness in ancestors, functions to emphasise the inevitability of the emergence of Schizophrenia within the current family, thus alleviating feelings of blame. At times, genetic explanations seemed to play a role in offsetting individual blame for the development of the illness. In the case of family history narratives – whereby the existence of mental disorder in the family was emphasised (often described in colourful detail by participants), genetic explanations seemed to both strengthen individual diagnostic claims, but also functioned to remove blame, by illustrating the extent to which genetic odds had been stacked against an individual:

> *Well, I think there is a very definite genetic link. My father had Bipolar Disorder and his father before him. So, there is a familial link there. It's probably a whole host of genes; it's not one thing simple. But there is certainly a genetic link there. So, in that sense you have a predisposition to developing it. So that, perhaps, if you find yourself in certain situations then that may trigger depression or mania. I mean, in my case, I think the surgery precipitated the depression – severe depression and then retirement. So, you're susceptible to triggers, perhaps more so than people who don't have that genetic profile.* (Carol, BipolarUK, interview).

In the following example, Bridget has initially cited epigenetics as the cause of her having developed bipolar disorder; when asked to elaborate upon this – the social factors (which she has described previously as different forms of abuse) are described as triggers to episodes. This combination of external social factors which are acting upon her, alongside genetic factors, also function to downplay the role of the self and individual volition in the causation of her 'episodes': -

> *I: …And so, yeah, what about epi-genetics, what does that - what role did that play I guess?*

*B: Well you know, seeing as though my mother has it, obviously, **I inherited something from her and then you know, all the environmental stuff that I've gone through, sort of, yeah, just kicks off the episodes**.* (Bridget, BPC facilitator, Interview).

Bridget's account of environmental stuff that 'just kicks off' episodes, does seem to relegate the environment to a subsidiary role, and was similar to many other participants' accounts, whereby social-psychological factors were relegated to the role of 'trigger', with the underlying disorder/genetics as the cause. This echoes Hedgecoe's (2001, p.885), description of the 'narrative of enlightened geneticization' in relation to Schizophrenia, which – whilst emphasizing the complexity and multi-factorial nature of Schizophrenia causation – implicitly emphasises the central role of genetics, by designating genetics the status of "baseline" and the only necessary casual factor, whilst depicting environmental factors as non-specific and conditional.

While genetic explanations appeared to hold a number of benefits for participants, these explanations could on occasion be somewhat reductionist and deterministic in nature, depicting the relationship between genes and disease in a straightforward and linear way, with little role for the self, agency, or individual volition in the equation. The following examples depict the ability of reductionist genetic explanations to deflect blame from individuals:

I: Do you think genetic explanations are helpful to be people?

*C: I would think so, yes. Because that's something **they can't do anything about, in terms of the diagnosis.** They can do something about how they manage their lives. But they can't do anything about the genetics. So, in some ways that's a comfort, isn't it? **Because it's nothing you could have done. There is nothing you have done that has caused it.*** (Carol, BipolarUK, interview).

In the following account, a deterministic genetic account is described as coming from a professional. In Diane's interview, although she indicates having had a particularly difficult childhood, this was not viewed by her psychiatrist as an important factor in her becoming unwell:

*D: I was once told by a psychiatrist that **even if I'd had the most wonderful upbringing and loving parents that at any given time there'd be a trigger to me becoming unwell***

I: Really? That's quite a strong statement!

D: Hmm! And that was a German psychiatrist and he said that to me – he didn't say it in a cold way at all – he just said it very matter of factly – he said 'Diane, it's just one of those things you know…' he said, 'I believe that there are pathological reasons why people are unwell.' (Diane, BPC participant, interview).

The phrase 'it's just one of those things' echoes the statement about bipolar disorder, made by Professor R (in chapter 5), about bipolar disorder being a matter of 'bad luck'. This alleged description of 'pathological reasons' for unwellness - and the implied role of genetics - is particularly deterministic in this case, with little space for socio-psychological factors; although triggers are mentioned, the implication is that regardless of social circumstances, something would have eventually triggered mental illness in Diane.

Previous scholars have raised concerns that genetic attributions tend to lead to essentialising assumptions - i.e. beliefs that a disorder is immutable and natural, with a specific etiology - which can also lead to genetic determinism (Dar-Nimrod & Heine, 2011). However, although genetic and biological explanations seemed to hold strong significance for most participants, they often did not seem to endorse simplistic explanations – understandings of causation were more nuanced, drawing on susceptibility models which included environmental stressors in interaction with genetic tendencies, reflecting findings from other studies which suggest the publics' resistance to genetic determinism (e.g. Condit, 1999; Condit, Parrot & Harris, 2006; Freese and Shostak, 2009).

Genetic explanations were therefore not necessarily reductionist, and were able to dovetail with various other types of explanatory types. For instance, Jack, who immediately mentions genetics when asked about the causes of bipolar disorder (and who has an undergraduate degree in genetics), combines his own spiritual beliefs with

genetic and epigenetic explanations. After having initially described his belief that people have astral bodies in addition to physical bodies he later returns to this concept, describing how spiritual bodies could impact on the expression of genes:

> *J: Maybe your brain is - if it is genetic maybe your brain is very similar to your ancestors - the way it is put together; but as I say, I know there's other - as I say, we've got other bodies apart from the physical body and that could control how your genes are expressed.*
>
> *I: Okay, so there's this sort of spiritual element?*
>
> *J: A bit of a spiritual element, yes.* (Jack, BipolarUK, Interview).

Most commonly, genetic explanations for bipolar disorder were described in terms of notions of susceptability, with various psychosocial factors acting as triggers; this was particularly encouraged on the BPC course, through the notion of the 'stress-vulnerability bucket', which represents a form of diathesis stress model, which is common within the literature on mental illness. The 'stress-vulnerability' bucket, depicts each individual as having a certain level of susceptibility which fills up the bucket: they then need a certain amount of 'stress' in order to fill the bucket completely and make it overflow (i.e. to trigger bipolar disorder).

> *Bridget directs a question at attendees, asking what they thought would be in their 'stress-vulnerability bucket', and James mentioned that often trauma and bereavement etc. can trigger these things off. Rachel comments that she thinks that was the case for her and her psychiatrist had explained that to her – she had had several bereavements in the same year (and although previously fine); this seemed to have triggered off the bipolar – she explains that there probably was something 'underlying' that had always been there but that these events caused some kind of brain overload: 'my brain said too much'(laughing).* (BPC course, Fieldnotes).

This theory of an underlying disorder waiting to be triggered is the way in which the onset of bipolar disorder was often described by interview participants, resembling what Richard Bentall calls the 'Time-bomb' hypothesis (2003). It depicts an underlying

(usually genetic) tendency which is triggered by stress, traumatic effects, or drug use, but that once triggered is irreversible (i.e. it constitutes permanent change in brain functioning). According to this model, trauma and stress etc. are positioned as triggers, as opposed to causes of the disorder. This language of triggering an underlying tendency has been found in other studies (e.g. Callard et al., 2012; Meiser et al., 2005).

By contrast, in the same session, a few of the other women talk about having been in foster care or having had difficulties in their childhood (Beverley and Diane), which they think contributed or laid the foundation for bipolar – for them this seems to be not merely a trigger, but something that shaped their development early on in life. However, they did not seem to view their 'condition' as any less permanent, or demonstrate any more optimism because of this, supporting the theory that childhood based causal explanations can be equally as essentialising and deterministic as genetic explanations, perhaps leading to beliefs in a permanent underlying tendency towards mental illness (Rangel & Keller, 2011). Explanations based on childhood factors can easily be coupled with the idea of a malfunctioning brain.

The stress-vulnerability model also fits well with self-management ideals, since it promotes the idea of a vulnerability which mainly shows itself when patient's do not manage to control 'stressors' in their lives. As Baart & Widdershoven (2013) find in interviews with bipolar service users, participants adhering to a 'susceptibility' view formulate a moral obligation to deal with the disorder, whereas those endorsing a 'disease' model were less inclined to see the potential for self-management and self-growth.

The following section discusses the way in which medication and its efficacy (or lack of efficacy) could be called upon as evidence for the presence of an underlying susceptibility, deficiency or chemical imbalance, contributing to the reification of bipolar disorder as a 'real' disease entity.

Effectiveness of medication as evidence of underlying disorder

During interviews, medication was a common topic of conversation, and was frequently tied into understandings and definitions of bipolar disorder. These definitions tended to reify the condition as something permanent and underlying (at times without the individual's awareness until it is triggered), requiring control with medication: -

> There were other people out there who had the same diagnoses. A couple of my friends had bipolar disorder and I knew that I, you know, it, it was **something tangible and it could be controlled with medication.** (Bridget, BPC facilitator, Interview)

> and I realised then that it was the third time it had happened and that **it was something that could be managed with medication. But it was something that wouldn't go away as well. It was something that I had to live with.** (Mary, BPC, Interview).

Bridget's statement above seems to link the idea of bipolar disorder being something real and 'tangible', with its ability to be controlled with medication. Similarly, Mary also seems to be connecting the permanent status of the disorder with its potential to be managed with medication.

At times, the effectiveness of medication was also taken to suggest evidence of a particular disorder. For instance, in the following case, Diane, who experienced post-partum psychosis following the birth of her first child, explains that she was immediately placed on anti-psychotics following the birth of her second child:

> and that's with the first one that I developed the illness. Um but when I had my other son 6 years later. I was **put onto medication within weeks of having him. And I I I had hardly any symptoms at all.** (Diane, BPC, Interview).

This account seems to imply that the medication prevented symptoms from occurring, perhaps with the assumption that symptoms would have occurred without the use of preventative medication. Similarly, David, who has described the difficulties he has had

in persuading his GP that he has bipolar disorder, explains how he views the eventual efficacy of lithium in treating his depression as 'proof' that he has an underlying 'bipolarity' to his disorder:

> *The diagnosis was a little bit uncertain – but the proof in the pudding was that the lithium was effective – at least for a time.*
>
> (Later in the interview)
>
> *…the sort of positive response of the drugs I was given indicates that it's a chemical dysfunction, I suppose* (David, BipolarUK, Interview).

For David, who has faced difficulties in getting professionals to accept his own understanding of his difficulties, the efficacy of a medication which is marketed as a mood-stabiliser, is seen as proof that he has an underlying problem with mood bipolarity – as opposed to simply a problem with unipolar depression (which is what he has previously been labelled with). This kind of reasoning is particularly interesting, given that lithium can also be used to treat unipolar depression which is resistant to traditional anti-depressant medication.

These notions of underlying disease are also revealed by accounts which involve retrospective self-diagnosis – implying a form of underlying disease which has been present in an individual without their awareness, and subsequently manifests when triggered by inappropriate medication or stress etc. The bipolar is suggested to exist in some way without any manifestations. This tends to privilege a somatic/ medicalised concept of disorder, since the efficacy of medication suggests an underlying chemical deficiency being corrected by medication. In addition, narratives of individual reactions to medication use or withdrawal are used to retrospectively diagnose individuals with an underlying, pre-existing disorder, acting as evidence to suggest the presence of a disease entity/chemical imbalance within that particular individual. In the following extract, for example, Carol suggests that her mania was triggered by using an anti-depressant (which are thought to trigger mania in individuals with bipolar disorder).

*It started with depression. Then I had a period of mania, because I had been given Venlafaxine as an antidepressant, which **if you have Bipolar Disorder can trigger mania**, which is exactly what happened. **I didn't know I had Bipolar at that stage**, but neither did the people who gave me the Venlafaxine, but that's what happened I became manic. I had all the symptoms of mania. I was admitted to hospital and then had the diagnosis of Bipolar in 2004.* (Carol, BipolarUK, Interview).

This account suggests that the bipolar is something which already existed within the participant prior to her awareness, but which then subsequently manifests following this triggering by anti-depressants. The anti-depressant is not positioned as the cause of disease (since the disease is already present) – but as the trigger to something which is already present in the individual. This presents bipolar disorder as a disease entity which is not 'caused' by, but 'triggered' by external factors, thereby reifying the existence of the entity within the individual.

In the following extract, Bridget describes a retrospectively self-diagnosed manic episode (she has previously explained that the diagnosis of bipolar disorder was not made until her late 30s). In this account, the occurrence of mania is depicted as a result of her ceasing to take mood stabilising medication (which at the time was being used to treat epilepsy), suggesting the underlying presence of a disorder which is being unintentionally corrected by psychotropic medication: -

*B: OK, **my first manic episode, I stopped, when I was doing my finals, I stopped taking my medication.***

I: For depression?

*B: For **epilepsy. Because the drugs I am on for epilepsy stabilises mania, you see. So that's why….***

I: So, you were already on medication?

B: I was already on sodium valproate for epilepsy, so when I was doing my finals, I knew that if I was on the medication, I wouldn't get my degree, so I stopped taking it. (Bridget, BPC facilitator, Interview).

Bridget's account reproduces an understanding of bipolar disorder (or mania) as resulting from a chemical imbalance within the brain, which is positioned as being *the* cause, with potential factors such as exam stress and pressure not considered as significant causal explanations. As such this predisposition to extreme mood elevation is separable from the self and from individual behaviour and agency, since it is due to the lack of a particular chemical compound within the brain.

Endogenous-reactive distinctions

The notion of a chemical deficiency/imbalance as *the* cause of bipolar disorder, suggests an endogenous model of illness, which can be contrasted with the way in which other mental disorders are conceptualised. In the following extract, Dan makes a distinction between unipolar depression and bipolar disorder, claiming that depression is 'reactive' and a 'modern malaise', whereas bipolar disorder is 'endogenous', an 'organic illness' and a 'disease of the mind'. This follows his claim that depression does not really exist, which although a strong statement, reflects a tendency among some participants to emphasise the seriousness of bipolar in comparison with other more 'common' mental disorders such as anxiety and depression etc. In the extract below, modern living is described as *causing* uni-polar depression, but as only triggering bipolar disorder.

> D: Yeah – no it's all reactive in my opinion.
>
> I: But do you think that means it's not depression though?
>
> D: Yeah it is depression its just I just **don't think its endogenous or an organic illness like bipolar is – I mean no one can deny that bipolar and schizophrenia really are diseases of the mind – whereas I think depression is a modern malaise…….** just think that modern living can make people depressed- you know the need to have money for everything, uhm advertising, television, thinking that you need things that you don't and keeping up with the joneses, that kind of thing and just social pressures particularly on the young – I think when you get a bit older you realise these

things aren't important, whereas when you're younger and you're in your teens and your 20s you strive to do the things that mark you out as being a success or something.

I: So, you think they might contribute to sort of depression

D: Yeah – they cause depression

I: But with something like bipolar do you think modern living – these kinds of things might ……?

D: Probably triggers it yeah probably triggers it. But I **think it's underlying – bipolar. You've either got it or you haven't** …uhm yeah. (Dan, Sefyll, Interview)

Interestingly, in this extract, the idea of an underlying and organic disease is also related to a categorical conceptualisation of bipolar disorder (as opposed to a continuum understanding).

Similarly, in the following extract, David - who has been previously diagnosed with depression - describes how he found bipolar disorder a more validating diagnosis, which seems to be tied to its conception as a more biological illness:

D: It was helpful actually because it meant that (pause) I could – because sometimes when you have something like depression you can feel that – you know if you'd only tried a bit harder, you know or pulled yourself together – you could have avoided all the pain and suffering over the years. But having this diagnosis uhm – while it doesn't absolve you of personal responsibility, it kind of indicates that there is something radically wrong with your brain chemistry and that youuuuu - you needn't feel so bad about the fact that when there have been challenging circumstances in your life - your mood has uuhm has has (inaudible) – and its because your brain biochemistry is such that it is not so resilient as other people's perhaps …. and in that sense it is helpful……there were reasons – there was a biological reason why I experienced these things – it wasn't just a lack of, a lack of uh…

I: willpower?

D: yeah. (David, BipolarUK, Interview).

In this extract, David - in a similar way to Dan - appears to be suggesting that bipolar disorder is a more biological and more organic form of illness than unipolar depression. Having a diagnosis of depression is deemed to be associated with moralising responses towards behaviour, since in the above depiction depression is connected with agency and thus individual responsibility (i.e. there is the potential to 'pull yourself together'). Bipolar disorder is positioned in contrast to this, since it is described as a deficiency in 'brain biochemistry', which is able to explain a person's lack of resiliency to live events. The statement that bipolar disorder suggests that there are 'reasons' (then converted to 'a biological reason') for certain experiences, carries the implication that unipolar depression does not constitute a reason for experiences of pain and suffering, by virtue of its lack of biological status. These extracts highlight the potential for bipolar disorder to offset blame in participants, particularly in comparison with other diagnoses, such as unipolar depression and personality disorders.

The next section further considers the way in which neurochemical explanations for bipolar disorder tended to be privileged, establishing the disorder's similarity to non-psychiatric conditions. As with genetic explanations, this emphasis on the neurochemical is also shown to diminish accountability in individuals, distancing the consequences of illness from the self.

Neurochemical explanations & comparisons with non-psychiatric conditions

Bipolar was frequently compared to non-psychiatric disorders by participants – most commonly epilepsy and diabetes. Comparing bipolar to diabetes privileges a similar explanation of mood fluctuations based on an imbalance of brain chemicals – requiring management through corrective medication and lifestyle, exonerating the individual from any responsibility for the illness offset, but also implying an expectation to manage the condition appropriately through lifestyle changes etc:

*I said before to someone who doesn't really understand it (bipolar), who has asked, **I see it as emotional diabetes….** and my tablets are my mental, my mental health drugs are my insulin.* (Jacob, BPC participant, interview).

*I felt as if I was, I don't know how I felt. I felt lonely I suppose, wondering what, what is actually happening to me. Why won't somebody sort of hold me and say look, you have this, this is what's wrong with you and this is how we are going to help you…. It's like, **if you were a diabetic, if you know you are a diabetic,** you know that you have to make lifestyle changes.* (Diane, BPC course, Interview).

As the second extract suggests, the reification of illness as a specific disease entity – while providing some explanation and comfort to this participant - also entails the responsibility to self-manage the disease appropriately; the benefit of receiving a diagnosis for Diane is that she is then able to know *how* to manage the disease appropriately. However, comparisons with physical illnesses such as diabetes and epilepsy give rise to forms of intervention which are physical as opposed to psychological or cognitive, e.g. exercise, diet, medication etc. which target the body at the molecular level. As will be discussed in the following section, psychological interventions tended to be reduced to the management of 'stress', which is also often conceived of in somatic terms. It was uncommon for participants to explain their mood fluctuations or their stress in terms of psychodynamic or cognitive-behavioural models, although trauma was on occasion cited as a stressor or a triggering factor.

As well as establishing the reality of bipolar as a disease entity – this physical reification served to eliminate the self from disease associated behaviours and 'symptoms': e.g. in the following extract, Bridget – who previously worked as a psychiatric geneticist - claims that bipolar disorder is a physical illness caused by chemicals in the brain, and therefore – although it changes her behaviour – this is *not her:*

B: As a scientist, I know it's all chemical. It's all physiological…. And I think that helps me, in both understanding and coming to terms with it because

I know that it's not mental as such…..You know, the brain is an organ, just like the liver is, or the heart……I mean, if you had heart disease, you know, heart disease is a physical illness, **but bipolar is as well, because it's a problem with the chemicals in the brain.**

I: Yeah.

B: So, mental illness, it, it shouldn't really be used as a term actually. It is a physical illness as far as I am concerned.

I: So, you think the term mental illness is actually inappropriate generally?

B: Yeah, to a certain extent. I mean. Oh, I don't know. I am trying to think of an example for the heart, or the liver, or pancreas or something, but just because something is wrong with your brain. I mean, you know, I imagine that phrase is never ever going to be stopped being used, **but its physical, you know. It's not, I mean, yes, it changes the way I behave sometimes, but that's all down to chemicals. It's not me.**

I: OK, that's interesting. So, you wouldn't see it as being any different really from any other physical illness, like, diabetes say?

B: No, no, no, never. I think the only difference between bipolar and say diabetes is that diabetes doesn't change the way you behave.

I: Yeah, yeah. So, that's the key difference with mental health?

B: Yeah, **but apart from that it's a physical illness.** (Bridget, BEPC facilitator, Interview).

In this extract, the bipolar is positioned as causing the changes in Bridget's behaviour – suggesting a one-way relationship between mood fluctuation and behaviour (i.e. physical changes in the body leads to mood change, which causes changes in behaviour); the effect on behaviour is viewed as being the key difference between 'mental' vs 'physical illness'. This relative causal positioning also serves to eliminate individual responsibility for behaviour. The phrase "*it's all down to brain chemicals. It's not me*", implies the creation of an inauthentic form of selfhood caused by

chemical changes within the brain, separating the illness and its associated effects from Bridget's true self.

Similarly, in the following account Claire explains that she finds illness explanations less stigmatising, compared with personality disorder, because it means there is 'nothing wrong with you as a person - there's just something wrong with the wiring or whatever in your brain':

> I: That's interesting – can you tell me more about that – why is an illness less stigmatising?
>
> C: Um – well to me a personality disorder seems really stigmatising because it seems like your being told that there is something wrong with the essence of who you are – whereas having a **more medical explanation – that there is nothing wrong with you as a person – there's just something wrong with the wiring or whatever in your brain – um and that made me think as well about epilepsy** – and that before epilepsy was understood people thought – people were frightened of people with epilepsy and thought It was actually the devil or whatever – and I thought that maybe it's the same thing – **maybe it is a physical illness just like epilepsy but we just don't understand it yet** - and that if there is more understanding than people won't be so afraid. The number of people who thought that people with epilepsy were possessed by the devil is probably hardly any but that didn't used to be the case (Claire, Sefyll, Interview).

While bipolar disorder and its associated conception as a 'real brain disorder' appeared to be appealing for many, a few participants attempted to take this somaticisation even further. For instance, Joshua describes how he describes his illness to others as a 'brain disorder', rather than bipolar disorder, because it is less likely to evoke trivialising responses:

> I usually say I've got brain problems- cos it's a lot easier and people don't generally ask… I think its more acceptable – I think if you say you've got a brain problem people accept it more – people don't question it. But with bipolar people generally think oh right he's lazy – its fashionable – a lot of

people get misdiagnosed and you know - but if I say brain disorder and my neurotransmitter don't do what they're supposed to and people just leave it like that – before I used to say bipolar and I had to explain it. (Joshua, BipolarUK, interview).

Similarly, David, whilst initially pleased about his upgrade from a unipolar to a bipolar diagnosis, then discovers that he has another condition, which for him better explains his mood problems through identifying what he later terms as the *'underlying problem'*:

Recently I had some bloods done under the guidance of a nutritionist – she did a detailed battery of tests for levels of different substances in my blood – and they diagnosed me with something called pyroluria - which is a … it's to do with – its quite controversial – it's to do with the way that – it's a genetic problem – it's the way I synthesise haemoglobin – my body synthesises it in a kind of inefficient fashion, with a by-product. And that by-product takes things like zinc and vitamin b3 out of my blood stream. Which means that they are not available to take part in various functions in the body in particular synthesis of neurotransmitters – soooo that is the the idea, is that I've got to rebalance my sort of biochemistry by sort of adding various supplements and sort of adjusting my diet – and this does seem to have been extremely successful. (David, BipolarUK, Interview).

This focus upon the biological aspects of mood problems could also seem to diminish the role of psychosocial factors in contributing to illness. In the following account of brain causality, the social causal factor is depicted as being a constant, i.e. it is an experience which is depicted as being identical for the whole family (i.e. the same experience) – the only difference being 'something in the brain' which accounts for the psychotic episode, again downgrading psychosocial causative factors, which might take into account the individual interpretations and meanings attached to particular social events (although interestingly here the difference in her brain is described as the 'trigger', which stood in contrast to other accounts).

> *…For example, when my father died or when my uncle died, everybody else in the family had the same experience, but nobody else had a psychotic episode. So why it happens to me is, obviously, **something different in my brain that triggers it.*** (Mary, BPC participant, Interview).

While neurochemical accounts were dominant, this is not to say that participants never drew on social or psychological accounts which implicated the self in illness narratives. On occasions, participants would relate their bipolar disorder to their childhood selves and temperaments, drawing on notions such as childhood sensitivity and introversion, or alternatively emphasizing thrill-seeking tendencies (this will be further explored in Chapter 6). The above participant – Mary – at another point in the interview discusses the possibility of her personality as a causal factor, in addition to brain dysfunction:

> *I guess it's to do with the **disordered dysfunction of the brain, maybe, I don't know**. But I've always been, in **my personality growing up, I would keep stress to myself.** I was very private with things that worried me. I wouldn't talk about them or I wouldn't…so I don't know if that hasn't helped. (Mary, BPC participant, interview).*

However, as in the above extract, when the self was implicated in the disorder – it tended to be articulated as an uncertain risk or triggering factor of the disorder – e.g. often through contributing to stress, which then acted as an initial trigger. Neurochemical explanations were dominant in participants' accounts, and often seemed to fulfil the function of alleviating self-blame. This preference for biological explanations in bipolar disorder are consistent with findings from autism research, which suggest that positive autistic identities often relate to a 'neurological self-awareness', and a rejection of psychological interpretations (Ortega, 2009). It appears to reflect the 'neurochemical self' (Rose, 2007) or the 'cerebralization' of the self (Ortega, 2009), whereby beliefs, desires, behaviours and emotions are addressed in neurochemical terms, and their social and cultural effects are also attributed to the brain. This emphasis on somatic accounts of the disorder have particular implications for self-management styles; as the following section will argue, there was also a tendency for participants to subscribe to particularly somatic forms of self-

management in relation to their bipolar disorder, whilst de-emphasising psychological therapies and causes.

Somatic self-management in bipolar disorder

Participants would frequently refer to self-management strategies in relation to their bipolar disorder, in both interviews and on the BPC courses (although this was explicitly encouraged on the BPC programme, as the programme had several session dedicated to mood-management and monitoring); this tallies with Weiner's suggestion, in her ethnographic account of US bipolar support groups, that discourses of self-control and drug-specificity surrounding the treatment of bipolar disorder, as well as beliefs that bipolar patients tend to remain "intellectually intact", have "given rise to a conception of bipolar disorder as a mental illness extraordinarily well suited to the self-management modality" (2011, p. 457).

I argue further that the somaticisation and reification of bipolar disorder as a physical entity which is separate from the self, encourages particular modes of self-management, and certain forms of accountability in relation to the disorder. Much of the self-management emphasised on the BPC course, and in participant accounts, is aimed either at managing mood at the molecular level though medication, physical activity, sleep, diet and stress management, or at involving significant others in changing the external environment, so as to minimise stress and 'triggers', and put into place prevention strategies. This tends to downplay the role of psychological (and particularly cognitive) factors in the causation and treatment of the disorder, suggesting that – as Rose (2007) has argued – there has been a general shift to somatic or molecular (as opposed to psychological) forms of selfhood, encouraged by the biomedical psychiatric gaze and its related technologies. In both the interviews and the BPC courses, participants frequently described bipolar disorder as an entity separate to the self that a person 'has', and which must be carefully worked with or managed, as illustrated by the following examples:

*You know, you've got to learn to be that different person, and when you are on the medication, this is how I see it, of being bipolar and being on medication, **I've had to make my illness and my medication like my work colleague…**they are my work colleague and I have to work with all that to be, to proceed in my life, haven't I?* (Jean, BPC participant, interview).

&:

*But I also have a very familial condition, I have Type 3 Hyperlipidaemia, which means I have high cholesterol, high triacylglycerol's in my blood inherited from my parents, my parents both had recessive genes. I inherited both of them so I've got the condition. My brother and sister do not have it, I do, because it's one in four. So that, in a sense**, I live with two life threatening conditions. One Bipolar and the other is the Type 3, but again, it can be managed with medication.*** (Carol, BipolarUK, interview).

With the above examples, bipolar is depicted as an illness or even – by Carol - as a 'life threatening condition', which a person 'has' (in some permanent sense) and must manage, through making sensible lifestyle choices, e.g. medication adherence, stress minimisation, diet, exercise etc. Furthermore, these obligations to adhere to lifestyle, self-monitoring and self-management practises, also allow individuals to take credit for remaining well, which could arguably help avoid the biographical disruption (Bury, 1982) or 'loss of self' (Charmaz, 1983), often associated with chronic illness, e.g.

I: So has having the diagnosis had any impact on how you see your future?

*C: Not really, because I'm, as I've explained, I've been discharged from the community mental health team and returned to primary care. So, **that I manage the bipolar well, I'm a good self-manager and I've done training about self-management.*** (Carol, BipolarUK, interview)

&:

*You know and yeah, I mean**, my life is quite good and I manage my condition well.** I take my meds absolutely religiously. I respect, I respect what I have to manage.* (Jacob, BPC participant, interview).

As argued by Rose (2007), biological understandings of illness do not inevitably give rise to fatalism or pessimism; while most of the participants seemed to view their bipolar disorder as lifelong conditions which would need to be managed on a permanent basis, many described a proactive engagement with positive coping strategies, and a positive outlook on their own potential wellbeing.

When discussing self-management, participants tended to call upon aspects of lifestyle etc. which target the brain and the body at a molecular level, e.g. drug/alcohol use, exercise, sleep, diet, medication etc. For instance, in his interview Jack emphasises the importance of exercise in staying well, due to the somatic effects of exercise induced hormones (endorphins):

> I am a great believer of you know, I do a bit of - a lot of walking with the ramblers, and I am a great believer that endorphins are the body's natural opiates you know…

When I ask Jack whether he thinks bipolar disorder is something that can be managed, his initial response is to again discuss the benefits of physical activity – which he describes as impacting upon the mind:

> *I think exercise is really important. Healthy body, healthy mind, healthy body. It makes you, it makes you mentally stronger. Exercise can make you mentally stronger.* (Jack, bipolarUK, interview).

It was far less common for participants to cite psychodynamic processes or cognitive theories, such as thinking and attribution styles when explaining or discussing the management of bipolar disorders.

Stress minimisation

The main aspect of self-management with the potential to operate on a psychological/cognitive level, mentioned by participants, concerned the minimisation of stress, which was described by most participants as a major potential trigger for the disorder. In participants' accounts, stress was often seen as something to avoid or

minimise – depicted as a factor arising from external circumstances (i.e. being given too much work to do, traumatic situations, or contact with other stressful individuals). These accounts – often de-emphasised the role of individual interpretation and cognition in the creation of stress (i.e. psychological explanations which foreground the self in generating stress, which would be dominant in Cognitive Behavioural Therapy), although for a few, mindfulness and meditation were cited as helpful in stress reduction. In the following examples, stress is depicted as an abnormal strain which is placed upon the individual, i.e. it is not the individual's ability to deal with stress which is being foregrounded here.

> *…That's one of the reasons I became ill **because I was just doing all the most horrible cases going** - I was going to the court of appeal and this kind of stuff – too much. You've gotta be very careful you don't get too stressed when you've got this. And I picked the wrong job.* (Dan, Sefyll, Interview).

&

> *Ok uhm it originally started when ehm id had a **severe nervous breakdown from overworking and having lots of responsibility** uhm that would have been 2001, so I was in secondary services, from that point on I was seeing a number of different doctors who didn't seem to sort of know what was wrong.* (Christian, Sefyll, Interview).

Similarly, when asked what he thinks causes people to develop bipolar disorder, although Jack's initial answer stresses the role of genetics and family history, he then proceeds to talk about overworking and the need for work/life balance:

> *J: So, I think a lot of it is genetic, there's a history of mental illness in my family, so I think I may have inherited it. Also, time management is important, managing your time and setting limits on what you can do and what you can't do. Don't be afraid to say to somebody - no I can't do that, I haven't got the time, or no I don't want to do that because I'd rather do this or ... I am afraid I am very busy at the moment, I'll have to see you some other time. Managing your time. I remember when I was working for British Telecom and I had this very important job to do and at the same time I was with a girlfriend and we*

were renovating a house. I foolishly was trying to balance renovating the house and doing a job in work and unfortunately the job in work suffered which never should have been the case. Should have put work first rather than out of work activities. It came to the stage where I, right at the very last moment I had to go into work and work really, really hard for about a month to get the job done. I did eventually do it but I just, I was just finishing work at half past four, going to the house at five, working until nine, working on the weekends, I wasn't having a very good work/life balance…. And that can make you unwell…. I wasn't relaxing, I wasn't going for walks and living in the moment and taking in the scenery and just appreciating other things in life apart from work. (Jack, bipolarUK, interview).

(later in the interview) I: *So how do you view the genetic causes of bipolar disorder specifically?*

J: Well it could be, I think it could be, you know … I think the reason a lot of people have a breakdown is because of stress… Stress, not being able to cope with stress. Now that's a brain thing, isn't it? Possibly. Could be something to do with your brain that you can't, the brain is thinking 100,000 thoughts a second but there's so much we don't know about the brain. (Jack, bipolarUK, interview).

In this extract, the relationship between what could be seen as psychosocial factors, such as the lack of work-life balance, relaxation, and living in the moment are all envisioned as operating on the brain through the mechanism of stress. Similarly, in the following extract, while Kim cites stress at work as the cause of her bipolar (and unusually cites it as the primary cause of her illness); later on she describes how this stress directly resulted in her illness by impacted upon her brain – 'overloading' it:

I: So, what do you think now looking back? Do you sort of agree with the diagnosis or….?

*I dooo (uncertainly) but I still think **that obviously the stress I was under in work was the cause of the problem because if I hadn't been under that stress I would have probably gotten through it ok** and would have reduced the um*

antidepressant but I think also the antidepressant played a part in making me

….

I: -sort of higher?

Higher yeah – I don't know obviously but em but that's what I think

(Later on in the interview….)

*Yes – I think obviously **stress** I think during that 13-week period **of trying to do too much and obviously was just too much for my brain to cope with and overloaded it and also with the antidepressant**s – I won't know if I'm right obviously but that's what I feel* (Kim, BPC participant, interview).

As these accounts suggest, cultural conceptions of stress are multi-faceted (Abbott, 2001). However, one dominant conception of stress has been as a physiological response to external threats (i.e. concerning stress hormones, such as cortisol, which are depicted in popular representations as acting upon the body in damaging ways). Similarly, participants often appeared to be drawing on a particularly somatic notion of stress – as something which acts upon the body and the brain on a molecular/physiological level as opposed to a psychological level.

Consistent with this tendency to emphasise somatic understandings of bipolar disorder, the following section illustrates the tendency for somatic interventions and treatments to be privileged in comparison with psychotherapeutic approaches, which were at times resisted within participant accounts.

Resistance towards psychotherapy for bipolar disorder

There was a considerable focus on medication as the principal method of treatment for bipolar disorder in the BPC course, both from the course materials and instructors, and in the discussions of attendees. Considerable discussion revolved around difficulties in finding the correct type, combination, and balance of medication for each individual – as such, Psychiatrists were important figures in the accounts of participants. As Weiner points out, bipolar disorder was once treated mainly with

lithium; however, in current times patients work with their psychiatrists "to develop and constantly tweak" a ''cocktail'' of sophisticated psychotropic medications, each chosen to act on a specific aspect of the disease (Weiner, 2011, p.456). This reflects the idea that such drugs specifically target particular systems within the brain which have malfunctioned. This idea of specificity in turn has important implications for patient identity, since it suggests a simple cause based in the brain – a brain problem which translates directly into 'illness', which can in turn be targeted by drugs that target these specific systems. In comparison, while the BPC course has a session devoted to psychotherapeutic approaches to bipolar disorder, these approaches were represented as a potentially helpful add-on to pharmaceutical approaches.

Several types of psychotherapy have been adapted to treat bipolar disorder, such as CBT, interpersonal therapy, and psychoeducation (Colom & Lam, 2005; Basco & Rush, 1996; Miklowitz & Goldstein, 1997). Psychotherapy alongside medications for bipolar disorder has also been associated with better clinical outcomes than medications alone (Lam et al., 2003; Parikh et al., 2014), and NICE guidelines recommend psychological therapies in the treatment of bipolar disorder (NICE, 2014). In general, however, psychotherapy for bipolar disorder has been under-emphasized, and there is evidence to suggest that relatively few individuals with bipolar disorder appear to access appropriate psychological interventions (Marwaha, Sal & Bebbington, 2014; Evans-Lacko, Kastelic, & Riley, 2011; NICE, 2014). This is in direct contrast to the way in which psychological approaches (CBT in particular) have been upheld as the gold standard remedy for more 'common' mental disorder, such as unipolar depression and anxiety.

In the BPC sessions on 'psychological therapies for bipolar disorder', a number of different therapy types are mentioned, but the emphasis is placed more on the importance of the patient-therapist relationship than on therapy type. Thus, the potential for cognitive/psychological processes to be considered as important causal factors in bipolar disorder is downplayed. Psychoeducation is described by James as the nearest thing to a therapeutic intervention designed particularly for bipolar - as there are '*no* types of therapy *specifically* for bipolar'; James also mentions that whilst other types of therapy work for the depressive aspect of bipolar, there is no 'therapy'

for mania: In one session, Jean jokes in response, *"you wouldn't want it though…you're living the dream",* to which everyone laughs and there is general agreement. So here, mania is not (like depression) conceived of as a reaction to a style of thinking or a traumatic event etc. – it is conceived of as an experience beyond cognitive control and explanation, unlike depression, which is viewed as being more amenable to psychotherapeutic intervention. This conceptualization of mania contrasts with psychological theories such as the 'manic-defense hypothesis' (e.g. Bentall, 2003), which suggest that mania is a defensive reaction against feelings of depression and low self-esteem etc.

> *In explaining CBT, James presents a slide with a cyclical model of the 'thought – feeling- behavior- mood' cycle, stating that the easiest way to break this cycle is by changing behavior. He gives the example of depression and feeling like you really don't want to go for a walk, but that this is the best thing to do. There is no slide on the use of CBT for preventing mania.*

This illustrates the way in which CBT can place responsibility within the individual, conceptualization emotions as controllable through will-power and determination. Callard et al. (2012) found that particular treatments and therapies can be interpreted as suggestive of particular causes, leading certain treatments options to be associated with blame or stigma. In the same way that some participants interpret the efficacy of medications as confirming the causal role of chemical imbalances within the brain, therapies such as CBT, with its focus upon individuals' thinking styles and behaviour, could be taken to imply a moral "blemish of individual character" (Goffman, 1963, p.4), leading to 'volitional stigma' (Easter, 2012), e.g.

> *During a discussion of the statement 'medications are only used because they are cheap' (intended to promote reactions and discussions in participants), there are murmurs of disagreement, but George mentions the difficulty in getting counselling on the NHS, and the waiting lists for these types of therapies. He bemoans the way that CBT is pushed onto psychiatric patients because it is a 'short solution', and mentions the difficulty of obtaining other types of therapy. He also comments that CBT is better for those people "with*

lifestyle problems…e.g. who can't get out of bed", which is not the problem
with people who have bipolar disorder.

This separation of bipolar disorder from 'lifestyle problems' illustrates the moral importance of constructing Bipolar disorder as an illness or a brain malfunction – as opposed to a problem with behavior or thought processes, and also implies that those disorders treated by CBT (e.g. unipolar depression and anxiety) – which target thought processes – are associated with moral deficiency in some way. Interestingly, although George bemoans the way in which CBT is foisted onto service users, many participants stated that they had not been offered any kind of psychotherapy, and many seemed unsure of its relevance for bipolar disorder. This moralisation of psychotherapeutic treatments, may be at least partly why such explanations and therapies were not emphasised by participants:

> *When James asks the group if anyone here has had any psychological*
> *therapies, people are not overly forthcoming (compared with medication*
> *talk), and he resorts to asking people one by one. The overall impression is*
> *that most in the group have either had negative experiences or a lack of*
> *experiences with psychological therapies. A few tell amusing anecdotes*
> *involving bizarre encounters with therapists: Jacob tells a funny story about a*
> *therapy session where the therapist didn't say a word to him – simply sat*
> *looking at him and waiting for him to speak. Rachel mentions a strange and*
> *unsuccessful attempt at hypnotherapy, and Jean recounts a CBT session,*
> *which she was not able to engage with, since the therapist reminded her of*
> *her mother. Derek is asked and states he has never had any therapy – "it has*
> *always been drugs and sectioning with me". He gives no indication that he*
> *thought therapy would help him - It seems as though he has not considered*
> *its relevance to him. Bridget asks if anyone ever spoke to him about it and he*
> *simply says "no".* (BPC fieldnotes).

Derek's reaction was a typical response to questions about psychotherapy during interviews with bipolar service users – therapy appeared often to have not been offered or considered according to several. This resistance did not only seem to come

from professionals, however. Some participants also suggested that psychotherapy was not an effective treatment for bipolar disorder:

> *Jo: 'CBT is not so effective for 'depression in bipolar disorder'. (BPC, fieldnotes).*

&

> *Chloe: 'talking therapies don't really work for this (i.e. bipolar disorder) because it's a biological thing…. it's to do with brain chemistry.'*

CBT in particular seemed to be resisted, while certain forms of psychotherapy appeared to be more appealing:

> *Michelle says she has tried both CBT and EMDR [Eye Movement Desensitisation and Reprocessing]: she is asked how she found CBT – she does not go into detail here, as she has just started CBT recently, but says she didn't find it very good at dealing with her emotions, i.e. she needed a release of sorts from emotions, which CBT couldn't deal with. She has only had a few sessions of EMDR (having had to postpone it and about to start up again), but seems more positive about this form of therapy – there is a lot of interest in this as most people have not heard of it and even James and Bridget don't know much about it (Gemma – an NCMH assistant, says that it is often used to treat trauma). Michelle describes what happens in a session – her therapist will get her to talk about whatever memory is troubling her and as she does this moves her hand back and forth (like a metronome). The others definitely seem interested in this and Bridget says she wants to try it (EMDR is practiced at the local research institute, and there are several enthusiasts of this therapy there). James points out that it sounds quite "out there" but is actually quite effective for some.* (BPC fieldnotes)

EMDR is based on the idea that negative thoughts, feelings and behaviours are the result of unprocessed memories and its goal is to reduce the long-lasting effects of distressing memories by engaging the brain's natural adaptive information processing mechanisms thereby relieving present symptoms (WHO, 2013). The treatment usually includes focusing simultaneously on (a) traumatic images, thoughts, emotions and

bodily sensations and (b) bilateral stimulation, such as repeated eye movements. This type of therapy may be appealing because it de-emphasizes individual volition as it gives the impression of directly targeting the brain through reprogramming at a neural level (as opposed to resolving life problems or changing thought patterns etc.).

In the following extract from the same BPC session, Jean's account also de-emphasises the cognitive /psychological aspects of her mental health management; instead, she emphasizes both physical activity and a more generic form of socializing (as opposed to 'therapy'). It is not necessary for her to engage with her disorder on a psychological level by going to therapy; on the contrary, engaging in 'ordinary' activities and non-bipolar related discussion is important presumably because it helps avoid becoming defined by her condition:

> *Jean comments that – as opposed to therapy - sometimes it is just helpful talking to people, e.g. when she goes out for walks and bumps into people with the dog etc. that makes her feel happy. She also talks about joining a walking group where you go on hikes and chat with other people "not about bipolar or mental illness …but just about ordinary things" and that makes her happy for the whole week. It sounds as though she is more of a believer in this than in conventional 'therapy'. Rachel adds that her psychiatrist has told her to go to the gym (presumably for the mood benefits?) and she does find it helps, even though she doesn't enjoy the gym.*

This tendency to resist psychologisation and psychotherapeutic forms of self-management, is consistent with Rose's (2007) suggestion that the psychological aspects of selfhood are becoming increasingly displaced by somatic and molecular understandings of personhood. Unlike many opponents of psychiatry and the 'biomedical' model, Rose argues that this molecular style of thinking does not lead to fatalism in the face of illness, but to choice. To be a somatic individual, Rose argues, ''is to code one's hopes and fears in terms of [the] biomedical body, and to try to reform, cure or improve oneself by acting on that body'' (Rose 2003, p. 54). The style of management suggested by the BPC course (and reflected in participants' interview accounts) resonates with a molecular style of intervention, which can promote a kind of optimism in individuals regarding their own potential for wellbeing. It is also

possible, that by resisting therapies which focus upon the cognitive aspects of selfhood, individuals may avoid engaging with explanations which are blaming and incite volitional stigma (Easter, 2012).

Conclusion

This chapter has illustrated the way in which bipolar disorder is reified as a disease entity by participants, emphasizing the way in which this can be used to separate the disorder from the self, thus avoiding blame and volitional stigma. However, while the reification of bipolar disorder and its conceptualization as a brain based genetic disorder may appear to avoid blaming individuals for the initial development of the disorder (by constructing this as an irreversible triggering of an underlying disease process), it does not free those diagnosed from the responsibility of managing their 'disorder' appropriately through medication and lifestyle choice. As Rose (2007) has pointed out, there is a moral urgency in the direction of 'self-surveillance', and it is expected that this will strengthen with advances in molecular medicine. This responsibility is illustrated well by the BPD 'STABILITY card' handed out to BEPC participants – (who are told to stick it on their fridge): STABILITY is an acronym, representing: Sleep, Treatment, Avoid, Be positive, Interaction, Lifestyle, Inform, Triggers, and *You can take control of your illness*. Participants are thus morally obliged to try and 'take control' of their illnesses, through appropriate self-management.

Although such genetic and neurochemical explanations can in some cases be deterministic and reductionist (as in Diane's case), these explanatory styles were more frequently combined with other forms of reasoning, and positioned as susceptibilities whereby illness could be triggered off by psycho-social factors (with stress being the most common form of trigger depicted). Despite this, the psychosocial factors were often positioned as secondary in importance to biogenetic factors, through their relegation to trigger status. In addition, even ostensible psychosocial factors such as stress, were often depicted in somatic terms, while more psychological and cognitive explanatory styles were often absent from patient narratives. This prioritization of

causes has clear implications for the modes of self-management encouraged by dominant understandings of bipolar disorder, with a general tendency to emphasise more physical and somatic styles of management over the psychological (particularly cognitive therapy). However, while psychological forms of therapy are currently recommended for bipolar disorder (e.g. by NICE guidelines), the tendency of participants to associate more psychological explanations with moralizing tendencies, suggests that attempts to 'psychologise' bipolar disorder could be perceived as having the potential to encourage 'volitional' stigma (Easter, 2012), and the blaming of patients. The significance of this reification and essentialisation of bipolar disorder for patient identities will be further considered in the following chapter, which will further explore the way in which those diagnosed relate to, and identify with their bipolar diagnosis.

Chapter 6

Relating to Bipolar Disorder: Explanation, Identification, and Essentialisation

Drawing again on material from the BPC courses and interviews with patients, this chapter further considers the way in which participants relate to their bipolar diagnosis and position their diagnosis in relation to themselves. Building on the previous chapter, I will illustrate the ways in which participants tended to depict the illness as an isolable force acting upon the self; in doing so they use their bipolar diagnosis to explain unusual or undesirable behaviour, distancing the tendency for mood changes from their personalities and temperaments, and distinguishing between 'normal' mood swings and bipolar mood fluctuations. Despite the obligation for the 'rational' self to manage the disorder (outlined in the previous chapter), this reification can also function to exempt participants from certain forms of accountability, since the illness is at times depicted as a force which overwhelms the rational self (usually in the form of mania or psychosis, but on occasion depression), leading to a limited capacity for agency. This limited agency can be emphasised by participants as a means of deflecting blame and volitional stigma (Easter, 2012), and of offsetting the delegitimization described by many.

However, in contrast to the above, some accounts also emphasised the inherent difficulty in distancing self and disorder, with some participants actively emphasising the link between their 'normal' selves and their bipolar. Extending upon findings from the previous chapter, I will consider the way in which understandings of bipolar disorder as a categorical entity could encourage participants to use their diagnostic status in order to promote a positive sense of self and inter-group cohesion with others labelled with this diagnosis – a trend referred to as 'strategic essentialism' (e.g. Haslam, 2011; Edie, 2010; Voronka, 2017). Similarly, I suggest a tendency for participants not only to positively identify with the diagnosis, but also a tendency for some to display a form of diagnostic possessiveness, in denying the validity of others' claims to the diagnosis. The diagnosis of bipolar disorder appears to confer a number

of advantages to participants (at least in comparison to other psychiatric diagnostic categories), and it is feasible that these advantages, combined with a wider culture of delegitimization, and the conceptualisation of bipolar disorder as a categorical entity (as opposed to a continuum), may reinforce tendencies towards diagnostic possessiveness and strategic essentialism, whereby participants would actively use their diagnostic status for particular purposes (e.g. explaining behaviour, accessing services and peer support, and finding meaningful work), but might also deny or invalidate other individuals' diagnostic claims. There are therefore implications for mental health problems which are not reified in the same way (problems attributed to personality, behavioural problems, and 'common' mental disorders etc.), as discussed in chapter 4.

Separating the disorder from the self

Reducing accountability & using diagnosis as an explanation for extreme behaviour

Despite the expectations (and potential benefits) to self-manage and monitor the disordered self, highlighted in the previous chapter, participants often stressed the limitations of self-management and self-control, by appealing to the uncontrollable and unpredictable nature of the irrational disease, which imposes upon the self, removing agency and exempting the individual from responsibility. For participants, emphasising the way in which bipolar disorder would make them behave in abnormal ways seemed to protect them from being morally implicated in any kind of disagreeable behaviour. Participants would frequently emphasise the fact that the bipolar disorder would lead them to behave in extreme ways abnormal to them e.g. -

> *During a discussion about sleep problems in a BPC session, Bev tells of a very recent experience of staying up for 3 nights without any sleep – her daughter moved house next door and she moved all their stuff in those 3 days and nights, much to the amazement of her daughter. She says she then crashed after those three nights and slept for a few hours in the day followed by a solid 12 hours at night. James (the convener) asks how she felt after that and she says she still*

felt high (and that she still felt high now). Derek says that he once stayed awake

for 5 nights and stalked a woman whom he believed he would marry. There

was an awkward silence at this admission, but James asks Derek a question

unrelated to the stalking, avoiding further discussion about the incident.

The use of extreme case formulation (Pomerantz, 1984) in descriptions of bipolar disorder has been found in previous research, particularly with regards to mania (Bysouth, 2007). During the BPC course, participants often depicted bipolar in terms of fluctuations between extremes which cannot easily be explained in social or psychological terms (e.g. in terms of cognitive or psychodynamic processes). This emphasis on the severity, extremity, and unusualness of behavior in relation to people's 'normal' behavior, illustrates the importance of conceptualizing the disorder as separate from the self in maintaining an individual's status as a moral person. For example, in the following extract Jacob attributes his violent behaviour to mania: -

Jacob - arguing that mania is not necessarily a nice experience – describes how

he attacked his own father while manic; although he describes this in a

horrified and shocked way (exclaiming that his father was 74 years old at the

time!), he speaks more with disbelief than with shame – as though he were a

different person when manic and does not relate to this person. Jacob has

spoken several times in very positive terms about his parents; at this point he

does not give any indication as to why he attacked his father – it is attributed

to the mania.

James then comments that although mania can be nice it might result in doing

things that are later regretted – and that he had heard a rule that those in

manic phases should wait 3 days before making any major decisions –although

he immediately acknowledges this would be impractical; Bridget (service user

co-facilitator) says 'there's no point in asking anybody's opinion (when manic)

because they would be wrong', again – emphasizing the extreme certainty

which characterizes mania and psychosis, and the inherent irrationality and

uncontrollability characterizing this state.

James's description emphasizes the fact that mania *causes* people to behave in regrettable ways – dismissing the possibility of individual agency during this time. Bridget emphasizes the extreme certainty with which delusional beliefs are held – this is seen as being a sign that true 'psychosis' is occurring, and that at such times there is no possibility of rational choice. Another effect of these extreme descriptions is to emphasise the uncontrollability of the mood changes and resulting behaviour, and to position the mood changes as preempting the irrationality, i.e. the mania happens first in a way which is beyond individual control and explains the 'irrational/abnormal' behaviour; thus, the individual is not irrational, the mania has caused them to be irrational.

Past research has also highlighted the way in which diagnosis can be used as an explanation to exonerate individuals. In particular, Pope's (2015) ethnographic study of a US residential treatment centre for female youth patients, found that citing the bipolar diagnosis in itself was enough to divert responsibility away from a patient who was previously being held accountable for her actions within a therapy group session. Within this context, the diagnosis "erases the diagnosed of any traces of personal responsibility" (Pope, 2015, p. 525). These findings also echo Brinkmann's suggestion that an ADHD diagnosis performs an explanatory function for participants attending Danish ADHD support groups, transferring responsibility from the person onto the diagnosis. This tendency to use diagnosis as a means to explain difficult feelings and behaviours also involves a process termed 'entification' (Valsiner, 2007, cited in Brinkmann, 2017), whereby psychological phenomena are turned into concrete entities with causal powers that lead directly to particular 'symptoms'. As argued in chapter 6, this 'entification' appears to be encouraged by neurobiological theories of aetiology and illness. Similarly, I argue that the freedom from accountability supported by this model of disorder is bolstered by accounts of bipolar which emphasise biochemical causation.

Often this limited agency would be emphasised by depictions of the unpredictability and unmanageability of mood 'episodes', whereby the self and agency are both removed as potential causative factors since these episodes are depicted as beyond control, prediction or prevention:

*B: But then saying that**, I can get manic for no reason whatsoever.** Luckily, it's not the same for depression. I don't mind getting manic.*

I: So, with depression, does there have to be a trigger?

B: Yeah, usually.

I: And the mania can happen just randomly …?

*B: Well, yeah, I mean there are things like, I had to get a letter and it was really stressing me out and I had a panic attack because it still hadn't arrived. **Now usually that wouldn't have bothered me but it did and I don't know why,** but you know, I, you know, you can't walk around wondering how you are going to be the next day because you won't live, otherwise* (Bridget, BPC facilitator, interview).

The assertion that there can be '*no* reason' for the mania can be presumed to mean – not that there is actually *no cause* but that there is no *psychosocial* cause beyond the imbalance of neurotransmitters; that this chemical change (and subsequent mood change) can happen independently of social or psychological factors. The term 'no cause' implies here that the bipolar (or the chemical imbalance resulting from bipolar disorder) is a sufficient and complete explanation for mania on its own. It has been noted that such medical explanations in fact constitute what has been described as an INUS condition – an insufficient but non-redundant part of a condition which is itself unnecessary but (deemed to be) sufficient for the occurrence of the effect (Mackie, 1988). As a number of scholars have pointed out, such causes are invariably part of an often-complex group of factors, but particular causes tend to be singled out as *the cause,* while others are ignored or relegated to the background (e.g. Gannet, 1999; Heslow, 1984; Wulff, 1984). This is despite the fact that the conditions singled out as causes - whether in medicine or otherwise - are rarely sufficient for their effects.

As in the above example, depression - by contrast - was often depicted as being understandable in terms of external /psychosocial triggers, which presumably play a role in causing the depression, and thus can be more easily amenable to prediction, and presumably intervention. In the above example, when an attempt is made to

clarify whether mania can happen 'randomly', Bridget does acknowledge that at times there are pre-indicators of mania (in this case alluding to stress and a panic attack), but maintains that this would not be enough to allow for prediction and intervention, since self-monitoring to this extent is depicted as extreme (i.e. over-monitoring) and a threat to authentically 'living', meaning that not all episodes can be predicted and not all warning signs acted upon. The implications here are that those with bipolar disorder – despite expectations to self-manage and self-monitor – can claim exemption from certain forms of moral accountability.

This ability to downplay agency often relied upon and was supported by biological notions of illness. For instance, when I ask Christian whether he has any control over his mood changes, he appeals to the notion of a 'chemical reaction' which makes him 'react to things', which is contrasted with the implied disclaimer statement later on (i.e. '*sometimes you can be doing all the right things…. but'*), again emphasising the limitations to control and prediction.

I: Is that something that you – do you have any control over that do you think?

*C: Uhm yeah – I mean some of it is – **with the bipolar some of it is very much a chemical reaction so I can just be – I can react to things and then that can affect my mood** – uhm but there are things you can do - so things like street drugs – to avoid or you know be very careful about alcohol consumption uhm caffeine intake, sleep patterns, routines, so that those kind of things can help with the stability as well. I did attend a four-day course – going back to 2011, which was a self-management course for people with bipolar, and there were some very helpful tips in there.*

I: Um – I was interested that you said about the chemical reaction – can you say a bit more about what you meant by that?

*C: I think sometimes you can be doing all the right things – uhm – **I suppose to give you a contrast there have been periods where I've been so severely ill - that nothing has worked and I've turned to alcohol and drugs as a way of self-medicating**. Ehm but there are periods where I've been doing everything*

*right – so you can be completely clean of alcohol and clean of drugs, you can monitor your caffeine intake, you can have a good routine, **but for some reason there seems to be a chemical reaction that just makes you either down – you know go low in mood – and there might not be a rational explanation for that – it just happens because it's a chemical reaction.***

I: Do you think there is any cause for that?

*C: I think **that's the nature of bipolar to be honest with you**. I mean I think you can self-manage quite well sometimes. Uhm and I suppose the difficulty with me is that having the dual diagnosis means that there will be other factors that come into play that can affect my mood as well. Uhm and sometimes it sounds strange to say but you know you can be watching a documentary – you could be in a good place and watching a documentary, something might - you might relate to something more uhm closely and then that can affect your mood quite quickly - you can drop in mood or or something good can happen and your mood goes up suddenly and there doesn't seem to be any tangible reason for it but **uhm it just feels a bit more chemical because that's the nature of bipolar***

I: Because it's so sort of inexplicable?

*C: Yeah - **and I've found that with people that I know with bipolar as well ehm that they can be doing the right things and then their mood can just change for no particular reason – ehm so it just seems that it can be more of a chemical reaction than an environmental one.*** (Christian, Sefyll, Interview).

Similarly to the account given above by Bridget, Christian appeals to the idea of mood changes 'for no particular reason' and 'no rational reason' – again presumably meaning no psychosocial reason – the chemical reaction is depicted as something which can occur suddenly, without warning and without reason - unpredictable and irrational in nature: Again, it is sufficient in itself. Although other possible influences are mentioned such as lifestyle factors (sleep, diet exercise, alcohol avoidance etc.) – these are positioned by comparison as unnecessary (i.e. they can play a role in the causation of mood episodes but they are not necessary). This version of

unpredictability is then also validated by the claim that others with the disorder also experience these mood changes, despite them 'doing all the right things'. The descriptions of agency are complex and contradictory within this extract however; whilst the extract as a whole appears to be minimising Christian's responsibility for his mood changes, and the chemical imbalance explanations appear to de-emphasis the role of his own volition, there are also glimpses of agency appearing at times which contrast with this. For instance, he implicates himself and his own decisions in describing how he turned to alcohol and drugs to manage his symptoms (albeit it, in a way which minimises the role of choice). Also, in describing his sudden mood fluctuations, he simultaneously describes these as chemical, due to their inexplicability, whilst also situating the mood changes as emotional reactions to a tv show (*'you might relate to something more uhm closely and then that can affect your mood quite quickly - you can drop in mood or or something good can happen and your mood goes up suddenly and there doesn't seem to be any tangible reason for it…'*). However, although there is space here for a more 'psychological' form of explanation (e.g. a personal reaction to the TV show, which is explained by an individual's past history, or by their interpretation of the show's contents), Christian still suggests that there is '*no tangible reason*' for the mood change (which can be taken as implying the chemical nature of the mood change). This extract therefore implies the ability of neurochemical explanations to 'bypass the self' (Healy, 2001), despite the potential for psychological explanations.

Appealing to this version of chemical reactivity – which is depicted here as a defining feature of bipolar disorder ('*the nature of bipolar disorder*') – therefore allows him to escape the form of self-monitoring and responsibility which would be associated with more psychosocial models of mood disorder, such as the thought-monitoring involved in CBT work. In the above extract, references to thinking styles and interpretations are notably absent as explanations, despite the fact that Christian is one of the participants who has received psychotherapy, which included elements of CBT. In general, the type of self-monitoring involved in CBT or other types of psychotherapeutic work, was not common in participant accounts, even with those few participants who had received CBT/ or other therapy in the past. The type of

illness which is perceived to result from chemical imbalances that directly influence mood, arguably leaves little room for psychological interventions and interpretations.

In agency minimising accounts, behaviours were often depicted as being secondary to changes in mood, so that mood changes were the instigators of an altered version of selfhood. Similarly, illness associated behaviours were also described as 'symptoms' of the illness, as opposed to - for instance - personal qualities. For example, in the following extract Dan describes irritability as a 'symptom' of bipolar disorder, and as a symptom of being 'high-functioning'.

> *Not really its just I'm – **one of the symptoms is you get quite irritable and I'm quite high functioning anyway so I do get irritated at uh many things.***
> (Dan, Sefyll, Interview)

Further on in the interview, he also attributes drinking excessively (he has previously been treated for drug and alcohol abuse in addition to bipolar disorder) as secondary to his 'energetic' or 'manic' state, claiming that this altered physical state allows him to drink vast quantities without it affecting him: -

> *I find that when I'm energetic, or **manic call it what you like – that I could literally drink vast amounts and you'd never know I was drunk. 4-5 bottles of wine***

Whilst limiting alcohol consumption is a key components of lifestyle self-management in bipolar disorder, Dan suggests that his excessive drinking emanates from (or is at least preceded by) his mania – which changes the way in which his body processes alcohol, enabling him to drink vast amounts without feeling its effect. Again, this version implies the limitations of rational self-management in bipolar disorder, by positioning excessive alcohol consumption as secondary to fluctuations in mood.

In the following extract, I asked Dan on his opinion on the notion of bipolar disorder being a 'brain disease'. Interestingly, the notion of the brain is again immediately taken up as a means of validating 'reckless' behaviour, which again is attributed to '*being bipolar*'.

I: So some people would say that bipolar is a kind of a brain disease. What do you think of that kind of thing?

D: Uh… I've had a lot of bumps on the head! There's no doubt my front-temporal lobe has been damaged a bit and that I'm therefore a bit more reckless than other people. The worst addiction I've ever had was when I had my last depression – I started gambling online and I lost about £200,000, lost everything I'd ever worked for - I'm bankrupt at the moment – now that's an extreme example and that's definitely to do with being bipolar (Dan, Sefyll, Interview).

In the following extract, Christian, who has a dual diagnosis of both bipolar disorder and emotionally unstable personality disorder (EUPD) (otherwise known as borderline personality disorder (BPD)) discusses receiving his PD diagnosis:

Uhm that was during an appointment I had when I suppose in addition to the em the bipolar side of things that there are periods when - particularly when I'm in a depressed mood – where I can be quite emotionally vulnerable em and struggle with things emotionally. (Christian, Sefyll, Interview)

The emotional vulnerability and struggling (which can be read here as symptoms of EUPD, although they are implied to be symptoms of depression) are depicted as secondary to changes in mood (which are associated with the bipolar disorder). His personality issues are thereby downgraded as a cause of his problems in comparison with the bipolar mood fluctuations.

Although participants often utilised their bipolar diagnosis as a means to explain their actions and behaviour, it must be noted that this did not necessarily protect them from moralizing or stigmatising responses from others. For instance, David describes below how he found bipolar disorder a more validating diagnosis than unipolar depression:

It felt that I'd got a – there was an illness – an illness that was more – a more serious and more well defined and I suppose it – somehow made it easier to explain myself to people – at work I needed to take things a bit easier or

things like that it somehow felt easier having something like bipolar. With

depression it felt more… (David, BipolarUK, Interview).

However, when I ask about whether his change in diagnosis (from uni to bipolar) effected family responses to him - he explains that it didn't make much difference, because in his family there was '*quite a lot of ignorance around these things'*. Similarly, this was also reflected within the narratives of other participants, who gave examples of family members and close others either not believing in the disorder, or not understanding it.

Distancing mood changes from personality and temperament

As described in chapter 5, diagnoses which are linked to personality traits (such as personality disorders) tended to be less favoured by participants, due to their tendency to locate the problem primarily within the individuals' own identity and volition. Similarly, many participants in interviews and the BPC courses, were keen to distance their fluctuating moods from their personalities and temperaments. In the following example, James (the convener) is quick to avoid associating bipolar disorder with any kind of pre-existing temperament (sensitivity); his description emphasizes that only once a person 'has' the disorder, it is their mood problems that precipitate the person's difficulties, rather than sensitivity leading to mood problems. Bev adds to this by emphasizing how her moods precede or cause both heightened sensitivity and behavior that would be out of character for her, thus again emphasizing that it is the mood shift that precedes (and presumably causes) the person's difficulties: -

When James comments on the complexity of the interaction between genes

and environment, Jean asks if people with bipolar are generally somehow more

susceptible to certain things and less able to cope with stress for instance

(presumably prior to the illness). James pauses to think and replies 'not really

…. But once a person develops the disorder they may experience greater

extremes of lows and highs – and more intense happiness and sadness for

instance'. Bev mentions how she feels more sensitive to certain things such as noise and people when low, and cannot stand to have people around; but when she is high she can tolerate a lot of noise. This turns into a group discussion of highs and lows and Bev telling someone to 'F off' when down – 'which I wouldn't normally do'. I am struck by how often people cite behavior followed by the statement that this is not normal for them i.e. it is not a reflection of who they really are. (BPC Fieldnotes).

So, although Jean considers whether those with bipolar as more sensitive to begin with, Bev describes her sensitivity as a manifestation of bipolar disorder; the mood change is the primary driver of other symptoms and behaviors. This has particular consequences for identity, since the precedence of the mood change minimises individual responsibility for resulting behavior.

Potential feelings of blame and responsibility are problems that the course explicitly addresses; during the session 'what is bipolar disorder', the initial slide contains three key messages, one of which is: *'Bipolar disorder is NOT a character flaw, a personality defect or your own fault'*. Feelings of blame and stigma also arise during group discussions, as in the following example: -

In a task where participants have to make a list of helpful/ unhelpful people in their lives, Jean comments that it is common for people to act as if 'it's your fault', or that 'you've caused all of it'. Rachel says she finds it common that people will say 'just pick yourself up and get on with it', particularly her husband and her work colleagues who are 'absolute bastards'. She then explains that she has never been off sick whether she has been depressed or manic, something she seems pretty determined about (but it seems as though things are not easy for her in work and as if she feels blamed by some of her colleagues). In addition, her husband is the type of person who is never ill and simply cannot understand any kind of illness. She tells how she had her gallbladder removed and was supposed to take a month off of work – but he told her to return after a few days as she 'only had some staples in her stomach'. Her husband also doesn't understand that her work (full time) exhausts her so that she has no energy for anything else after coming home from work and he

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expects her to do things. Jean also comments that some family members can develop a blasé attitude towards bipolar after getting used to it, saying things like 'oh…she's off on one again!' and that they don't seem to care anymore because they are so used to it. Rachel says, 'that is how they cope with us' and 'it's very difficult to cope with people with bipolar disorder'. Nobody disagrees with this – apparently justifying the behavior. Bridget comments that it could be a generational thing – in previous times 'we would have been locked up'. Jean agrees saying 'oh yes, my mother is very old school - they were in the war, so….'

Some of the accounts here, such as Rachel's emphasis on her work ethic and the cliched phrase '*pick yourself up*' (which is reminiscent of the 'pull yourself together' idiom, commonly espoused by anti-stigma promotions), reproduce neoliberal discourses surrounding work and the welfare state, reflecting the way in which ideas of valid personhood are bound up in notions of economic productivity and self-sufficiency. In this last statement regarding previous generations and their attitudes regarding mental illness (which – as indicated by Bridget's assertion that '*we would have been locked up*', are positioned as unenlightened), presumably Jean is suggesting here that people were 'tougher' or more resilient in the days of the war, but also that as a result of their difference in circumstance that their viewpoints are outdated. These attempts to both position those demonstrating a judgemental or blaming response as ignorant or outdated, and attempts to position the self as industrious and responsible (qualities which patients also enacted within clinical interactions) suggest a concern with such moralizing responses from others.

While this section has illustrated participants' attempts to distance themselves (or their authentic selves) from their disorders and its consequences, the separating of the self from a disorder which fundamentally shapes a person's thoughts, feelings and behaviour, is arguably likely to generate difficulties, when notions of personhood are so intricately tied to the way in which an individual thinks, feels, and behaves. The following section will illustrate some of the complexities involved in these attempts to separate self and disorder, in part because mood changes are a 'normal' aspect of life, making it difficult to distinguish between 'normal' mood swings and mood changes

associated with the disorder. Some participants also provide accounts which seem to more closely relate their bipolar disorder to their own personalities and temperaments.

Difficulties separating the disorder from the self

Distinguishing between 'normal' ups and downs and 'bipolar' mood changes

As others have pointed out, the use of diagnosis as an explanatory device can become circular in nature, since it functions to explain the very features which support its presence (Brinkmann, 2017; Timimi, 2009). The diagnosis thus becomes self-affirming, and anything may be taken as a symptom affirming the diagnosis (Brinkmann, 2017). This can also be used against those with the diagnosis in an essentialising sense; for instance – whereas participants tended to distinguish between what they described as 'normal' ups and downs, and bipolar mood fluctuations, family members were reported to view any 'normal' fluctuation in mood as a potential symptom of the disorder. For instance, in one BPC session, Rachel complains that her husband will ask her if she has 'taken her meds' when she is having a 'normal' high or low (despite the fact that she does not take medication). In a further, BPC session:

George says that his partner is very supportive and knows quite a lot about bipolar, although sometimes she doesn't know whether his behavior is due to an episode and gets upset (he is presumably saying that she gets offended by mood swings not realizing that this is part of an episode for him). Aakif then comments that this is the difficulty with bipolar – in drawing a line between 'what is just normal ups and downs and what is actually caused by the bipolar'. He says that although his wife has read up on bipolar and is somewhat of an expert, she will sometimes attribute his behavior to bipolar when perhaps she shouldn't, i.e. when he just happens to be in a bad mood, she'll say 'you're being bipolar now'. Anne adds that it is a problem that bipolar can be used against people (presumably 'normal' behavior being attributed to bipolar and cast as abnormal when it shouldn't be).

This tendency for participants to distinguish between 'normal' ups and downs, and 'bipolar' ups and downs, is possibly another indicator of the prominence of categorical understandings of bipolar disorder, since it was often taken for granted that there was a clear difference between the two. However, Aakif problematises this ability to draw a line between normal mood swings and bipolar symptoms, although in his following comment he seems to suggest that this is something that *should* be done. His comment supports Weiner's suggestion (2011) that the reification of bipolar disorder as an isolable 'disease' to be managed, "fails to capture the ways in which it is experienced as neither a fixed object nor apart from the self, but rather as a temporal formation that expresses or realizes the self in a particular, if pathological, way". So, although service users may attempt to separate the illness from themselves, it is ultimately impossible to draw a firm line between self and disorder.

Anne's comment highlights the way in which a bipolar diagnosis can also be essentialising – the individual can become synonymous with the disorder, and their behaviour is more likely to be framed as symptomatic of the underlying disorder by other individuals. This was something that other participants voiced concern about, - a circular thinking whereby various behaviors and traits will be assumed to relate to the mental disorder; any mood change or unusual way of thinking may thus be taken as a symptom. Therefore, while the diagnosis may be usefully deployed by individuals to explain and justify unwanted behaviour, it can also in turn be used as an explanation by others in ways which are harmful and unhelpful. For example, during one discussion, a few of the BPC attendees state that they believe in paranormal forces such as psychic abilities, but voice worries that they will not be taken seriously due to their pathological labels:

> *Jean mentions that although she believes she has psychic ability she would not divulge this to her psychiatrist (in fact she said she was asked this by a psychiatrist and said 'no', presumably because she feared her beliefs would be pathologised as part of her diagnosis). She recounts this lie with a smile – rather than shame, in a way that implies that the risk of having their beliefs, values and behavior interpreted as a sign of their 'illness' is a well-known problem for individuals with this kind of disorder.* (BPC fieldnotes).

Thus, while participants would often attempt to separate and draw a line between their 'normal' selves and their disordered selves in various ways, these attempts could be thwarted by others, who might interpret various forms of thoughts, feelings and behaviour as symptoms of bipolar disorder. At times, however, as the following section will suggest, participants themselves would relate bipolar to their normal selves, personalities and temperaments, often when using the disorder to explain past behaviour.

Linking disorder and self: Using the diagnosis to explain past behaviour.

Some individuals used the diagnosis to retrospectively explain past behaviour or tendencies (prior to diagnosis), at times in ways that seemed to relate the disorder to the individual's personality and temperament. For instance, Eleri starts her diagnostic narrative by immediately reminiscing about her childhood self, emphasizing her lack of stability even then. Stating that she has '*never been…stable'*, she implies that the bipolar has always been present in some sense:

> *It started - I mean I've never been, you know stable, I've never had a stable mood, even when I was a child. But you know we had no reason to think that it was bipolar and it was never that severe that I was hospitalised or anything like that. But I did suffer from severe depression and anxiety and I was treated for that with antidepressants. And you know after a time of being treated I was fine but I kind of think my mood went up a little bit after that. I suddenly became really clever, really confident.* (Eleri, BipolarUK, Interview).

This extract also functions to validate the participants' diagnostic status, by citing evidence to suggest an underlying tendency towards bipolarity (suggesting that she 'went up' after taking anti-depressants), in a similar way to those accounts which emphasise family histories of mental disorders. While Eleri links her bipolar disorder to her past self, the following account links a participant's illness to their childhood personality. Prior to the following account, Jack (who has since gone on to achieve a degree) has been discussing his regrets about not having achieved educationally at

school. In the first sentence below, he relates his difficulties at school to his bipolar disorder, despite not having been diagnosed at the time:

> *J: Yes, yes I would have, yes. But I think it may have been because I was unwell.*
>
> *I: Okay, - so you think being unwell started quite early then?*
>
> *J: I never seemed to, when I was younger I never seemed to mix with my peers, you know - children the same age as me… I always felt a little bit ostracised, a bit out on a limb. I just didn't do the same things they did. I found it difficult to play, just found it difficult to play…. I was too serious.* (Jack, BipolarUK, Interview).

Interestingly, while many participants tended to distance their disorder from their personality, Jack appears to be linking his tendency to be serious and his inability to socialize and play with his illness. Jack also talked about his relief on receiving his diagnosis because of its ability to explain why he had done certain things:

> *I: did getting the diagnosis change at all how you saw yourself?*
>
> *J: Actually, I felt relieved to have a diagnosis, because it answered a lot of questions. I thought oh good that explains a lot… this means okay I am suffering from a mental illness, I didn't know that before, I just assumed that everyone was the same as me. I didn't realise I was different to other people. Having a diagnosis made me think gosh yes, that's the reason I did that, because I am bipolar, and people with bipolar do these sorts of things. So, having a diagnosis and a label was good for me.* (Jack, BipolarUK, Interview).

These accounts linking people's past histories to their current diagnosis could (similarly to the above explanatory accounts) also function to minimise responsibility for past conduct, by depicting the symptoms of disorder as the reason for certain past events. In addition to offsetting blame, these narratives connecting diagnosis to past selves could also be a means to construct a coherent sense of self. For instance, it is noteworthy in the above extract that Jack describes himself not as *having* bipolar, but as *being* bipolar ('I am bipolar'), which seems to have provided him with a new narrative with which he can reinterpret his past history. Claims of '*being* bipolar' were

also apparent within the accounts of other participants, and seemed to suggest a close identification with the diagnosis.

Findings here echo what Baart and Widdershoven (2013) observed in their focus groups with BD service users: That while some imagine the disease as an outside force acting on the person to change their behaviour, others view their personalities as inextricable from the disorder itself, creating difficulty in ascertaining what belongs to the diagnosis and what belongs to the person. For these individuals, 'normal' personality traits, such as sensitivity, can be related to bipolar disorder. While these researchers suggest that participants have different tendencies in this respect, in the current research, participants sometimes gave alternate and contradictory accounts of their relationship between themselves and their disorder, at times depicting bipolar as an outside and separate force, and at other times relating it to their own personalities and identities.

While disentangling the disorder from the self could be problematic, it seemed clear from many accounts that participants found their bipolar diagnosis useful, particularly in its function as an explanatory device. The following section further considers the ways in which individuals are able to positively identify with and mobilise around this diagnosis, processes which are shown to depend in part, on the tendency to essentialise the illness, and conceptualise it as a discrete entity (rather than as a continuum).

Identifying with the Diagnosis: Strategic Essentialism & Diagnostic Possessiveness

Previous research has indicated the cultural validation attached to the bipolar diagnosis, enabling people to organise politically around the category (Lakoff, 2000; Martin, 2007), and encouraging patients to use the diagnosis as a lens through which to interpret their experiences (often placing pressure on psychiatrists do the same) (Whooley, 2010). As is explored in chapter 4 of this thesis, patients often approach clinical encounters with pre-existing notions regarding their own diagnosis (see also

Whooley, 2010), and diagnosis often involves an element of negotiation between patients and professionals (Healy, 2001). The potential of bipolar disorder to alleviate 'volitional stigma' (Easter, 2012) could be one reason for the prevalence of apparent diagnosis seeking behaviour with this disorder, in addition to popular associations of the disorder with celebrity and creativity (e.g. see Chan & Sireling, 2010). Diagnosis provides a narrative by which behaviour and symptoms can be explained, and by which blame can be averted, as illustrated by previous extracts in this chapter.

Multiple advantages of being diagnosed with bipolar disorder were apparent from participant accounts, and with some participants there was a process of active diagnosis seeking, and a feeling of validation upon receiving a formal diagnosis (as seen in Jack's account above). Even for those participants describing their initial diagnosis as a feeling of loss, there often followed a narrative of acceptance and appreciation, after the initial disappointment. Some described the desire to know what was 'wrong' in order to know how to best manage the disorder, and through this being able to research the condition. A formal diagnostic label also allowed individuals to seek out and socialize with others with the same diagnosis:

> *I: Yeah… – um, so what did you find reassuring about that – was it because he kind of normalised it?*
>
> *C: Yeah and um **by having a diagnosis that meant that I could find other people like me- so if I hadn't have had the diagnosis – I wouldn't have been able to go to the manic depression fellowship – but it kind of opened the door for me to do that** – whereas if I had not been given the label I wouldn't have been able to do that – does that make sense?* (Claire, Sefyll, interview).

It is interesting here that Claire refers to others with a diagnosis of bipolar disorder as being 'people like me', suggesting that bipolar disorder is an essential aspect of a person's identity, even constituting a certain type of person. Occasionally, participants would draw on ideas akin to the neurodiversity concept, which has been strongly aligned with Autistic Spectrum Disorder (ASD) groups, whereby individuals are viewed as being essentially different to those who are 'neurotypical' (although this term was not used by participants). Another example of this was seen in one of the BPC courses,

where one of the participants talks about the benefits of attending groups like the BPC, because of the opportunity to be around *'like-minded people'*. This conceptualisation of bipolar disorder as representing a *style of thinking* seems to more closely resemble that of a personality type, as opposed to an illness which operates on the self as a separate entity.

As noted above, the diagnosis could be deployed as an explanation in itself for behaviour and 'symptoms'. In the following extract, it is represented as a reason for thinking in a certain way:

> *I: It sounds like quite a positive…*

> *B: It was, in every way, because **I have bipolar**, I have - you know, I now know what I am. When I say what I am, I mean, you know, you know, **now I have got a reason for thinking the way that I do…. behaviour, the way that I sometimes do - I mean, you know, thinking and behaving.** I have met some brilliant friends. I am doing loads of voluntary work that I love and you know, more than I used to - so I have made loads of friends through that. Whereas before I was diagnosed with bipolar, you know, there, there was none of that.* (Bridget, BPC facilitator, interview).

This extract not only illustrates the power of diagnosis in explaining and legitimising behaviour, and how important the concept of bipolar can be in defining the self; it also illustrates some of the social advantages which can be gained from diagnostic membership, providing a social network of other individuals who also identify with the bipolar category (e.g. from bipolar support groups or other 3rd sector organizations) and in providing a meaningful social role (e.g. MH advocacy work as individual's with 'lived' experience').

It seemed that bipolar disorder was a diagnosis that participants could willingly and easily identify with and group themselves around. For instance, Gwen, a woman in her fifties, who has had mental health difficulties since her teen years, but has only in the last year been diagnosed with bipolar disorder (having previously been diagnosed with treatment resistant depression and BPD), explains that it is only since receiving her bipolar diagnosis that she has been actively attending service user groups:

G: I suppose I haven't really done anything very much as a service user. This is the first group that I've done, and the BipolarUK. Because usually I just want to be me and just get on with life and not be ...

I: Yeah - not be labelled.

G: Not be labelled, no. but I thought I'd go to the BipolarUK, sort of ...and it does feel like, because it is only 1% of people have bipolar 1, I think that's quite, not rare but it is, 1% isn't very many so it means I've got to meet 99 people before I find another person. (Gwen, BPC participant, interview).

Several participants therefore seemed to find bipolar a helpful and useful diagnosis with which they could (at least to some extent) positively relate. For instance, Gwen, spoke about the difficulties caused by being initially mislabeled (in her opinion) with borderline personality disorder (BPD), which she argues has led to her being mistreated and misunderstood by mental health services. She also tells about her attempts and eventual success in having the label officially changed to bipolar type 1, following a consultation at the second opinion clinic (she has also started attending bipolarUK meetings since her diagnosis). In the following extract, I ask her how she felt about having the BPD diagnosis removed, but interestingly, she instead immediately starts talking about the usefulness of the bipolar diagnosis:

I: how did that make you feel having that diagnosis taken away?

G: That was a relief, yes, I felt much better about myself. I mean it is not something that I tell people. As we say in the group some people tell people straight away. I mean there's still something that only very few friends know and sort of need to know basis so it is not something I go around…. I am not consciously aware that I've got bipolar all the time, I just feel it is a part of my identity but it is not the whole of me…. But it is just a useful diagnosis when it comes to explaining symptoms and also if I do have another episode of psychosis then hopefully it'll be picked up and managed better than last time. So, it is useful in terms of treatment. (Gwen, BPC participant, interview).

A confusion surrounding diagnosis was common in many of the participants; most had at some point had an alternative diagnosis prior to receiving a diagnosis of bipolar

disorder. These ranged from unipolar depression, post-partum psychosis, schizophrenia, and BPD. Five participants had been diagnosed with BPD, which has been noted to be a particularly stigmatising diagnosis. Those diagnosed with BPD in particular, displayed a clear preference for the bipolar diagnosis (as did those attending services). This tendency for individuals with bipolar disorder to be initially 'misdiagnosed' is highly common (Hirschfeld, Lewis, & Vornik, 2003; Morselli & Elgie, 2003; Ghaemi, Sachs, Chiou, Pandurangi & Goodwin, 1999). This diagnostic uncertainty (often conceived of as misdiagnosis) points to a potential problem with essentialising tendencies that emphasise the homogeneity of disorders: With diagnoses such as bipolar disorder, which are often uncertain, overlap symptomatologically with other disorders, and have high rates of comorbidity (Krishnan, 2005; McElroy et al., 2001; Regier et al., 1990), identificatory practises which draw a line between those *with* and those *without* a particular diagnosis, could be potentially harmful for those who do not quite meet the criteria for diagnosis. As suggested in the previous chapter, bipolar disorder tended to be conceptualised as a categorical entity, rather than as existing on a continuum with 'normal' mood fluctuations (or alternatively as being part of a spectrum of disorders which overlap, alongside disorder such as schizophrenia and unipolar depression). The categorical view of disorder has often been associated with essentialism, since possessing an essence determines category membership, and a person can either have or not have an essence (Diesendruck & Gelman, 1999). While this tendency could be helpful in terms of establishing firm category boundaries (and thus a stable sense of identity) for those with the diagnosis, it also has the potential to exclude those who's symptom patterns deviate from the diagnostic norm, or where there is more uncertainty surrounding diagnosis.

The following interview extract exemplifies this tendency for diagnosis – to not only facilitate social cohesion through the sharing of common experiences and identities – but also to homogenise and standardise bipolar disorder. Jack, who co-runs a local bipolarUK group, describes how this diagnosis can bring people closer together:

Well there's a lot of people I know that have had bipolar and their lives have changed because of it. And I've got a lot of friends who have had bipolar and

I've met them through the support group…. And I think people who have got bipolar are very close to each other because they know what it's like to have been hospitalised, they know what it is like to have those crazy manic thoughts…. (Jack, BipolarUK, Interview).

While the understanding of shared experience may be helpful for participants, this assumption could also be potentially problematic, since (in this case) it is predicated on the basis of hospitalisation and 'crazy, manic thoughts', which are not experiences that everyone with a diagnosis of bipolar disorder will relate to; in particular those diagnosed with bipolar II, or cyclothymia, do not by definition experience 'mania', and will not necessarily have been hospitalised. Jack's statement homogenises the experiences of those with bipolar disorder, and seems to position mania as the more salient feature of the disorder, even though depression is thought to be the predominant mood symptom, which is more problematic and life limiting to those with the diagnosis (Judd, 2002; 2003).

This tendency to homogenise the category of bipolar disorder may represent a form of 'strategic essentialism', which describes how "members of groups, while being highly differentiated internally, may engage in an essentializing and to some extent a standardizing of their public image, thus advancing their group identity in a simplified, collectivized way to achieve certain objectives" (Eide 2010, p.76). This standardising and simplifying of group identities can be seen in Jack's account above, and points to some of the potential drawbacks of such practices. The term strategic essentialism has its history in post-colonialist theory and was originally used by Spivak to denote a *conscious* political practise, "a *strategic* use of positivist essentialism in a scrupulously visible political interest" (Spivak, 1996, p.214). However, more recently it has been applied to the identity politics of categories other than race, and has continued to be utilised as a minority strategy for influencing mainstream social perceptions (Veronka, 2017). In contrast, whilst participants seemed to essentialise bipolar in ways which may have benefited them, it often did not seem as though this was a conscious political choice or strategy on their part (i.e. the essential nature of the bipolar category seemed to be taken for granted by participants). Eide argues that there are considerable risks associated with the practice of strategic essentialism, particularly

when it is not a part of a *deliberate* choice on the part of those within the essentialised group:

> "*The risk is that, by doing so, they may be playing into the hands of those whose essentialism is more powerful than their own – whether they are researchers, editors, politicians or empire-builders... The problem occurs when the practice of strategic essentialism is not the result of a deliberate choice and an assessment of a delicate balance, but rather is partly the result of media conventionalism that requires people and groups to essentialize themselves in order to highlight issues that have nothing to do with their daily ontology of being...*" (Eide, 2010, p.76)*.*

Such homogenisation regarding diagnosis could also have harmful implications for those who do not fit 'typical' notions concerning a diagnostic category. For instance, one participant described his feelings of victimisation at a local bipolarUK group, due to the other members denying the validity of his diagnostic status, considering him to be insufficiently unwell to be deemed to genuinely have bipolar disorder. Describing how he would tend to go to meetings with a 'bipolar face' - when I ask for clarification, he explains:

> *The bipolar face yeah – it's like inside you're feeling really anxious and crap but you put a face on it you know? And I found that with people who have very very severe bipolar – my bipolar is sort of medium on the scale – but I think there are some who get mania quite often and I get depression – and I think they're the ones that looked at me and thought 'oh he's not so bad – he's making it up you know...I've had one person saying I don't know why you're here there's nothing wrong with you. I can see it from their point of you in that they're very very ill but just because they don't get depressed as much ...* (Joshua, BipolarUK, Interview).

According to the above account, the mania is treated as the more fundamental or defining aspect of bipolar disorder, a tendency which makes sense given the salience of mania in the diagnosis of bipolar (episodes of depression are not required to attain

a diagnosis; episodes of mania/hypomania *are* required). This extract again underlines the tendency for depression to be viewed as more easily trivialised than mania.

Many individuals described a difficult and complex journey towards their bipolar diagnosis, and even those who had received a diagnosis of bipolar disorder described experiences of invalidation (particularly from health professionals and also from other service users). Many described a fight to be taken seriously by mental health services and to obtain a diagnosis, consistent with the diagnostic seeking behaviour illustrated in chapter 5. For those on the boundaries of a diagnosis – where diagnosis was uncertain and debated by different professionals (often between BPD and bipolar disorder), considerable distress was articulated, due partly to the uncertainty, but also due to the stigma attached to other disorders. In the following extract, a participant with a diagnosis of unipolar depression, who's psychiatric appointment I had observed - describes her reaction to the suggestion that she displayed some indications of bipolar disorder, but did not quite meet diagnostic criteria:

> *C: Well the other diagnosis that was in the mix since last November was ...*
>
> *I: Oh, - another one?*
>
> *C: Well, it was at the same time as the dissociation, saying that they were ruling out bipolar because **although I had characteristics of mood instability, I don't become elated enough to meet the markers**. So, with the dissociation was a suggestion that **I have something… - untrue bipolar, and I was thinking god I can't even have proper bipolar**, you know the experience of the highs and the lows because I don't meet the high.*
>
> *I: Yeah, okay - I've never heard of untrue bipolar.*
>
> *C: I think it was a description to say yes there is this characteristic but the change is not enough for it to be recognised.*
>
> *I: Yeah…. - so how did you feel when you heard that?*
>
> *C: Well it's a bit like failure isn't it - it's a bit like you can't even have the right diagnosis.* (Cerys, CMHT 2, Interview).

During the consultation I observed, the Psychiatrist had emphasised to Cerys that she did not think she had bipolar disorder, despite treating her with an anti-psychotic medication commonly prescribed for bipolar disorder (quetiapine, which was stated by the psychiatrist as being good for helping to control impulsivity). Cerys's assertion that not meeting the criteria for the '*right diagnosis*' is a '*failure*', indicates the potential downsides of a categorical understanding of a diagnosis, that has clear boundaries.

Research has shown that placing mental disorder on a continuum with 'normality' could act to reduce the perceived differentness between the mentally ill and the mentally well (Corrigan et al., 2016; Schomerus, Angermeyer, & Matschinger, 2013); given that the separation between "us" and "them" is thought to be central to the process of stigmatization (Link & Phelan, 2001), models of disorder which emphasise the boundaries between disorder and 'normality', may thus contribute to the othering of those with mental illness. Conversely, categorical understandings could also encourage various forms of division between those with different categories of mental disorder, encouraging the redirecting of prejudice towards those in 'lesser' groups. This tendency amongst participants to reinforce the boundaries between bipolar and 'normality', or between bipolar and other disorders, could also at times lead to practices of diagnostic possessiveness, whereby participants would undermine the authenticity of other individuals' claims of having bipolar disorder. Several participants complained about those who would claim to have bipolar disorder, when they didn't 'really have it', implying that this was trivializing and undermining the seriousness of their illness. Bipolar disorder was talked therefore about as something that you 'had' or 'didn't have' – with no in between. For example:

> *Before the beginning of a session Derek says that the taxi driver who brought him here asked him what course he was attending; on finding out the taxi driver claimed, 'I think I have bipolar'! There was much muttering over this and Bridget mentions how if she had a penny for every time someone said this to her (on telling them she has bipolar) she would be very rich. There is general agreement over this and discussion of the misconceptions about bipolar – Bridget concedes everyone has ups and downs – 'but nobody does it as well as*

us'. It is generally deemed insulting and undermining towards those who do 'have bipolar' for others to try and stake a claim. Bridget says that she often responds to those who say this by asking 'do you ever wake up and wish you didn't have it?' (i.e. wishing they didn't 'have it' is taken to indicate that the person genuinely does have it).

Although Bridget acknowledges a continuum of highs and lows, she also establishes a binary dichotomy between those who do and don't have bipolar, emphasising the severe suffering caused by the disorder, and also suggests that in order to qualify for category membership a person has to have suffered sufficiently. The question 'do you ever wake up and wish you didn't have it?' appears to be a means for Bridget to test the authenticity of a person's claim to the disorder (i.e. not wanting it is a sign of genuineness, thus implying that actively claiming to have the disorder is a sign of inauthenticity). This reflects findings from clinical settings, whereby active diagnosis-seeking tendencies were often met with skepticism from professionals. This is potentially problematic given that many of the participants who were interviewed (including Bridget) described a process of initial self-diagnosis, and a subsequent resistance from professionals. This policing of the boundaries of the disorder was also something found in the interviews with service users, with several referring to the 'fashionable' misuse of the bipolar label. In addition to these discussions regarding people who claim to but don't have bipolar, there were also instances where other mental disorders – such as anxiety and unipolar depression - were trivialized (compared with bipolar disorder) by participants.

A further factor potentially influencing the increased acceptability of bipolar diagnosis is its increased attention from celebrities claiming to have the disorder; celebrities were mentioned by a number of participants, and at times appeared to provide a means of identifying with the diagnosis. For example, in the following extract, Dan describes his dislike of the label depression, since he does not view his personality as depressive. The bipolar diagnosis by contrast – despite involving depression as a symptom, is not taken as indicative of having a miserable personality, but is associated with creativity and humour, represented by a positive celebrity role model.

*D: Yeah – when I was diagnosed with depression I thought – you know – me depressed? I know I get **really down but I'm not a miserable person – I'm normally quite good fun to be around normally – so manic depression was yeah ok I can accept that** – and **you look at people who've got it – you know – Spike Milligan I think being the main one I look at – I think – ah he's just like me – sort of sense of humour and things like that**

I: Ok that's interesting…

*D: Not so much Stephen fry – **I don't even think he's got it!***

This association of bipolar with creativity and humour (personality attributes) could again be related to the concept of neurodiversity, since the diagnosis here is taken to imply a particular type of person (and in this case a person with positive and valued attributes); for validation, he looks to people who are *"just like me"*, such as Spike Milligan, - although not Stephen Fry who he suggests does not genuinely have bipolar. Further on in the interview, Dan again questions Stephen Fry's claim to the diagnosis:

I: But you think perceptions have changed a bit over the years?

*D: Yeah – I think the media I suppose. Its one good thing that Stephen fry's done – even **if he hasn't got** it he seems to have um publicised it and picked a couple of good case studies um.*

I: Yeah there's quite a few celebrities as well that have come forward…

*D: Yeah – like the one off Star Wars – carry fisher – **she's definitely got it.***

I: Catherine Zita jones?

D: Nah!

I: Kerry Katona? (laughing)

*D: Yeah, **she probably has it** – she's the one off of the adverts, isn't she?* (Dan, BipolarUK, Interview).

Interestingly, another participant - Claire - also refuted Stephen Fry's claim to have bipolar:

C: *I suppose I find it less…maybe I find it – I feel like I can see that there has been a change in society over the past 20 years – it feels easier to talk about it now – - Stephen fry - even though I hate him and find him really annoying!*

I: *Yeah, he is really annoying I'm glad I'm not the only who thinks that! (laughing)*

C: *And I'm not even sure that he even has bipolar.* (Claire, bipolarUK, Interview).

In a further example, some hostility was directed towards a BipolarUK representative during one of the BPC courses, because she confessed to not having a bipolar diagnosis, but was in a position whereby she could represent and work for those with this disorder:

During the final session of each BPC course, a BipolarUK representative would attend the session to briefly advertise the services offered by the charity. In one of these sessions the representative acknowledged during her speech that she did not herself have a diagnosis of bipolar disorder, but mentioned the peer support service, whereby individuals with a diagnosis could provide telephone support to others with a bipolar diagnosis. At the end of her talk, she was challenged by one of the course attendees, who asked her why – if she didn't have diagnosis of bipolar – she felt she could represent those who did. The BipolarUK representative stumbles a bit here, and tries to explain that although she doesn't have a diagnosis herself she has family members with a diagnosis, thus presumably trying to establish a personal investment in the condition.

It is interesting here that - not only is it taken as problematic to have someone without a diagnosis of bipolar working as a service provider for those with a diagnosis - but also that the representative for bipolarUK felt the need to state that she did not have a diagnosis of bipolar, indicating implicitly that this could be taken as problematic in some way.

It is possible that the advantages surrounding this diagnostic category, in addition to the culture of delegitimization surrounding diagnosis, and the conceptualisation of bipolar disorder as a categorical entity, encourages a possessiveness regarding diagnosis, whereby the authenticity of an individual's diagnosis claim can easily be undermined by others (particularly other service users and professionals). As such, while bipolar seems in one sense work to unify those who fit neatly within its categorical boundaries, it can also act in a divisive way, by re-enforcing the boundaries – not only between mental illness and wellness – but between different forms of mental disorder, which are not all accorded equal status.

Conclusion

While this chapter points to some of the benefits and strategic uses of bipolar disorder by patients, it does not intend to argue that those living under this label are privileged; on the contrary, most participants reported various forms of intolerance in relation to their mental health difficulties, often from colleagues, professionals, family members, and from others with the same diagnosis. This seemed to come mainly in the form of blame and volitional stigma, as opposed to stereotypes regarding violence and unpredictability. As with many forms of chronic health difficulties, bipolar disorder has the potential to erode the sense of self-worth of those diagnosed; for instance, the following comment by Jean underlines the potential of bipolar disorder to threaten an individual's sense of moral worth: - *'you need to learn to love yourself – that's hard when you have bipolar - and to remember you are a nice person'.* (BPC course, fieldnotes). It could arguably be this threat to self-worth which drives this need for a label which is able to offset blame, and facilitates the formation of social bonds with others through the sharing of common narratives.

Such moralizing reactions from society may partly explain why participants seemed to privilege accounts which construct bipolar disorder as categorically distinct, both from the self and from 'normality', enabling the diagnosis to be utilized as an explanatory device, which offsets blame and 'volitional stigma' (Easter, 2012). Separating the mood fluctuations of bipolar disorder from individual temperament, from outside

events (i.e. they occur for no reason), and from 'normal' mood changes, enables the disorder to be viewed as a separate entity which invades the self. The use of more biomedical understandings of bipolar disorder to circumvent blame tends to support the argument that biomedical explanations can situate illness and its aetiology outside of identity, and remove responsibility, whereas psychosocial explanations are more likely to situate responsibility and cause within individual identity (Luhrman, 2000).

By contrast, some accounts (i.e. those drawing on ideas similar to neurodiversity) positioned bipolar disorder as a fundamental aspect of the self, almost as a personality type. These accounts – which depict those with bipolar as being similar types of people who think in similar ways, contributes to the homogenizing practices of strategic essentialism, whereby individuals group themselves around a particular category, deriving benefits from the social relationships and identity affirmation associated with the category. As a diagnosis that is culturally associated with creativity, celebrity status, and with particularly somatic understandings of aetiology which accord it the status of a 'real' illness, bipolar disorder seems uniquely positioned to provide a form of cultural validation to those diagnosed, enabling individuals to collectively mobilise around the category, and to utilize the diagnosis in maintaining a positive self-image.

However, while the reification and essentialisation of bipolar seems to de-stigmatize in various ways, there are potential negative implications associated with this kind of categorization; firstly, they may increase the potential for circular thinking – whereby various behaviors and traits may be assumed to relate to the disorder, to the point where the individual can become synonymous with their disorder. Secondly, by emphasizing the boundaries between those who 'have' and 'don't have' the disorder, this may increase perceptions of differentness towards individuals with the disorder, and may also promote practices of diagnostic possessiveness, fueling the tendency to undermine the diagnostic claims of others, thus excluding them from participation in potentially helpful social relations. This focus on the importance of diagnosis may also create problems for those who do not meet the criteria for diagnosis, an issue highlighted in chapter 5.

Chapter 7: Discussion

Drawing on ethnographic research conducted within several UK mental health settings, this thesis has considered the role of diagnosis – in particular bipolar disorder - in constituting patient identities and in shaping professional categorisation practices. While much previous research has focused upon the relative merits of 'biomedical' vs 'psychosocial' understandings of mental health difficulties, this thesis has taken a more nuanced approach, by exploring how psychiatric classificatory accounts can be used within mental health service interactions and within patient accounts to construct patient identities, and to prioritise patients within the mental health system. Findings have shown how psychiatric classifications can be negotiated, ascribed, and withheld in order to legitimate and contest various forms of suffering. In particular, the thesis has demonstrated how diagnostic categories, such as bipolar disorder, can be used to interpret and medicalise morally problematic forms of experience and behaviour. Since much of the previous literature has focused upon schizophrenia and unipolar depression (as discussed in chapter 2), this study also contributes to the relatively sparse amount of research which has explored the relationship between identity, stigma, and understandings of bipolar disorder.

This chapter will summarise and reflect upon the significance of the main findings that have emerged from this study, outlining how the thesis has answered the initial research questions posed in Chapter 2: 1) What function do psychiatric diagnoses play in the everyday ordering and configuring work of patients by professionals in mental health settings? 2) How are biological and molecular/somatic visions of personhood mobilised and prioritised by mental health professionals and patients, and what are the implications for identity and expectations regarding self-management? And 3) How is bipolar disorder in particular conceptualised by professionals and patients?

Finally, suggestions will also be made for further potential research in relation to these findings, followed by a consideration of some of the methodological limitations of the study.

Summary of Findings

As has been noted, psychiatric diagnosis has become a pervasive way of understanding the self within modern culture (Brinkmann, 2017). This thesis suggests that individuals with a bipolar diagnosis tend to identify strongly with the label, using it to explain their behaviour, to access services, and to connect with others. This ability of the bipolar diagnosis (and to some extent other diagnoses) to legitimise the suffering and problematic behaviours of subjects, can lead to a tendency for it to be both sought after by patients, but contested by professionals and amongst patients. Chapter 4 for instance, illustrates how, in seeking access to more specialised mental health services with limited resources, potential patients can face the trivialisation and delegitimisation of their problems by professionals, which at times manifests in the withholding of diagnosis. This negation of diagnosis is facilitated by the categorical understanding of mental disorder (Zachar & Kendler, 2007) as something that a patient either does or does not have, which creates difficulties for patients who appear to be on the boundaries of a diagnostic category (such as Hannah and Joyce, in Chapter 4). This categorical conceptualisation of disorder is also evident within Chapter 5, whereby patients describe bipolar disorder as something that individuals' either have or do not have, and in Chapter 6, where participants are seen to exclude others from category membership, displaying a form of diagnostic possessiveness. Chapter 6 also illustrates some of the potential consequences of diagnostic exclusion or uncertainty, resulting from this essentialised category which creates divides between those considered to 'have' the disorder and those who are not.

Whilst diagnosis itself functioned to medicalise aspects of moral life, its ability to perform this function is shown to partly depend upon its conceptualisation as a neurobiological entity. Findings suggest that bipolar disorder gives rise to particularly somatic concepts of personhood and self-management; its conceptualisation as an essentialised and reified illness category, with its cause located within the brain, enabled a legitimisation of psychiatric 'symptoms' for both patients and professionals. This tendency to emphasise biomedical explanations aligns with previous research indicating that mental health patients have a preference for biogenetic and neuroscientific explanations, finding them less blaming (e.g. Laegsgaard, Kristensen,

& Mors, 2009; Illes, Lombera, Rosenberg, & Arnow, 2008; Easter, 2012; Buchman et al., 2013). Somatic self-understandings seem to be helpful for participants, due to the apparent ability for such explanations to 'bypass the self' (Healy, 2001), and offset volitional stigma (Easter, 2012). The reification of bipolar disorder also enables the illness to be more easily separated from personality and the self; although on occasion bipolar disorder was intimately linked with temperament and personality in a way reminiscent of 'neurodiversity' styles of thought.

In addition, findings concur with previous research suggesting that personality based explanations seem to be particularly associated with blaming reactions, particularly from mental health professionals (e.g. Bonnington & Rose, 2014; Lam, Salkovskis, & Hogg, 2016; Nehls, 1998; Markham, 2003; Sulzer, 2015). As Dobranski (2009) suggests, because individuals with these disorders are deemed to be responsible for their actions, they are held morally accountable, and thus blameable for their actions. This type of 'volitional' stigma (Easter, 2012), was what participants displayed the most concern with in all research settings, as opposed to the stereotypes regarding violence and dangerousness which are particularly associated with schizophrenia. This is consistent with research by Lee et al. (2014), suggesting that blame and shame may be a particularly salient aspect of stigma for bipolar disorder. Similarly, Bonnington and Rose (2014) demonstrate how normalisation can be problematic for individuals with bipolar disorder.

This finding contrasts with arguments that fears regarding dangerousness and unpredictability are more salient aspects of mental health stigma than blame (e.g. Angermeyer, Holzinger, Carta, & Schomerus, 2011). In studies involving population-based methods, where participants are responding to abstract concepts, such as a generic 'person with mental illness', violence and dangerousness may be a more likely concern to research respondents. The everyday concerns of individuals within 'real-life' settings (e.g. family members, colleagues, and mental health professionals) are likely to differ to those responding to a survey construct; it is conceivable that in many everyday situations where people with mental illness are subject to stigmatised reactions from those familiar and close to them (health professionals, family members, friends etc.), blame may be a more significant factor than fears regarding

dangerousness, particularly within a culture which celebrates responsibility, autonomy, and choice (Schwartz, 2004). The salience of blame and trivialisation may also explain why neurobiological explanations seem to appeal to those with the bipolar label. As suggested by Schnittker (2008), it may be that neurobiological understandings are more harmful for disorders that are associated with violence, such as schizophrenia.

While neurobiological understandings of bipolar disorder generally performed a validating or absolving function within participant accounts, this did not necessarily equate to a pessimism or determinism regarding prognosis. For instance, while the BPC promotes an understanding of bipolar disorder which is validating and non-trivialising, there is a strong emphasis upon self-management, which is consistent with the ways in which knowledge about molecular genetics tends to – rather than being fatalistic – locate individuals within "new communities of obligation and identification", part of a "reshaping of personhood along somatic lines" (Novas & Rose, 2000, p.485), which introduces new responsibilities and prudentialism. Nevertheless, the version of bipolar disorder promoted by the course, and within participant accounts, emphasises its status as an agency-limiting biological entity.

While it may be the case that 'biomedical' understandings of mental disorder have the potential to stimulate certain types of stigmatising assumptions, this research indicates that this is dependent upon the style and framing of explanations, rather than a product of all biological accounts. For instance, the neurodiversity movement exemplifies the ability of neurobiological understandings of differences to promote positive notions of selfhood. In addition, as shown in chapter 5, biological understandings of illness can be incorporated into and combined with alternative frameworks which are more 'psychosocial' in nature, reflecting research by Bröer and Heerings (2013).

Consistent with the dominance of biological accounts of bipolar disorder, the forms of self-management promoted by the course, and adopted by participants, appeared to be largely somatic by nature. Psychological (in particular, cognitive or psychodynamic) interpretations and treatments were downplayed in relation to bipolar disorder. What emerged within some participant accounts seemed to suggest that psychological

understandings of mental health difficulties could be stigmatising through their tendency to attribute agency – and by extension blame - to individuals. For instance, participants in chapter 5 were seen to resist psychological (particularly cognitive) explanations and therapies, at times associating these with moral or personal deficiency. This could also be seen in chapter 4, with those individuals experiencing traumatic events and/or receiving psychological therapies (i.e. Laura, Joyce and Roxanne) being consequently labelled with personality disorders, seemingly due to the assumed association between psychological aetiology and personality disorders.

Given that participants in this study tended to resist psychological explanations and treatments, whilst embracing biomedical categories explanations for bipolar disorder, the following section will suggest that some of the tendencies to criticise medicalisation in relation to mental health may need to be re-considered.

Re-evaluating historic critiques of psychiatric diagnosis

This thesis has argued that the process of diagnostic categorisation within psychiatry is in part a moral activity with particular implications for patients, their interactions with staff, and their prioritisation within the mental health system. While the focus of criticism in relation to psychiatry has often focused upon the negative consequences of diagnostic labelling, more attention needs to be paid to the potential negative consequences and uses of withholding particular psychiatric diagnoses, since this can also lead to forms of stigmatisation, and can justify the withholding of services. This has been noted in relation to diagnoses of a contested nature (e.g. Dumit, 2006; Glenton, 2003; Werner & Malterud, 2003), however, with regards to psychiatric diagnoses, stigma research has tended to focus on the consequences of receiving a diagnostic label, as opposed to the effects of *not* receiving a diagnosis. As Brinkmann (2014) argues, critical social researchers can no longer, like the anti-psychiatric movement from the 1960s and 1970s, simply accuse psychiatrists of enforcing medicalization from above (by assuming that it is only doctors that stigmatize individuals and pathologise illness); patients and citizens themselves are increasingly

pressing for "pathologisation from below" (McGann, 2011, cited in Brinkmann, 2016, p.2), seeking out diagnoses as explanations for various life problems, and turning to the vocabulary of psychiatry as the preferred 'language of suffering' (Brinkmann, 2014). It could easily be assumed - and many professionals in the current research did seem to assume - that steering patients away from secondary mental health services would be akin to de-stigmatising them; similarly, refraining from diagnosing an individual could also be framed as a benevolent act which avoids the infliction of a potentially stigmatising mark upon patient identities. However, the current study suggests a different picture, whereby any stigma averted by the withholding of secondary services or diagnostic labels, is potentially offset by the normalisation and demedicalisation of patient's problems, leaving individuals with a lack of support for their difficulties (particularly given the low-intensity of primary mental health support).

Some have argued that diagnostic and medical narratives of illness do not take adequate account of individuals' lived experiences of illness, nor the way in which patients account for and explain their problems (e.g. Hunter, 1991). However, the current research suggests that medical and individual narratives can align well, promoting positive identificatory and self-management practices; a bipolar diagnosis seemed able to provide helpful accounts for many participants. In health problems which are vulnerable to invalidation, such as mental disorders, a label and its assumed explanatory narrative can provide a validating function for sufferers, as has been found for other contested disorders with uncertain aetiology, such as back pain (Lillrank, 2003), CFS (chronic fatigue syndrome) and MCS (multiple chemical sensitivity) (Dumit, 2006).

Within the social sciences, there has historically been a tendency to critique trends such as medicalisation and geneticisation (e.g. Freidson, 1970; Lippman, 1991; Zola, 1972), and within mental health, psychiatry and its associated methods and technologies have tended to face the brunt of criticisms, with concerns regarding the pathologisation of everyday concerns and 'normal' reactions to life events (e.g. Horwitz, 2002, 2010; Wakefield, 2010). However, the current research suggests that

psychological accounts and explanations can also be experienced as potentially damaging, through their tendency to shift responsibility (and blame) onto those who are already subject to blaming and shaming from multiple sources. The assumption that those with psychotic disorders *lack* agency, and those with more 'common' disorders (such as anxiety and depression), or personality disorders *possess* agency, continues to exert some influence within mental health settings, consistent with previous research which has highlighted similar mind/brain and deviance/disorder dualisms within psychiatry (e.g. Luhrman, 2000; Dobranski, 2009; Kirmayer, 1988, 1994; Miresco & Kirmayer; 2006). Recent research suggests that these assumptions are overly simplistic, since individuals experiencing psychosis report elements of agency both leading up to and during psychotic episodes (Jones et al., 2016). This agency can also be seen in the present research, for instance within accounts regarding the role of stress in the lead up to illness, where participants highlighted the need to actively manage their stress-levels.

Further research is needed to explore the current uses, definitions, and assumptions underlying the key terms and concepts which inform mental health policy, such as 'severe mental disorder', 'psychotic disorder', and 'common mental health problem'. In addition, tendencies to medicalise certain diagnostic categories (such as bipolar disorder and schizophrenia), whilst demedicalising others, and the consequences for patients labelled with these disorders, should be investigated more fully. This research raises questions over the usefulness of current frameworks for differentiating between psychotic, neurotic and personality-based problems for conceptualising patient's difficulties and for clinical resource allocation. Tendencies to critique medicalisation and its role in stigmatising patients (from social scientists and from anti-psychiatry groups), may fuel forms of discrimination, which involve the demedicalising of certain types of patients (e.g. with Personality Disorder), as a means of withholding services, responsibilising patients and trivialising their experiences.

However, while diagnosis and medicalisation hold certain advantages for patients, chapters 4 and 6 illustrate the potentially harmful effects of essentialised understandings of diagnosis, which may reinforce the line between those who 'have' bipolar disorder and those who do not. The following sections will consider some of

the negative implications of reified and essentialised understandings of diagnosis, firstly in the way these are used as explanations for behaviour, and secondly, in their potential to create divisions between different disadvantaged groups.

The circularity of diagnostic explanations

Although neurobiological notions of illness and disorder may provide de-stigmatising effects, there are potential problems with the way in which diagnoses such as bipolar disorder are reified, essentialised, and used in order to perform explanatory work. Psychiatric diagnoses such as bipolar disorder, are not based upon the presence of biomarkers (e.g. using blood samples or brain scans), but are made on the basis of evaluating and judging symptoms, often derived from patient narratives. As such, when diagnoses are used as explanations for behaviours, this leads to a circularity, whereby problematic behaviours are used to provide evidence for the presence of a disorder, and the disorder is used to explain the problematic behaviours (Brinkmann, 2017; Timimi, 2009). Thus, individuals may – based on problematic behaviour – seek help or search for information (by searching the internet for instance), and a diagnosis may then be assigned as an apparent explanation for these behaviours; in order to justify that this diagnosis is the true cause of these difficulties – the only evidence which can be supplied are the problematic behaviours (or 'symptoms') themselves. This could be problematic since it compels individuals to display symptoms which affirm their diagnoses, particularly where there is a culture of scepticism within mental health services.

Further, diagnostic approaches to individuals' problems risks downplaying the social conditions of people's sufferings, and therefore may impede meaningful social change (Brinkmann, 2016). Brinkmann (2016), drawing on work by Mol (2002) and Gannik (2012) on situational theories of illness, argues for the need to find a middle ground between essentialist understandings of mental disorder, which locate the problem within the individual, and extreme social constructionist understandings, which imply that problems are created only by the fact that we categorise them (making them

potentially delegitimising). Situational theories of illness suggest that individuals *do* or *perform* illness in relation to physical or social environments, meaning that an individuals' difficulties are not located only in one space (i.e. the brain), but are "distributed among the brain, the body and the environment" (Fuchs, cited in Brinkmann, 2016, p.126). A situational theory would suggest that an individual does not 'have' bipolar within all situations and contexts, but only at times when particular contextual mediators are present, making the enactment of a particular disorder possible[31]. This approach would stimulate further questions regarding what mediators are involved in making the enactment of particular disorders possible, and how these can be changed in order to help those who are suffering (Brinkmann, 2016).

The above mentioned diagnostic circularity also relates to the interactions between the classified and classification systems referred to by Hacking as the 'looping effects of human kinds' (1995). Given the degree to which diagnostic categories, such as bipolar disorder, have penetrated popular awareness, many individuals are likely to identify with these categories, interpreting and possibly adapting their behaviour in the light of diagnostic definitions. Attempts by individuals like Hannah (Chapter 4) to persuasively negotiate their diagnosis by arguing for the recognition and validation of non-visible and internal symptoms in diagnostic decision making, could lead to the widening of diagnostic categories to include those with less 'typical' symptomatology. In this way patient diagnosis-seeking could contribute to changes in the way that diagnoses are defined and classified. The implications of this broadening of diagnostic categories will be further considered in the following section, particularly in relation to bipolar disorder.

The expanding and contesting of diagnostic boundaries in bipolar disorder

As described in Chapter 1, bipolar disorder is a diagnosis which has substantially evolved in recent history; originally named manic depression, the category initially referred to those admitted to psychiatric hospitals with severe episodes of psychosis

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[31] Enactment in this context does not refer to a deliberate enactment by a discrete actor, but involves a range of mediators and a number of different individuals, organisations, systems, discourses, and material objects (Mol, 2002, p.25).

or mood disturbances. However, the boundaries of this diagnosis have since expanded considerably, with the term bipolar disorder now applied to individuals managing their mental health conditions within the community (Healy, 2008; 2010), an expansion arguably facilitated by the classification (e.g. within DSM-V) of several subcategories of the disorder (e.g. BD II, Cyclothymia and BD NOS), which include those experiencing less extreme symptoms. This expansion has also been seen in other diagnostic categories in psychiatry (e.g. autism), but arguably has been particularly pronounced in bipolar disorder; perhaps, in part due to the media attention and celebrity endorsements received by this diagnosis (as discussed in Chapter 2). This category has become increasingly popular, as noted by psychiatrists (Chan & Sierling, 2010), who suggest that this may be largely due to the increased media attention surrounding the disorder. In addition, as illustrated in empirical chapter 4, this category also appears to have currency within (and outside of) secondary mental health services, whereby – as a disorder classified as a severe and enduring mental illness (SMI) – it is taken seriously by professionals, meaning that its application warrants action. It more easily facilitates access to the 'sick role' (Parsons, 1951), exempting individuals from usual duties and obligations, and obligating a response from mental health (and other) services.

Arguably, since many other diagnostic categories do not possess this currency value or capital, bipolar disorder has become particularly sought after within diagnostic settings. The increased 'awareness' of the diagnosis and the diagnosis seeking from patients (and the grouping of patients around this diagnosis) has arguably contributed to the expansion of this category. This expansion has led to the inclusion of less 'typical' variations of the disorder (e.g. cyclothymia), which - in line with Hacking's 'looping effect' (1995) - has changed the category itself. As suggested by Healy (2008; 2010), the pharmaceutical industry has also been influential here.

However, given that bipolar disorder continues to retain its status as an SMI, which when assigned obligates more intensive forms of support (such as input from a psychiatrist), the expansion of the category inevitably produces opposing forces which push against this expansion, particularly when public services are under strain. This may come from - as shown in Chapter 4 - professionals who may withhold such a

diagnosis partly because giving a diagnosis implies a requirement to provide support to diagnosed individuals (in the case of BD, it implies the need to see a psychiatrist for assessment as a minimum), making referral back to primary mental health services more difficult. Or, as illustrated in Chapter 6, resistance can come from service users who rely on the currency value of the diagnosis in order to explain their difficulties and access services; the potential dilution of the category that could come with its expansion to include less extreme forms of the illness could potentially reduce the currency of the category and its associated benefits (as suggested by Gwen in Chapter 6, the rarity of the diagnosis is part of its appeal). This may be partly what results in tendencies towards diagnostic possessiveness in some of those with the diagnosis. This may, in turn, be particularly disadvantaging for those who's diagnostic status remains unconfirmed or uncertain, for those who remain slightly below diagnostic thresholds, and for those who exhibit 'atypical' manifestations of the disorder (e.g. those with BD II, cyclothymia and those for whom depression is the more dominant manifestation of the disorder). Since mania appears to be the dominant 'pole' of bipolar disorder, those experiencing depression predominantly may be subject to downgrading or delegitimising responses from professionals and other service users. It is also interesting to note that the privileging of mania within the bipolar category (meaning that someone who has *only* experienced mania may receive a bipolar diagnosis, whereas a person who has only experienced episodes of depression may not) may mean that a person diagnosed with bipolar disorder may have more in common symptom-wise with someone diagnosed with recurrent unipolar depression, than they would with another person diagnosed with bipolar disorder (e.g. who may not have experienced depression). This has implications for the way in which services are structured (e.g. BipolarUK).

As places where lay and professional knowledge regarding illness intersect and where diagnostic negotiations occur, sites such as the BPC course and diagnostic /screening assessments are arguably spaces where the boundaries of these diagnostic categories are being continually negotiated and contested by different actors. One of the primary empirical contributions of this thesis lies in its illustration of this process in action; it also highlights the psycho-social implications of the broadening and contesting of

diagnostic boundaries, particularly in the case of bipolar disorder, a diagnosis which many readily identify with. Furthermore, this work illustrates the potential negative effects of such diagnostic identification, particularly when a diagnostic category is essentialised, as is often the case with bipolar disorder. This thesis contributes to the sociology of diagnosis, through drawing on the theory of 'strategic essentialism' (Eide, 2010; Spivak, 1990; Voronka, 2017) to illuminate the way in which essentialised understandings of a diagnosis can feed into diagnostic identificatory practices and diagnostic possessiveness in service user groups, which can disadvantage those who are on the boundaries of categories or who display 'atypical' symptom patterns (e.g. those who predominantly experience depression as opposed to mania). Thus, while essentialised notions of diagnostic categories can promote inter-group cohesion amongst patient groups, they can also create distance – not only between those with and without a diagnosis – but also amongst those with a diagnosis. The following section will consider the potential downsides associated with essentialised notions of diagnosis, and suggest some possible alternatives to the practise of strategic essentialism.

Alternatives to strategic essentialism

As a number of theorists have pointed out, the formation of group identities (e.g. surrounding diagnosis) can promote social critique and change, as individuals identify with and group themselves around a particular category in order to form a resistance against stigma and discrimination, to engage in political activism, and to campaign for improved services (Crabtree, Haslam, Postmes & Haslam, 2010; Rose, 2007). However, while the tendencies towards a biologically essentialising form of diagnostic identity seemed to elicit positive self-definitions amongst many of the participants, the current research also indicates that such essentialising practices can be potentially harmful, in their tendency to underscore differences between categories. This can be a disadvantage for those who do not quite meet the criteria for a diagnosis such as bipolar disorder, for which specialised services exist (e.g. BipolarUK), and for those

labelled with highly stigmatising but related diagnoses, such as BPD. Services such as the BPC programme and BipolarUK are structured around a relatively recent diagnostic concept (bipolar disorder), which has evolved (partly for political and social reasons) to emphasise polarity and mania, establishing a barrier between those with bipolar and unipolar disorders. It is possible that organising mental health service provision around such diagnostic categories may to some extent be divisive.

As suggested in chapter 6, forms of strategic essentialism that unconsciously rely on taken-for-granted assumptions regarding illness categories, may re-produce rather than challenge existing inequalities. Some have argued for the need to encourage solidarity across categories of disablement, moving past the tendency to stress specific ways of deviating from normality, and bringing different marginalised groups into conversation with one another (e.g. McWade, Milton, & Beresford, 2015). These authors suggest that "*a dialogue between mad studies, neurodiversity, and disability studies might move us beyond the limitations of identity based politics that create 'insiders' and 'outsiders'*" (McWade, Milton, & Beresford, 2015, p.307). The 'mad-pride' movement, which has emerged in recent years, might also provide a potential alternative to forms of diagnosis-based essentialism; this movement has:

> "*re-claimed the language of madness to challenge the contemporary medical monopoly on the labelling and description of unusual mental states. Activists also have emphasized the connections between madness and art, theatre, spirituality, and a valuable sensitivity to individual and collective pain.*" (Schrader, Jones, & Shattell, 2013, p.62).

As opposed to essentialised notions of disease categories, Schrader, Jones, & Shattell (2013, p.62) suggest that an *"active socio-political minority identity of madness"*, or a *"mad identity"*, is:

> "*not so much about a person's "intrinsic craziness," as the active and thoughtful positioning of the self with respect to dynamic social narratives regarding mental difference and diversity.*"

As observed in chapter 6, this 'active and thoughtful positioning of the self' was less apparent within participant accounts of bipolarity, which seemed to more closely

resemble notions of fixed and 'intrinsic' illness or disease, with its emphasis upon the alleged presence or absence of this intrinsic essence or entity. The danger in this way of understanding mental health difficulties is in its ability to encourage division between those judged to 'have' the disorder and those who are not; this could be particularly harmful since different mental health diagnoses are accorded different levels of moral status both within and outside of the mental health system. In addition, the continuing uncertainty surrounding the practise of psychiatric diagnosis and its reliance on patient narratives, arguably makes it easier to deny the claims of those seeking a diagnosis (and likewise to informally attribute stigmatising diagnoses such as BPD to individuals who are deemed to be 'difficult').

However, this tendency to seek out and rely on diagnostic labels as a means of understanding the self and explaining behaviour, is also driven by social factors, such as the importance of diagnostic labels in accessing vital services, such as support groups, and in qualifying for welfare support (Jutel, 2009). While wider social systems demand diagnostic labels as explanations, there will be a continuing demand for diagnostic labels from individuals. Similarly, mental health services are often diagnostically driven. Given that professionals would also frequently refer to diagnoses such as bipolar disorder as something that a person either had or did not have, there may be some disparity between professional practise and current psychiatric theory, which acknowledges the complexity and uncertainty involved in diagnosis, and the problematic nature of disease specificity (Frances, 2013). While some professionals may in theory view diagnostic categories as imperfect tools which guide their practise, this was not something which was often communicated to patients, who may interpret these categories as identity defining and absolute; again, this can have harmful consequences for those on the boundaries of a diagnosis, and even for those who have an affirmed diagnosis, who may still (as in Joshua's case) have their diagnostic status and thus their status as authentically ill undermined.

Limitations & Methodological Considerations

While this thesis has focused upon the micro-interactions of individuals within mental health services, some have argued that research into stigma should move beyond a focus upon micro-interactions or individual illness experiences, and pay more attention to the broader macro and social-structural factors which shape these interactions (e.g. Hatzenbuehler & Link, 2014; Link & Phelan, 2001). For instance, previous research has indicated that diagnosis has been more likely to occur when resources were available to treat patients (Estroff, 1993). Similarly, within the current study, it is important to interpret findings from the respective settings in relation to their specific contexts – in particular, the differences between the CMHTs, whereby there was a strong tendency to trivialise the concerns of patients, and the BPC courses, where patient's experiences were validated. The tendency to responsibilise patients and trivialise their experiences of distress are likely to be related to the fact that CMHTs are specialised mental health services with limited resources, which exist within a policy context which has increasingly moved towards the prioritisation of those with 'severe mental illness' (CVUHB, 2012; WAG, 2010). The high numbers of individuals being referred to (and rejected from) secondary mental health services could indicate a level of unmet need arising from primary mental health services in Wales (which provide less intensive treatment options); an unmet demand for more intensive treatment options could in turn have fuelled a demand for more specialised diagnoses in order to access services. It would be interesting to see whether there are similar trends within mental health service in England, where there are differences in the structure of services[32].

In contrast, while the biological discourses on the BPC programme may appear to have a legitimising and de-stigmatising function, it is important to note that the nature of these courses are substantially differently to NHS mental health services. The BPC course is run by a nationally renowned research centre with an interest in recruiting participants for research purposes (trivialising patients' experiences would be

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[32] For instance, the IAPT scheme (Increasing Access to Psychological Services and Therapies), has sought to increase access to psychological interventions for those in PMH services.

counterproductive in this case, since the centre partly depends upon participants to take part in research and to spread the word about the centre's work). For such institutions, attempts at educating the public about science and technology are part of strategies for 'making up' biological citizens, who form and mobilise around particular diagnostic categories (Rose, 2007), particularly since the course communicates knowledge regarding the types of research which are conducted by the centre (in particular genetic research). The biological discourses promoted by such institutions have been a fundamental aspect of the 'de-stigmatising' of conditions through establishing their status as real diseases.

While participants appeared to adopt neurobiological accounts in a de-stigmatising sense, it must be pointed out that this tendency may not translate into de-stigmatisation more generally. While participants seemed to emphasise the biological nature of their difficulties, describing these conceptualisations as helpful in explaining the disorder to themselves and to others, participants (particularly on the BPC course) frequently talked about experiences of being held accountable by work colleagues or family members; being diagnosed with what is often deemed to be a severe mental illness was not always sufficient to protect subjects from blaming reactions. As O'Connor and Joffe (2013) conclude, neuroscientific ideas often become incorporated into existing frameworks of understanding, in ways that perpetuate rather than challenge existing conceptualisations, meaning that beliefs relating to free-will, self-control, individual responsibility and essentialism are likely to remain consistent. It seems to be within the self-conceptions of psychiatric patients – that neuroscientific knowledge has made its biggest impact, although still in partial and conditional ways (O'Connor and Joffe, 2013). However, this study suggests that certain diagnoses (in this case bipolar disorder) - when considered to have an underlying biological aetiology - can be seen to limit agency and responsibility within certain contexts. While this may have applied within the context of the BPC course, within more resource limited settings (such as CMHTs) it may be more accurate to say – not that diagnosis always confers validity or negates moral responsibility – but that the withholding of certain diagnoses can be used as a form of delegitimization and downgrading, justifying decisions not to provide support to patients.

As mentioned in chapter 3, a further point is that most of the general observations were conducted within a CMHT which had a high number of student referrals. It is possible that the tendencies to trivialise and delegitimise patients' experiences may partly arise from more general attitudes regarding university students. It might also be the case that those types of patients who are more like to take part in research are also more likely to be higher functioning[33], and to have an interest in neurobiological understandings of mental health. For many of the individuals interviewed, the scientific theories regarding bipolar disorder appeared to be of interest, as these were often individuals who identified with their diagnosis, actively participating in support networks designed specifically for individuals with this label. As such the current research does not account for those who actively reject diagnostic labels, and for those who avoid contact with mental health services.

Finally, while this thesis has focused upon the blame and volitional stigma, this does not mean to say that individuals did not discuss other forms of stigma attached to the bipolar label. Although stereotypes regarding dangerousness and violence were not concerns expressed by participants, at times there was talk about potential discrimination from employers and insurance companies, and from family members, which may have resembled a kind of prognostic pessimism or a negative form of essentialisation. The ethical approval process undertaken for this study is also testament to the kinds of negative assumptions regarding people with labels of bipolar disorder, who are considered to be an especially vulnerable (and potentially risky) group, simply by virtue of belonging to this diagnostic category.

Conclusion

This thesis emphasises the importance of accounting for the ways in which individuals interpret, conceptualise and interact with their diagnostic label, since this informs the ways in which they are compelled to 'self-manage', the social networks they are permitted to participate in, and the ways in which they account for their own

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[33] As mentioned in chapter 3, a disproportionate number of interview participants were volunteering as bipolarUK group facilitators or mentors.

experiences and behaviours. It does not attempt to provide any straightforward answers regarding the usefulness of psychiatric diagnosis, or the relative merits of 'psychosocial' or 'biomedical' models of illness. As has been noted (e.g. O'Connor and Joffe, 2013), the consequences of neuroscience for attitudes to social groups are complex, and dependent on context and framing; however, this research does suggest that – while certain political groups (i.e. those associated with the 'hearing voices' movement) take a clearly critical stance towards biological understandings of mental disorder, psychological understandings of distress also have the potential to stigmatise individuals. The implications of psychiatric diagnosis are equally complex. Essentialised and categorical notions of diagnoses such as bipolar disorder may have the potential to re-enforce social divisions, both between and within groups; however, given the social function of and advantages conferred by diagnosis - i.e. its importance in determining access to vital services and welfare support (Jutel, 2009) – demands for diagnostic specificity are unlikely to diminish without changes in the way that support services are structured.

References

Abi-Rached, J. M. (2008). The implications of the new brain sciences. *EMBO Reports*, 9, 12, 1158–1162.

Abbott, A. (2010). The Duality of Stress. In *Chaos of Disciplines* (pp. 34-60). Chicago: University of Chicago Press.

Akiskal, H. (1983). Diagnosis and classification of affective disorders: new insights from clinical and laboratory approaches. *Psychiatric Developments*, 1, 2, 123- 160.

Alberti, K. (2000) 'Multicentre Research Ethics Committees: Has the Cure been Worse than the Disease?' *British Medical Journal,* 320, 1157–8.

Allen, D. (2000). Doing occupational demarcation: The "boundary-work" of nurse managers in a district general hospital. *Journal of Contemporary Ethnography*, *29*, 3, 326-356.

American Psychiatric Association (1952). *Diagnostic and Statistical Manual of Mental Disorders*. Washington, DC: American Psychiatric Association.

American Psychiatric Association (1968). *Diagnostic and Statistical Manual of Mental Disorders (2nd ed.)* Washington, DC: American Psychiatric Association

American Psychiatric Association (1980). *Diagnostic and Statistical Manual of Mental Disorders (3rd ed.).* Washington, DC: American Psychiatric Association.

American Psychiatric Association (1987). *Diagnostic and Statistical Manual of Mental Disorders. (3rd ed. Revised).* Washington, DC: American Psychiatric Association.

American Psychiatric Association (1994). *Diagnostic and Statistical Manual of Mental Disorders (4th ed.)* Washington, DC: American Psychiatric Association.

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders: DSM-5 (5th ed.). Arlington, VA: American Psychiatric Association.

Andreasen, N. (2001). *Brave New Brain: Conquering Mental Illness in the Era of Genome.* Oxford: Oxford University Press.

Angell, M. (2011). The illusions of psychiatry. *The New York Review of Books*, *58*, 12, 20-22.

Angermeyer, M. C., Holzinger, A., Carta, M. G., & Schomerus, G. (2011). Biogenetic explanations and public acceptance of mental illness: systematic review of population studies. *The British Journal of Psychiatry*, 199, 5, 367-372.

Angermeyer, M. C., & Matschinger, H. (2003). The stigma of mental illness: effects of labelling on public attitudes towards people with mental disorder. *Acta Psychiatrica Scandinavica*, 108, 4, 304-309.

Angermeyer, M. C., & Matschinger, H. (2005). Causal beliefs and attitudes to people with schizophrenia: trend analysis based on data from two population surveys in Germany. *The British Journal of Psychiatry*, *186*, 4, 331-334.

Angrosino, M., & Mays de Perez, K. (2000). Rethinking observation: From method to context. In K. Denzin, & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (second ed., pp. 673–702). Thousand Oaks, CA: Sage.

Angst, J. (2007). The bipolar spectrum, *The British Journal of Psychiatry*, 190, 3, 189-191.

Angst J., Gamma A., Benazzi F., Ajdacic V., Eich D., & Rossler, W. (2003). Toward a re-definition of subthreshold bipolarity: epidemiology and proposed criteria for bipolar-II, minor bipolar disorders and hypomania. *Journal of Affective Disorders*; 73, 133-46.

Anspach, R. R. (2010). Gender and health care. In: C. E. Bird, P. Conrad, A. M. Fremont & S. Timmermans (Eds), *Handbook of medical sociology* (6th ed.). Nashville, TN: Vanderbilt University Press.

Anspach, R. R. (2011). Preface. In McGann, P. J. & Hutson, D. J. (Eds), *Sociology of diagnosis* (pp. xiii-xxix). Emerald Group Publishing Limited.

Aronowitz, R. (2001). When do symptoms become a disease? *Annals of Internal Medicine*, 134, 9, 2, 803–8.

Aspinwall, L., Brown, T., & Tabery, J. (2012). The double-edged sword: Does biomechanism increase or decrease judges' sentencing of psychopaths?. *Science*, *337*, 6096, 846-849.

Atkinson, P. (1995). *Medical talk and medical work*. London: Sage.

Atkinson, P. & Hammersley, M. (1998). Ethnography and Participant Observation. In N. Denzin & Y. Lincoln (Eds.), *Strategies of Qualitative Inquiry.* London: Sage.

Atkinson, P. & Pugsley, L. (2005). Making sense of ethnography and medical education. *Medical Education*, 39, 2, 228-234.

Austin, J. (1975). *How to Do Things with Words* (second revised ed.). Oxford University Press: London.

Avdi, E., Griffin, C., & Brough, S. (2000). Parents' constructions of the problem during assessment and diagnosis of their child for an autistic spectrum disorder. *Journal of Health Psychology,* 5, 241–254.

Bag, B., Yilmaz, S. & Kirpinar, I. (2006) Factors influencing social distance from people with schizophrenia. *International Journal of Clinical Practice*, 60, 3, 289–294.

Baillarger J. (1954). De la folie à double-forme. *Annual Medical Psychology (Paris)*, 6, 367-391.

Barr, W. (2000). Characteristics of severely mentally ill patients in and out of contact with community mental health services. *Journal of Advanced Nursing*, 31, 3, 1189–1198

Barrowclough, C., Haddock, G., Lowens, I., Connor, A., Pidliswyj, J., & Tracey, N. (2001). Staff expressed emotion and causal attributions for client problems on a low security unit: An exploratory study. *Schizophrenia Bulletin*, 27, 3, 517-526.

Bastian, B., & Haslam, N. (2006). Psychological essentialism and stereotype endorsement. *Journal of Experimental Social Psychology*, *42*, 2, 228-235.

Bennett, L., Thirlaway, J., & Murray, A. (2008). The stigmatizing implications of presenting schizophrenia as a genetic disease. *Journal of Genetic Counselling*, 17, 550–559.

Bentall, R. (2004). *Madness explained: Psychosis and human nature*. Penguin UK.

Berrios, G. (1988). Depressive and manic states during the nineteenth century. In A. Georgotas & R. Cancro (Eds.), *Depression and Mania* (pp. 13-25). New York: Elsevier.

Berrios, G., & Dening, T. (1996). Pseudohallucinations: a conceptual history, *Psychological Medicine*, 26, 753–764.

Berrios, G. (2004). Of mania: Introduction. *History of Psychiatry*, 15, 1, 105-124.

Bhui, K. & Bugra, D. (2002). Explanatory models for mental distress: Implications for Clinical Practise and Research. *British Journal of Psychiatry*, 181, 6-7.

Blaxter, M. (1978). Diagnosis as category and process: the case of alcoholism, *Social Science and Medicine*, 12, 9–17.

Blaxter, M. (1997). Whose fault is it? People's own conceptions of the reasons for health inequalities. *Social Science & Medicine*, 44, 6, 747–756.

Bonnington, O. & Rose, D. (2014). Exploring stigmatisation among people diagnosed with either bipolar disorder or borderline personality disorder: A critical realist analysis. *Social Science & Medicine*, *123*, 7-17.

Booth, T., & Booth, W. (1994). The use of depth interviewing with vulnerable subjects: Lessons from a research study of parents with learning difficulties. *Social Science Medicine*, 39, 415-424.

Bos, A., Kanner, D., Muris, P., Janssen, B., & Mayer, B. (2009). Mental illness stigma and disclosure: Consequences of coming out of the closet. *Issues in Mental Health Nursing*, 30, 509–513.

Bos, A., Schaalma, H. & Pryor, J. (2008). Reducing AIDS-related stigma in developing countries: The importance of theory- and evidence based interventions. *Psychology, Health & Medicine*, 13, 450–460.

Bosk, C. (1979). *Forgive and remember: managing medical failure*. University of Chicago Press.

Bosk, C. (2001). Irony, Ethnography & Informed Consent, In C. B. Hoffmaster (ed.), *Bioethics in Social Context* (pp. 199-220). Temple University Press.

Bosk, C., & De Vries, R. (2004). Bureaucracies of mass deception: Institutional review boards and the ethics of ethnographic research. *The Annals of the American Academy of Political and Social Science*, 595, 1, 249-263.

Bowker, G. & Star, S. (1999). *Sorting Things Out: Classification and its Consequences*. Cambridge, MA: MIT Press.

Boyle, M. (2013). The persistence of medicalisation: Is the presentation of alternatives part of the problem? In S. Coles, S. Keenan, & B. Diamond (Eds.), *Madness Contested: Power and Practice* (pp. 3-22). Ross-on-Wye, UK: PCCS Books.

Boysen, G., & Vogel, D. (2008). Education and mental health stigma: The effects of attribution, biased assimilation, and attitude polarization. *Journal of Social and Clinical Psychology*, 27, 5, 447-470.

Brewer, J. (2000). *Ethnography*. Buckingham: Open University Press.

Brinkmann, S. (2017). 'Mad or normal? Paradoxes of contemporary diagnostic cultures'. *i Tidsskrift for Forskning i Sygdom og Samfund,* 26, 169-183.

Brinkmann, S. (2013). The pathologization of morality. In K. Keohane & A. Petersen (Eds.), *The Social Pathologies of Contemporary Civilization* (pp. 103-118). Farnham: Ashgate.

Brinkmann, S. (2014). Languages of suffering. *Theory & Psychology*, 24, 630-648.

Brinkmann, S. (2016). *Diagnostic Cultures: A Cultural Approach to the Pathologization of Modern Life*. Farnham: Ashgate.

Bröer, C. & Heerings, M. (2013). Neurobiology in public and private discourse: The case of adults with ADHD. *Sociology of Health & Illness*, 35, 1, 49–65.

Brown, P. (1987). Diagnostic conflict and contradiction in psychiatry. *Journal of Health and Social Behaviour*, 28, 1, 37–50.

Brown, P. (1990). The name game: toward a sociology of diagnosis. *The Journal of Mind and Behaviour*, 11, 3–4, 385–406.

Brown, P. (1995) Naming and framing: the social construction of diagnosis and illness. *Journal of Health and Social Behaviour*, Health Module, 34–52.

Brown, P. & Zavestoski, S. (2004). Social movements in health: an introduction. *Sociology of Health and Illness*, 26, 6, 679–94.

Browne, A. (2000). The potential contributions of critical social theory to nursing science. *Canadian Journal of Nursing Research*, 32, 2, 35-35.

Buchanan, D., Boddy, D. & McCalman, J. (1988). Getting In, Getting On, Getting Out and Getting Back. In A. Bryman (Ed.) *Doing Research in Organisations* (pp. 53-67) London: Routledge.

Buchman, D., Illes, J. & Reiner, P. (2010). The paradox of addiction neuroscience. *Neuroethics* 4, 2, 65–77.

Buchman, D. Borgelt, E. Whiteley, L. & Illes, J. (2013). Neurobiological narratives: Experiences of mood disorder through the lens of neuroimaging. *Sociology of Health & Illness*. 35, 1, 66–81.

Budd, R., James, D., & Hughes, I. (2008). Patients' explanations for depression: a factor analytic study. *Clinical Psychology & Psychotherapy*, 15, 1, 28-37.

Bysouth, D. (2007). *Jolly good nutter: a discursive psychological examination of bipolar disorder in psychotherapeutic interactions* (Doctoral dissertation, Murdoch University).

Callard, F., Rose, D., Hanif, E., Quigley, J., Greenwood, K., & Wykes, T. (2012). Holding blame at bay? 'Gene talk' in family members' accounts of schizophrenia aetiology. *Biosocieties*, 7, 3, 273–293.

Cardiff and Vale University Health Board (2012). *Operational policy for integrated community mental health teams*.

Cartwright, S. (1981 [1851]) Report of the diseases and physical peculiarities of the negro race. In A. Caplan, H. T. Englehardt, & J. McCartney (Eds), *Concepts of Health and Disease*. Reading, MA: Addison-Wesley Publishing Company.

Casey, P., Dowrick, C., & Wilkinson, G. (2001). Adjustment disorders: Fault line in the psychiatric glossary. *British Journal of Psychiatry*, 179, 479-480.

Castiglioni, M., & Laudisa, F., (2014). Toward psychiatry as a 'human' science of mind. The case of depressive disorders in DSM-5, *Frontiers in Psychology*, 5, 1517.

Castle, D., White, C., Chamberlain, J., Berk, M., Berk, L., Lauder, S., Murray, G., Schweitzer, I., Piterman, L. & Gilbert, M., (2010). Group-based psychosocial intervention for bipolar disorder: randomised controlled trial. *The British Journal of Psychiatry*, 196, 5, 383-388.

Cederström, C., & Spicer, A. (2015). *The Wellness Syndrome*. Cambridge, UK: Polity Press.

Clarke, J. & James, S. (2003). The radicalized self: The impact on the self of the contested nature of the diagnosis of chronic fatigue syndrome. *Social Science & Medicine*, 57, 8, 1387–1395.

Chan, D., & Sireling, L. (2010). 'I want to be bipolar'… a new phenomenon. *The Psychiatrist*, 34, 3, 103-105.

Charmaz, K. (1991). *Good Days, Bad Days: The Self in Chronic Illness and Time*. New Brunswick, NJ: Rutgers University Press.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative research*. Sage Publications Ltd: London.

Chew-Graham, C., Slade, M., Montana, C., Stewart, M., & Gask, L. (2007). A qualitative study of referral to community mental health teams in the UK: exploring the rhetoric and the reality. *BMC Health Services Research,* 7, 117.

Choudhury, S., McKinney, K. & Merten, M. (2012) Rebelling against the brain: Public engagement with the 'neurological adolescent'. *Social Science & Medicine,* 74, 4, 565–573.

Choudhury, S., Nagel, S. & Slaby, J. (2009). Critical neuroscience: Linking neuroscience and society through critical practice. *BioSocieties,* 4, 1, 61–77.

Clarke, J. & James, S. (2003). The radicalized self: the impact on the self of the contested nature of the diagnosis of chronic fatigue syndrome. *Social Science & Medicine*, *57*, 8, 1387-1395.

Coffey, A. & Atkinson, P. (1996). *Making sense of qualitative data: Complementary research strategies.* Sage: Thousand Oaks, CA.

Cohn, S. (2004). Increasing resolution, intensifying ambiguity: An ethnographic account of seeing life in brain scans. *Economy and Society*, 33, 1, 52–76.

Colom F., Vieta, E., Reinares, M., Martinez-Aran, A., Torrent, C., Goikolea, J., et al. (2003). Psychoeducation efficacy in bipolar disorders: beyond compliance enhancement. *Journal of Clinical Psychiatry*, 64, 1101-5.

Colom, F., Vieta, E., Sanchez-Moreno, J., Palomino-Otiniano, R., Reinares, M., Goikolea, J., et al. (2009). Group psychoeducation for stabilised bipolar disorders: 5-year outcome of a randomised clinical trial. *British Journal of Psychiatry*, 194, 260-5.

Colombo, A., Bendelow, G., Fulford, B. & Williams, S. (2003). Evaluating the influence of implicit models of mental disorder of processes of shared decision making within community-based multi-disciplinary teams. *Social Science & Medicine*, 56, 7, 1557-1570.

Conrad, P. (1975). The discovery of hyperkinesis: notes on the medicalization of deviant behavior. *Social Problems*, 23, 1, 12–21.

Conrad, P. (1979). Types of medical social control. *Sociology of Health and Illness*, 1, 1, 1–11.

Conrad, P. (1992). Medicalization and social control. *Annual Review of Sociology,* 18, 209–32.

Conrad, P. (2001) Genetic optimism: framing genes and mental illness in the news. *Culture, Medicine, and Psychiatry*, 25, 225–247.

Conrad, P. (2007). *The Medicalization of Society: On the Transformation of Human Conditions into Treatable Disorders.* Baltimore: Johns Hopkins University Press.

Conrad, P. and Schneider, J., W. (1980). *Deviance and Medicalization: From Badness to Sickness*. St. Louis, MO: The C.V. Mosby Company.

Conrad, P. & Stults, C. (2010). The internet and the experience of illness. *Handbook of Medical Sociology*, *6*, 179-91.

Condit, C. (1999). How the public understands genetics: non-deterministic and non-discriminatory interpretations of the "blueprint" metaphor. *Public Understanding of Science,* 8, 3, 169–180.

Cooke, A. (2017). *Understanding psychosis and schizophrenia: why people sometimes hear voices, believe things that others find strange, or appear out of touch with reality, and what can help*. Canterbury Christ Church University: British Psychological Society.

Copolov, D., Trauer, T. & Mackinnon, A. (2004). On the non-significance of internal versus external auditory hallucinations. *Schizophrenia Research*, *69*, 1, 1-6.

Corbin, J., & Strauss, A. (2008). Basics of qualitative research: Techniques and procedures for developing grounded theory. *Thousand Oaks*.

Corbin, J., & Morse, J. M. (2003). The unstructured interactive interview: Issues of reciprocity and risks when dealing with sensitive topics. *Qualitative inquiry*, *9*, 3, 335-354.

Corrigan, O. (2003) 'Empty Ethics: The Problem with Informed Consent'. *Sociology of Health and Illness* 25, 3, 768–92.

Corrigan, P. (2000). Mental health stigma as social attribution: Implications for research methods and attitude change. *Clinical Psychology: Science and Practice*, 7, 1, 48-67.

Corrigan, P., Rowan, D., Green, A., Lundin, R., River, P., Uphoff-Wasowski, K. & Kubiak, M. (2002). Challenging two mental illness stigmas: personal responsibility and dangerousness. *Schizophrenia bulletin*, 28, 2, 293.

Corrigan, P. and Watson, A. (2004). Stop the stigma: Call mental illness a brain disease. *Schizophrenia Bulletin,* 30, 3, 477–479.

Corrigan, P., Schmidt, A., Bink, A., Nieweglowski, K., Al-Khouja, M. A., Qin, S., & Discont, S. (2016). Changing public stigma with continuum beliefs. *Journal of Mental Health*, 1-8.

Coyle, A. and Wright, C. (1996). 'Using the Counselling Interview to Collect Research Data on Sensitive Topics'. *Journal of Health Psychology*, 1, 431–40.

Crabtree, J., Haslam, S., Postmes, T. & Haslam, C. (2010). Mental health support groups, stigma, and self-esteem: Positive and negative implications of group identification. *Journal of Social Issues*, 66, 3, 553–569.

Craddock, N., Antebi, D., Attenburrow, M., Bailey, A., Carson, A., Cowen, P., ... & Fazel, S. (2008). Wake-up call for British psychiatry. *The British Journal of Psychiatry*, 193, 1, 6-9.

Craddock, N. & Owen, M. (2005). The beginning of the end for the Kraepelinian dichotomy. *The British Journal of Psychiatry*, 186, 5, 364-366.

Crawford, R. (2006). Health as a meaningful social practice. *Health,* 10, 4, 401-420.

Creese, A. (2008). Linguistic ethnography. In *Encyclopedia of language and education* (pp. 3424-3436). Springer, Boston, MA.

Crisafulli, M., Von Holle, A., & Bulik, C. (2008). Attitudes towards anorexia nervosa: The impact of framing on blame and stigma. *International Journal of Eating Disorders*, 41, 4, 333-339.

Crisp, A., Gelder, M., Rix, S., Meltzer, H., & Rowlands, O. (2000). Stigmatisation of people with mental illnesses. *The British Journal of Psychiatry*, 177, 1, 4-7.

Cutcliffe, J., & Happell, B. (2009). Psychiatry, mental health nurses, and invisible power: Exploring a perturbed relationship within contemporary mental health care. *International Journal of Mental Health Nursing*, 18, 2, 116-125.

Cieurzo, C. & Keitel, M. (1999). Ethics in qualitative research. In M. Kopala & L. A. Suzuki (Eds.), *Using qualitative methods in psychology* (pp. 63-75). Thousand Oaks, CA: Sage Publications.

Dar-Nimrod, I. & Heine, S. (2011). Genetic essentialism: On the deceptive determinism of DNA. *Psychological Bulletin*, 137, 5, 800–818.

Davis, B. (1990). Research and psychiatric nursing. In *Psychiatric and Mental Health Nursing* (pp. 434-467). Boston: Springer.

De Brigard, F., Mandelbaum, E. & Ripley, D. (2009). Responsibility and the brain sciences. *Ethical Theory and Moral Practice,* 12, 5, 511–524.

Deacon, B. & Baird, G. (2009). The chemical imbalance explanation of depression: reducing blame at what cost? *Journal of Social and Clinical Psychology*, 28, 4, 415-435.

Del Porto, J. (2004). Bipolar disorder: evolution of the concept and current controversies. *Revista Brasileira de Psiquiatria*, 26, 7-11.

Denzin, N. & Lincoln, Y. (2000). *Handbook of Qualitative Research.* (2nd edn.). London: Sage.

Department of Health (1995)*. Building bridges: A guide to arrangements for inter-agency working for the care and protection of severely mentally ill people.* London: HMSO.

Department of Health (1999a). *A National Service Framework for Mental Health.* London: HMSO.

Department of Health. (1999b). *Department of Health Effective Care Co-ordination in Mental Health Services: Modernising the Care Programme Approach.* HMSO, London.

Department of Health (2002). *Mental Health Policy Implementation Guide: Community Mental Health Teams.* London: HMSO.

Department of Health (2009). *Research Governance Framework for Health and Social Care in Wales* (2nd edition). London: HMSO.

Dietrich, S., Beck, M., Bujantugs, B., Kenzine, D., Matschinger, H., & Angermeyer, M. (2004). The relationship between public causal beliefs and social distance toward mentally ill people. *Australian and New Zealand Journal of Psychiatry*, 38, 5, 348-354.

Dietrich, S., Matschinger, H. & Angermeyer, M. (2006). The relationship between biogenetic causal explanations and social distance toward people with mental disorders: Results from a population survey in Germany. *International Journal of Social Psychiatry*, 52, 2, 166–174.

Dickson-Swift, V., James, E., Kippen, S. & Liamputtong, P. (2006). 'Blurring Boundaries in Qualitative Health Research on Sensitive Topics'. *Qualitative Health Research,* 16, 853–71.

Dickson-Swift, V., James, E. L., Kippen, S., & Liamputtong, P. (2007). Doing sensitive research: what challenges do qualitative researchers face? *Qualitative research*, 7, 3, 327-353.

Dingel, M., Karkazis, K., & Koenig, B. (2011). Framing nicotine addiction as a "disease of the brain": social and ethical consequences. *Social Science Quarterly*, 92, 5, 1363-1388.

Dingwall, R., (1980). Ethics and ethnography. *Sociological Review,* 28, 4, 871-91.

Dingwall, R. & Murray, T. (1983). Categorisation in accident departments: 'good' patients, 'bad' patients and children. *Sociology of Health & Illness*, 5, 2, 127–48.

Dixon-Woods, M., Kocman, D., Brewster, L., Willars, J., Laurie, G. & Tarrant, C. (2017). A qualitative study of participants' views on re-consent in a longitudinal biobank. *BMC medical ethics*, 18, 1, 22.

Dobransky, K. (2009). The good, the bad, and the severely mentally ill: Official and informal labels as organizational resources in community mental health services. *Social Science & Medicine,* 69, 722–728.

Dodier, N. & Camus, A. (1998). Openness and specialisation: dealing with patients in a hospital emergency service. *Sociology of Health & Illness*, 20, 4, 413–44.

Dumit, J. (2003). Is it me or my brain? Depression and neuroscientific facts. *Journal of Medical Humanities,* 24, 1, 35–47.

Dumit, J. (2004). *Picturing Personhood: Brain Scans and Biomedical Identity*. Princeton, NJ: Princeton University Press.

Dumit, J. (2006). Illnesses you have to fight to get: Facts as forces in uncertain, emergent illnesses. *Social Science & Medicine*, 62, 3, 577-590.

DuVal, G. (2004). Ethics in psychiatric research: Study design issues. *Canadian Journal of Psychiatry*, 49, 1, 55–59.

Easter, M. (2012). 'Not all my fault': Genetics, stigma, and personal responsibility for women with eating disorders. *Social Science & Medicine,* 75, 8, 1408–1416.

Easter, M. (2014). Interpreting genetics in the context of eating disorders: evidence of disease, not diversity. *Sociology of Health & Illness*, 36, 6, 840-855.

Edley, N. (2001). Analysing masculinity: Interpretative repertoires, ideological dilemmas and subject positions. *Discourse as data: A guide for analysis*, 189-228.

Eichelman, B., Wikler, D., & Hartwig, A. (1984). Ethics and psychiatric research: Problems and justification. *American Journal of Psychiatry*, 141, 3, 400–405.

Eide, E. (2010). Strategic Essentialism and Ethnification: Hand in Glove? *Nordicom Review,* 31, 2, 63-78.

Ellison, N., Mason, O., & Scior, K. (2013). Bipolar disorder and stigma: A systematic review of the literature. *Journal of Affective Disorders*, 151, 3, 805-820.

Ely, M., Anzul, M., Friedman, T., Garner, D. & Steinmetz, A. (1991). *Doing Qualitative Research: Circles within Circles*. London: Falmer Press.

Emerson, R., Fretz, R. & Shaw, L. (1995). 'Processing fieldnotes: Coding and memo-ing'. In *Writing Ethnographic Fieldnotes*, pp. 142-168. Chicago, IL: University of Chicago.

Estroff, S. (1993). Identity, disability and schizophrenia: the problem of chronicity. In S. Lindenbaum & M. Lock (Eds.) *Knowledge, power and practice: the anthropology of medicine and everyday life.* University of California Press.

Etherington, K. (1996). The counsellor as researcher: Boundary issues and critical dilemmas. *British Journal of Guidance and Counselling*, *24*, 3, 339-346.

Evans-Lacko, S., Kastelic, E. & Riley, A. (2011). Mental health service use before and after diagnosis of early-onset bipolar disorder. *The Journal of Behavioral Health Services & Research*, 38, 3, 398-413.

Eysenck, H. (1970). ''The Classification of Depressive Illness.'' *British Journal of Psychiatry,* 117, 241-50.

Falret J. (1954). Mémoire sur la folie circulaire, forme de maladie mentale caractérisée par la reproduction successive et régulaire de l'état maniaque, de l'état mélancolique, et d'un intervalle lucide plus ou moins prolongé. *Bull Acad Med (Paris)*, 19, 382 415.

Farah, M. (2012). Neuroethics: The ethical, legal, and societal impact of neuroscience. *Annual Review of Psychology*, 63, 1, 571–591.

Fein, E. (2011). Innocent machines: Asperger's syndrome and the neurostructural self. In M. Pickersgill & I. van Keulen (Eds.) *Sociological Reflections on the Neurosciences,* (pp.27–49). Bingley: Emerald.

Feltes, P., Doorduin, J., Klein, H., Juárez-Orozco, L., Dierckx, R., Moriguchi-Jeckel, C., & de Vries, E. (2017). Anti-inflammatory treatment for major depressive disorder: implications for patients with an elevated immune profile and non-responders to standard antidepressant therapy. *Journal of Psychopharmacology*. 31, 9, 1149–1165.

Ferguson, I. (2007). *Reclaiming social work: Challenging neo-liberalism and promoting social justice*. London: Sage.

Fine, C. (2010). *Delusions of gender: How our minds, society, and neurosexism create difference*. WW Norton & Company.

Foucault, M. (1967). *Madness and civilization: A history of insanity in the age of reason* (R. Howard, Trans.). London: Tavistock.

Foucault, M. (1977). *Discipline and Punish* (A. Sheridan, trans.). New York: Pantheon.

Frank, A. (2000). The standpoint of the storyteller. *Qualitative Health Research*, 10, 354-365.

Frances, A. (2013). *Saving Normal. An Insider's Revolt Against Out-of-Control Psychiatric Diagnosis, DSM-5, Big Pharma, and the Medicalization of Ordinary Life.* New York: HarperCollins.

Freese, J., & Shostak, S. (2009). Genetics and social inquiry. *Annual Review of Sociology*, 35, 107-128.

Freidson, E. (1970). *Professional Dominance: The Social Structure of Medical Care.* Aldine: Chicago.

Frith, U. & Happe, F. (1999). Theory of mind and self-consciousness: What is it like to be autistic? *Mind Langu*age, 14, 1–22.

Gannett, L. (1999). What's in a Cause?: The Pragmatic Dimensions of Genetic Explanations, *Biology & Philosophy*, 14, 349–374.

Garfinkel, H. (1967). *Studies in ethnomethodology*. New Jersey: Prentice Hall.

Gauld, R. (1999). Ethics committees and qualitative health research in New Zealand. *New Zealand Medical Journal*, 112, 1089, 195-197.

Georgotas, A. & Cancro, R. (1988). *Depression and Mania*. New York: Elsevier.

Ghaemi, S., Sachs, G., Chiou, A., Pandurangi, A. & Goodwin, K. (1999). Is bipolar disorder still underdiagnosed? Are antidepressants overutilized? *Journal of Affective Disorders*, 52, 135–44.

Ghaemi, S. (2003). *The concepts of Psychiatry: A pluralistic approach to mind and mental illness*. Baltimore: Johns Hopkins University Press.

Gibson, G. (1978). Categorization of hospital emergency capabilities: some empirical methods to evaluate appropriateness of emergency department utilization. *The Journal of Trauma*, *18*, 2, 94-102.

Giles, D. (2006). Constructing identities in cyberspace: The case of eating disorders. *British Journal of Social Psychology*, 45, 3, 463-477.

Glaser, B., & Strauss, A. (1967). Grounded theory: The discovery of grounded theory. *The Journal of The British Sociological Association*, 12, 27-49.

Glenton, C. (2003). Chronic back pain sufferers—striving for the sick role. *Social Science & Medicine,* 57, 11, 2243–2252.

Goffman, E. (1959). *The presentation of self in everyday life*. London: Penguin.

Goffman, E. (1961). *Asylums*. Penguin, Harmondsworth.

Goffman, E. (1963). *Stigma: notes on the management of spoiled identity.* London: Penguin.

Goldstein, B., & Rosselli, F. (2003). Etiological paradigms of depression: the relationship between perceived causes, empowerment, treatment preferences, and stigma. *Journal of Mental Health*, 12, 551–563.

Goodley, D., & Parker, I. (2000). Critical psychology and action research. *Annual Review of Critical Psychology*, 2, 3-18.

Goodwin, F. & Jamison, K. (1990). *Manic Depressive Illness*. Oxford University Press: New York.

Grausgruber, A., Meise, U., Katschnig, H., Schony, W., & Fleischhacker, W. (2007). Patterns of social distance towards people suffering from schizophrenia in Austria: a comparison between the general public, relatives and mental health staff. *Acta Psychiatry Scandanavia*, 115, 310–319.

Griffiths, L. (2001). Categorising to exclude: the discursive construction of cases in community mental health teams. *Sociology of Health & Illness*, 23, 5, 678-700.

Griffiths, K. & Christensen H. (2004). Commentary on the relationship between public causal beliefs and social distance toward mentally ill people. *Australian & New Zealand Journal of Psychiatry*, 38, 355–357.

Grob, G. (1991). Origins of DSM-I: a study in appearance and reality. *American Journal of Psychiatry*, 148, 421-431.

Gruenberg, A., Goldstein, R. & Pincus, H. (2005). Classification of depression: research and diagnostic criteria: DSM-IV and ICD-10. *Biology of Depression*, *11*, 43.

Grunebaum, M., Luber, P., & Callahan, M. (1996). Predictors of missed appointments for psychiatric consultations in a primary care clinic. *Psychiatric Services*, 47, 848–852.

Guillemin, M., & Gillam, L. (2004). Ethics, reflexivity, and "ethically important moments" in research. *Qualitative Inquiry*, 10, 2, 261-280.

Gummesson, E. (2000). *Qualitative methods in management research* (2nd Ed.), Sage: London.

Hacking, I. (1995). 'The Looping Effects of Human Kinds'. In D. Sperber, D. Premack & A. Premark (Eds.), *Causal Cognition: A Multidisciplinary Debate* (pp.351-394). Oxford: Clarendon Press.

Hacking, I. (2009a). Autistic Autobiography. *Philosophical Transactions of the Royal Society of London B: Biological Sciences*, 364, 1522, 1467-1473.

Hacking, I. (2009b). Humans, aliens & autism. *Daedalus*, 138, 3, 44-59.

Hall, W., Carter, L. & Morley, K. (2004). Neuroscience research on the addictions: A prospectus for future ethical and policy analysis. *Addictive Behaviors,* 29, 7, 1481–1495.

Hamilton, M. (1978). *Fish's Outline of Psychiatry*. John Wright & Sons: Bristol.

Hammersley, M. & Atkinson, P. (2007). *Ethnography: Principles in Practice.* Routledge: Abingdon.

Hannigan, B. & Allen, D. (2003). 'A Tale of Two Studies: Research Governance Issues Arising from Two Ethnographic Investigations into the Organisation of Health and Social Care'. *International Journal of Nursing Studies,* 40, 685–95.

Harland, R., Antonova, E., Owen, G. S., Broome, M., Landau, S., Deeley, Q., & Murray, R. (2009). A study of psychiatrists' concepts of mental illness. *Psychological Medicine*, 39, 6, 967-976.

Haslam, N. & Ernst, D. (2002). Essentialist beliefs about mental disorders. *Journal of Social and Clinical Psychology*, *21*, 6, 628-644.

Haslam, N. (2011). Genetic essentialism, neuroessentialism, and stigma: Commentary on Dar-Nimrod and Heine (2011). *Psychological Bulletin,* 137, 5, 819–824.

Hatzenbuehler, M. & Link, B. (2014). Introduction to the special issue on structural stigma and health. *Social Science & Medicine*, 103, 1-6.

Healy, D. (2008). *A Short History of Bipolar Disorder*. Johns Hopkins University Press, Baltimore

Healy, D. (2010). From Mania to Bipolar Disorder. In L. Yatham & M. Maj (Eds.), *Bipolar disorder: clinical and neurobiological foundations* (pp.1-7). John Wiley & Sons.

Healy, D. (2012). *Pharmageddon*. Berkeley, CA: University of California Press.

Hedgecoe, A. (2001). Schizophrenia and the narrative of enlightened geneticization. *Social Studies of Science*, 31, 6, 875-911.

Hemler, J. (2013). "The medicalization of compulsive shopping: a disorder in the making?." *Krankheitskonstruktionen und Krankheitstreiberei*. *Springer Fachmedien Wiesbaden*, 133-159.

Hesslow, G. (1984). What is a genetic disease? On the relative importance of causes. In Nordenfolt, L., & Lindahl, B. (Eds.), *Health, disease, and causal explanations in medicine* (pp.183-193). Springer: Dordrecht.

Hewitt, L. (2007). Ethical Components of Researcher Researched Relationships in Qualitative Interviewing, *Qualitative Health Research*, 17, 8, 1149-59.

Hillman, A. (2014). 'Why must I wait?' The performance of legitimacy in a hospital emergency department. *Sociology of Health & Illness*, 36, 4, 485-499.

Hirschfeld, R., Lewis, L., & Vornik, L. (2003). Perceptions and impact of bipolar disorder: How far have we really come? Results of the National Depressive and Manic-Depressive Association 2000 survey of individuals with bipolar disorder. *Journal of Clinical Psychiatry.* 64, 161–74.

Hochschild, A. (1983). *The Managed Heart*. Berkeley: University of California Press.

Horwitz, A. (2002). *Creating Mental Illness*. Chicago: University of Chicago Press.

Horwitz, A. (2011). Creating an age of depression: the social construction and consequences of the major depression diagnosis. *Society and Mental Health*, 1, 1, 41-54.

Hughes, D. (1988). When nurse knows best: some aspects of nurse/doctor interaction in a casualty department. *Sociology of Health & Illness*, 10, 1, 1–22.

Hutchinson, H., Wilson, M., & Wilson, H. (1994). Benefits of participating in research interviews. *Image Journal of Nursing Scholarship*, 26, 161-164.

Illes, J. & Racine, E. (2005). Imaging or imagining? A Neuroethics challenge informed by genetics. *The American Journal of Bioethics,* 9, 2, 5–18.

Illes, J, Lombera, S., Rosenberg, J. & Arnow, B. (2008). In the mind's eye: Provider and patient attitudes on functional brain imaging. *Journal of Psychiatric Research,* 43, 2, 107–114.

Iselin, M. & Addis, M. (2003). Effects of etiology on perceived helpfulness of treatments for depression. *Cognitive Therapy and Research*, 27, 2, 205-222.

Jackson, J. (2000). *Camp pain: Talking with chronic pain patients.* University of Pennsylvania Press: Philadelphia, PA.

Jaspers, K. (1962). *General Psychopathology*. Manchester University Press: Manchester.

Jeffery, R. (1979). Normal rubbish: deviant patients in casualty departments. *Sociology of Health & Illness,* 1, 1, 90-107.

Joffe, H. & Haarhoff, G. (2002). Representations of far-flung illnesses: The case of Ebola in Britain. *Social Science & Medicine*, 54, 6, 955-969.

Johnstone, L. & Boyle, M. with Cromby, J., Dillon, J., Harper, D., Kinderman, P., Longden, E., Pilgrim, D. & Read, J. (2018). *The Power Threat Meaning Framework: Overview.* Leicester: British Psychological Society.

Jones, L. & Cochrane, R. (1981). Stereotypes of mental illness: A test of the labelling hypothesis. *International Journal of Social Psychiatry*, 27, 99-107.

Jones, N., Shattell, M., Kelly, T., Brown, R., Robinson, L., Renfro, R., Harris, B. & Luhrmann, T. (2016). "Did I push myself over the edge?": Complications of agency in psychosis onset and development. *Psychosis*, 5498, 1–12.

Jorm, A. & Griffiths, K. (2008). The public's stigmatizing attitudes towards people with mental disorders: how important are biomedical conceptualizations?. *Acta Psychiatrica Scandinavica*, 118, 4, 315-321.

Jorm, A. & Oh, E. (2009). Desire for social distance from people with mental disorders. *Australian & New Zealand Journal of Psychiatry*, 43, 3, 183-200.

Jorm, A., Reavley, N. & Ross, A. (2012). Belief in the dangerousness of people with mental disorders: a review. *Australian & New Zealand Journal of Psychiatry*, 46, 11, 1029-1045.

Josselson, R. (2007). The ethical attitude in narrative research. In D. Clandinin, (Ed.) *Handbook of narrative inquiry: Mapping a methodology* (pp.537-566). London: Sage.

Judd, L., Akiskal, H., Schettler, P., Endicott, J., Maser, J., Solomon, D., Leon, A., Rice, J. & Keller, M. (2002). The long-term natural history of the weekly symptomatic status of bipolar I disorder. *Archive of General Psychiatry,* 59, 6, 530-7.

Judd, L., Schettler P., Akiskal H., Maser, J., Coryell, W., Solomon, D., Endicott, J. & Keller, M. (2003). Long-term symptomatic status of bipolar I vs. bipolar II disorders. *International Journal of Neuropsychopharmacology*, 6, 2, 127-37.

Junginger, J. & Frame, C. (1985). Self-report of the frequency and phenomenology of verbal hallucinations. *Journal of Nervous and Mental Disease*, 173, 149–155.

Jutel, A. (2009). Sociology of diagnosis: a preliminary review. *Sociology of Health & Illness*, 31, 2, 278-299.

Jutel, A. (2012). Doctor's orders: Diagnosis, medical authority and the exploitation of the fat body. In J. Wright & V. Harwood (Eds.) *Biopolitics and the 'Obesity Epidemic'* (pp. 68-85). Routledge.

Jutel, A. & Nettleton, S. (2011). Towards a sociology of diagnosis: reflections and opportunities. *Social Science & Medicine*, 73, 6, 793-800.

Kahan, D., Jenkins-Smith, H. & Braman, D. (2011). Cultural cognition of scientific consensus. *Journal of Risk Research*, 14, 2, 147-174.

Kahlbaum, K. (1882). Über cyclisches Irresein. *Der Irrenfreund*, 10, 145-157.

Kavanaugh, K., & Ayres, L. (1998). "Not as bad as it could have been": Assessing and mitigating harm during research on sensitive topics. *Research in Nursing and Health,* 21, 91-97.

Keehner, M., Mayberry, L. & Fischer, M. (2011). Different clues from different views: The role of image format in public perceptions of neuroimaging results. *Psychonomic Bulletin & Review,* 18, 2, 422–428.

Kelly, P. (2012). The brain in the jar: A critique of discourses of adolescent brain development. *Journal of Youth Studies,* 15, 7, 944–959.

Kendall, T., Pilling, S., Tyrer, P., Duggan, C., Burbeck, R., Meader, N. & Taylor, C. (2009). Guidelines: Borderline and Antisocial Personality Disorders: Summary of NICE Guidance. *British Medical Journal*, 338, 7689, 293-295.

Kendell, R. (1968). *The classification of depressive illnesses* (No. 18). Oxford: University Press.

Keohane, K. & Petersen, A. (2013). *The Social Pathologies of Contemporary Civilization*. Farnham: Ashgate.

Keown, P., Holloway, F. & Kuipers, E. (2002). The prevalence of personality disorders, psychotic disorders and affective disorders amongst patients seen by a community mental health team in London. *Social Psychiatry and Psychiatric Epidemiology*, 37, 225–229.

Kermode, M., Bowen, K., Arole, S., Pathare, S. & Jorm, A. (2009). Attitudes to people with mental disorders: a mental health literacy survey in a rural area of Maharashtra, India. *Social psychiatry and psychiatric epidemiology*, 44, 12, 1087-1096.

Kessler, R. (2010). The prevalence of mental illness. In T. Scheid & T. N. Brown (Eds.), *A Handbook for the Study of Mental Health: Social Contexts, Theories, and Systems*. (2nd edition, pp.46-63). Cambridge: Cambridge University Press.

Kessler, R., Chiu, W., Demler, O. & Walters. E. (2005). ''Prevalence, Severity, and Comorbidity of 12-month DSM-IV Disorders in the National Comorbidity Survey Replication.'' *Archives of General Psychiatry*, 62, 617-27.

Khalidi, M. (1993) "Carving Nature at the Joints," *Philosophy of Science,* 60, 1, 100-113.

Killaspy, H. (2000). Prospective controlled study of psychiatric out-patient non-attendance: Characteristics and outcome. *The British Journal of Psychiatry*, 176, 2, 160–165.

King, C. (2001). Severe mental illness: managing the boundary of a CMHT. *Journal of Mental Health,* 10, 1, 75–86.

Kincaid, H. & Sullivan, J. (2014). *Classifying Psychopathology: Mental Kinds and Natural Kinds*. Cambridge, MA: The MIT Press.

Kirk, S. & Kutchins, H. (1992)*. The Selling of DSM: The Rhetoric of Science in Psychiatry*. New York: Aldine de Gruyter.

Kirmayer, L. J. (1988). Mind and body as metaphors: hidden values in biomedicine. In *Biomedicine Examined*, pp. 5793. Springer: Netherlands.

Kirmayer, L. J. (1994). Improvisation and authority in illness meaning. *Culture, Medicine and Psychiatry*, 18, 2, 183-214.

Kleinman, A., Eisenberg, L. & Good, B. (1978). Culture, illness, and care: clinical lessons from anthropologic and cross-cultural research. *Annals of Internal Medicine*, 88, 2, 251–8.

Klerman, G. L. (1981). The spectrum of mania. *Comprehensive Psychiatry*, 22, 1, 11-20.

Koerner, B. (2002). First you market the disease… then you push the pills to treat it. *The Guardian,* 30 July.

Koivisto, K., Janhonen, S., Latvala, E. & Väisänen, L. (2001). Applying ethical guidelines in nursing research on people with mental illness. *Nursing Ethics*, 8, 4, 328-339.

Kovack, M. (2009). *Indigenous Methodologies: Characteristics, conversations and contexts.* Toronto: University of Toronto Press.

Kraepelin, E. (1899). Psychiatrie, in Ein Lehrbuch fur Studirendeund Aertze. Barth, Leipzig (Translation S. Ayed), (1960). Canton, MA: Science History Publications.

Kraepelin, E. (1921). *Manic-depressive insanity and paranoia* (trans. M. Barclay). Edinburgh: Livingstone.

Krishnan, K. (2005). Psychiatric and medical comorbidities of bipolar disorder. *Psychosomatic Medicine.* 67, 1, 1-8.

Kruse, G. R., Rohland, B. M. & Wu, X. (2002). Factors associated with missed first appointments at a psychiatric clinic. *Psychiatric Services*, 53, 9, 1173–1176.

Kvaale, E., Haslam, N. & Gottdiener, W. (2013). The 'side effects' of medicalization: A meta-analytic review of how biogenetic explanations affect stigma, *Clinical Psychology Review*, 33, 782–794.

Kvaale, E., Gottdiener, W. & Haslam, N. (2013). Biogenetic explanations and stigma: A meta-analytic review of associations among laypeople. *Social Science & Medicine*, 96, 95-103.

Kylmä, J., Vehviläinen-Julkunen, K. & Lähdevirta, J. (1999). Ethical Considerations in a Grounded Theory Study on the Dynamics of Hope in HIV-Positive Adults and Their Significant. *Nursing Ethics*, *6*, 3, 224-239.

Laegsgaard, M., Kristensen, A., & Mors, O. (2009). Potential consumers' attitudes toward psychiatric genetic research and testing and factors influencing their intentions to test. *Genetic testing and molecular biomarkers*, *13*, 1, 57-65.

Laegsgaard, M., Stamp, A., Hall, E. & Mors, O. (2010). The perceived and predicted implications of psychiatric genetic knowledge among persons with multiple cases of depression in the family. *Acta Psychiatrica Scandinavica*, 122, 6, 470–480.

Laing, R. D. (1964). Schizophrenia and the family. *New Society*, 16, 14-17.

Lakoff, A. (2006). *Pharmaceutical reason: Knowledge and value in global psychiatry*. Cambridge University Press.

Lam, D. & Salkovskis, P. (2007). An experimental investigation of the impact of biological and psychological causal explanations on anxious and depressed patients' perception of a person with panic disorder. *Behaviour Research and Therapy*, 45, 2, 405–411.

Lam, D., Salkovskis, P. & Hogg, L. (2016). 'Judging a book by its cover': An experimental study of the negative impact of a diagnosis of borderline personality disorder on clinicians' judgements of uncomplicated panic disorder. *British Journal of Clinical Psychology*, 55, 3, 253-268.

Lam, D., Watkins, E., Hayward, P., Bright, J., Wright, K., Kerr, N., Parr-Davis, G. & Sham, P. (2003). A randomized controlled study of cognitive therapy for relapse prevention for bipolar affective disorder: outcome of the first year. *Archives of General Psychiatry*, 60, 2, 145-152.

Langer, E. & Abelson, P. (1974). A patient by any other name: clinician group difference in labelling bias. *Journal Consult Clinical Psychology*, 42, 4–9.

Larossa, R., Bennett, L. & Gelles, R. (1981). Ethical dilemmas in qualitative family research. *Journal of Marriage and the Family*, 43, 303-313.

Latimer, J. (1997). Giving patients a future: the constituting of classes in an acute medical unit. *Sociology of Health and Illness*, 19, 2, 160–185.

Latimer, J. (2000). Socialising disease: medical categories and inclusion of the aged. *The Sociological Review*, 48, 3, 383-407.

Lauber, C., Nordt, C., Falcato, L. & Rössler, W. (2004). Factors influencing social distance toward people with mental illness. *Community mental health journal*, *40*, 3, 265-274.

Laurila, J. (1997). Promoting research access and informant rapport in corporate settings: Notes from research on a crisis company. *Scandinavian Journal of Management*, 13, 4, 407-418.

Lebowitz, M. (2014). Biological conceptualizations of mental disorders among affected individuals: A review of correlates and consequences. *Clinical Psychology: Science and Practice*, 21, 1, 67-83.

Lebowitz, M. & Ahn, W. (2012). Combining biomedical accounts of mental disorders with treatability information to reduce mental illness stigma. *Psychiatric Services*, 63, 496–499.

Lebowitz, M., Ahn, W. & Nolen-Hoeksema, S. (2013). Fixable or fate? Perceptions of the biology of depression. *Journal of consulting and clinical psychology*, 81, 3, 518.

Lebowitz, M., Pyun, J. & Ahn, W. (2014). Biological explanations of generalized anxiety disorder: effects on beliefs about prognosis and responsibility. *Psychiatric Services*, 65, 4, 498-503.

Lebowitz, M., Rosenthal, J. & Ahn, W. (2016). Effects of biological versus psychosocial explanations on stigmatization of children with ADHD. *Journal of Attention Disorders*, 20, 3, 240-250.

Lee, S. & Mysyk, A. (2004). The medicalization of compulsive buying. *Social Science and Medicine,* 58*,* 9*,* 1709–18*.*

Lee, R. & Renzetti, C. (1990). The problems of researching sensitive topics. *American Behavioral Scientist,* 33, 510-528.

Lee, A., Laurent, S., Wykes, T., Andren, K., Bourassa, K. & McKibbin, C. (2014). Genetic attributions and mental illness diagnosis: effects on perceptions of danger, social

distance, and real helping decisions. *Social psychiatry and psychiatric epidemiology*, 49, 5, 781-789.

Leech, N. & Onwuegbuzie, A. (2007). An array of qualitative data analysis tools: A call for data analysis triangulation. *School Psychology Quarterly*, 22*, 4, 557.

Leonhard, K. (1959). *Die Aufteilung der endogenen Psychoses*. Akademie Verlag: Berlin.

Liamputtong, P. & Ezzy, D. (2005). *Qualitative Research Methods*. South Melbourne: Oxford University Press.

Lillrank, A. (2003). Back pain and the resolution of diagnostic uncertainty in illness narratives. *Social Science and Medicine*, 57, 6, 1045–54.

Lincoln, T., Arens, E., Berger, C. & Rief, W. (2008). Can anti-stigma campaigns be improved? A test of the impact of biogenetic vs psychosocial causal explanations on implicit and explicit attitudes to schizophrenia. *Schizophrenia Bulletin*, 34, 984–994.

Link, B., Phelan, J., Bresnahan, M., Stueve, A., & Pescosolido, B. (1999). Public conceptions of mental illness: labels, causes, dangerousness, and social distance. *American Journal of Public Health*, 89, 9, 1328-1333.

Link, B. & Phelan, J. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27, 1, 363-385.

Lipson, J. (1994). Ethical issues in ethnography. In J. M. Morse (Ed.), *Critical issues in qualitative research methods*, pp. 333-355. Thousand Oaks, CA: Sage.

Lofland, J. & Lofland, J. (1995). *Analyzing Social Settings: A Guide to Qualitative Observation and Analysis.* Belmont: Wadsworth Publishing.

Lofland, J., Snow, D., Anderson, L., & Lofland, L. (2006). *Analyzing Social Settings: A Guide to Qualitative Observation and Analysis* (Belmont, CA: Wadsworth/Thomson Learning).

Luhrmann, T. (2000). *Of two minds: The growing disorder in American psychiatry*. Alfred A. Knopf.

Lüllmann, E., Berendes, S., Rief, W. & Lincoln, T. (2011). Benefits and harms of providing biological causal models in the treatment of psychosis — an experimental study. *Journal of Behavior Therapy and Experimental Psychiatry*, 42, 447–453.

Lupton, D. (1997). Consumerism, reflexivity and the medical encounter. *Social Science & Medicine*, *45*, 3, 373-381.

Madill, A. (2015). Conversation analysis and psychotherapy process research. In *Psychotherapy Research* (pp. 501-515). Springer, Vienna.

Madison, D. S. (2012). *Critical Ethnography: Method, Ethics and Performance*. Sage: Thousand Oaks, CA.

Magliano, L., De Rosa, C., Fiorillo, A., Malangone, C. & Maj, M. (2004). Perception of patients' unpredictability and beliefs on the causes and consequences of schizophrenia: a community survey. *Social Psychiatry and Psychiatric Epidemiology*, 39, 410–416.

Malla, A., Joober, R. & Garcia, A. (2015). "Mental illness is like any other medical illness": a critical examination of the statement and its impact on patient care and society. *Journal of Psychiatry & Neuroscience*, 40, 3, 147.

Malone, S. (2003). Ethics at Home: Informed Consent in Your Own Backyard. *Qualitative Studies in Education*, 16, 6, 797–815.

Malterud, K. (2005). Humiliation instead of care? *Lancet*, 9488, 785–6.

Markham, D. (2003). Attitudes towards patients with a diagnosis of 'borderline personality disorder': Social rejection and dangerousness. *Journal of Mental Health*, 12, 6, 595-612.

Martin, E. (2007). *Bipolar Expeditions: Mania and Depression in American Culture.* Princeton, NJ: Princeton University Press.

Martin, J., Pescosolido, B. & Tuch, S. (2000). Of fear and loathing: The role of "disturbing behavior," labels, and causal attributions in shaping public attitudes toward people with mental illness. *Journal of Health Social Behaviour*, 41, 208–223.

Martin, J., Pescosolido, B., Olafsdottir, S. & McLeod, J. (2007). The construction of fear: Americans' preferences for social distance from children and adolescents with mental health problems. *Journal of Health and Social Behaviour*, 48, 50–67.

Martin, J. & Frost, P. (1996). The Organizational culture war games: A struggle for intellectual dominance. In Clegg, S., Hardy, C. & Nord, W. (Eds.). Handbook of Organizational Studies (pp. 599-619). Thousand Oaks, CA: Sage.

Marwaha, S., Sal, N. & Bebbington, P. (2016). 'Chapter 9: Bipolar disorder'. In S. McManus, P. Bebbington, R. Jenkins & T. Brugha (Eds.) *Mental health and wellbeing in England: Adult Psychiatric Morbidity Survey 2014*. Leeds, NHS Digital.

McCabe, R., & Priebe, S. (2004). Explanatory models of illness in schizophrenia: comparison of four ethnic groups. *The British Journal of Psychiatry*, 185, 1, 25-30.

McCabe, D. & Castel, A. (2008). Seeing is believing: The effect of brain images on judgments of scientific reasoning. *Cognition,* 107, 1, 343–352.

McElroy, S., Altshuler L., Suppes, T., Keck, P. Jr, Frye, M., Denicoff, K., Nolen, W., Kupka R., Leverich, G., Rochussen, J., Rush, A. & Post, R. (2001). Axis I psychiatric comorbidity and its relationship to historical illness variables in 288 patients with bipolar disorder. *American Journal of Psychiatry*, 158, 3, 420-6.

McEvoy, P. & Richards, D. (2007). Gatekeeping access to community mental health teams: A qualitative study. *International Journal of Nursing Studies*, 44, 3, 387–395.

McEvoy, P., Richards, D. & Owen, J. (2000). Selective access: prioritizing referrals at the primary care/community mental health team interface. *Clinical Effectiveness in Nursing*, 4, 163–172.

McLeod, J. (1997). *Narrative and Psychotherapy*. London: Sage.

McPherson, S. & Armstrong, D. (2006). Social determinants of diagnostic labels in depression. *Social Science & Medicine*, 62, 1, 50-58

McWade, V, Milton, D. & Beresford, P. (2015). Mad Studies and neurodiversity: a dialogue. *Disability & Society,* 30, 2, 305-309.

Mehta, S. & Farina, A. (1997). Is being 'sick' really better? Effect of the disease view of mental disorder on stigma. *Journal of Social and Clinical Psychology*, 16, 4, 405–419.

Meiser, B., Mitchell, P., McGirr, H., Van Herten, M., & Schofield, P. (2005). Implications of genetic risk information in families with a high density of bipolar disorder: An exploratory study. *Social Science & Medicine*, 60, 109–118.

Mendelson, G. (2003). Homosexuality and psychiatric nosology. *Australian and New Zealand Journal of Psychiatry*, 37, 6, 678–83.

Michalak, E., Livingston, J., Hole, R., Suto, M., Hale, S. & Haddock, C. (2011). It's something that I manage but it is not who I am: reflections on internalized stigma in individuals with bipolar disorder. *Chronic Illness,* 7, 209–224.

Miklowitz, D. (2009). Group psychoeducation increases time to recurrence in stabilised bipolar disorders. *Evidence Based Mental Health*, 12, 110.

Miresco, M. & Kirmayer, L. (2006). The persistence of mind-brain dualism in psychiatric reasoning about clinical scenarios. *American Journal of Psychiatry*, 163, 5, 913-918.

Mitchell, A. & Selmes, T. (2007). A comparative survey of missed initial and follow-up appointments to psychiatric specialties in the United Kingdom. *Psychiatric Services*, 58, 6, 868–871.

Mitchell, A. & Selmes, T. (2007). Why don't patients attend their appointments? Maintaining engagement with psychiatric services. *Advances in Psychiatric Treatment*, 13, 6, 423–434.

Mol, A. (2002). *The Body Multiple: Ontology in Medical Practice*. Durham: NC Duke University press.

Moncrieff, J. (2009). A critique of the dopamine hypothesis of schizophrenia and psychosis. *Harvard review of psychiatry*, 17, 3, 214-225.

Moreno, C., Laje, G., Blanco, C., Jiang, H., Schmidt, A., & Olfson, M. (2007). National trends in the outpatient diagnosis and treatment of bipolar disorder in youth. *Archive of General Psychiatry*, 64, 1032-1039.

Morse, J. & Field, P. (1995). *Qualitative Research Methods for Health Professionals.* Thousand Oaks, CA: Sage.

Morselli, P. & Elgie, R. (2003). GAMIAN Europe. GAMIANEurope/ BEAM survey I— global analysis of a patient questionnaire circulated to 3450 members of 12 European advocacy groups operating in the field of mood disorders. *Bipolar Disorder*, 5, 265–78.

Moyle, W. (2002). Unstructured interviews: challenges when participants have a major depressive illness. *Journal of Advanced Nursing*, 39, 3, 266-273.

Moynihan, R. & Cassels, A. (2005). *Selling Sickness: How the world's biggest drug companies are turning us all into patients.* New York: Nation Books.

Murray, R. (2017). Mistakes I have made in my research career. *Schizophrenia bulletin*, 43, 2, 253-256.

National Institute for Health and Clinical Excellence (NICE) (2014). *Bipolar disorder (update): the management of bipolar disorder in adults, children and adolescents in primary and secondary care.* (Clinical Guideline 185). London: NICE.

National Institute for Health and Care Excellence (NICE) (2014). *Bipolar disorder: assessment and management*, (Clinical Guideline 185). London: NICE.

Nayani, T. & David, A. (1996). The auditory hallucination: a phenomenological survey, *Psychological Medicine*, 26, 177–189.

Nehls, N. (1998). Borderline personality disorder: Gender stereotypes, stigma, and limited system of care. *Issues in Mental Health Nursing*, 19, 2, 97-112.

Nelson, R. & Merz, J. (2002). Voluntariness of consent for research: an empirical and conceptual review. *Medical Care*, 40, 9, 5-69.

North, C. & Suris, A. (2017). Advances in Psychiatric Diagnosis: Past, Present, and Future, *Behavioral Sciences*, 7, 2, 27.

Novas, C. & Rose, N. (2000). Genetic risk and the birth of the somatic individual. *Economy and Society*, 29, 4, 485–513.

Novas, C. (2006). The political economy of hope: Patients' organizations, science and biovalue. *BioSocieties*, 1, 3, 289-305.

O'Connor, C., Rees, G. & Joffe, H. (2012). Neuroscience in the public sphere. *Neuron*, 74, 2, 220–226.

O'Connor, C. & Joffe, H. (2013). How has neuroscience affected lay understandings of personhood? A review of the evidence. *Public Understanding of Science,* 22, 3, 254-268.

Oeye, C., Bjelland, A., & Skorpen, A. (2007). Doing participant observation in a psychiatric hospital—Research ethics resumed. *Social Science & Medicine*, 65, 11, 2296-2306.

Okumus, F., Altinay, L. & Roper, A. (2007). Gaining access for research: reflections from experience. *Annals of Tourism Research*, 34, 1, 7-26.

O'Malley, P. (1992). 'Risk, Power and Crime Prevention'. *Economy and Society*, 21, 252-75.

O'Neill, O. (2006). 'Rethinking Informed Consent', 2006 Athena Lecture, Imperial College, May.

Onyett, S. Standen, R. & Peck, E. (1997). The challenge of managing community mental health teams. *Health and Social Care in the Community*, 5, 1, 40-47.

Ortega, F. (2009). The cerebral subject and the challenge of neurodiversity. *BioSocieties,* 4, 4, 425–445.

Osborn, D., & Fulford, K. (2003). Psychiatric research: What ethical concerns do LRECs encounter? A postal survey. *Journal of Medical Ethics*, 29, 1, 55–56.

Oulis, P., Mamounas, J., Hatzimanolis, G. & Christodoulou, G. (1997). A clinical study of auditory hallucinations. *Psychiatriki*, 8, 177–186.

Pekkala, E. & Merinder, L. (2002). Psychoeducation for schizophrenia. *Cochrane Database Systematic Review,* 2, 1-41.

Parikh, S., Hawke, L., Velyvis, V., Zaretsky, A., Beaulieu, S., Patelis-Siotis, I., MacQueen, G., Young, L., Yatham, L. & Cervantes, P. (2015). Combined treatment: impact of optimal psychotherapy and medication in bipolar disorder. *Bipolar disorders*, 17, 1, 86-96.

Parens, E., & Johnston, J. (2010). Controversies concerning the diagnosis and treatment of bipolar disorder in children. *Child and Adolescent Psychiatry and Mental Health*, *4*, 1, 9.

Parker, G. (2000). Diagnosis, classification and differential diagnosis of the mood disorders. In M. Gelder, et al. (Eds.), *The New Oxford textbook of psychiatry*. Oxford: Oxford University Press.

Papadopoulos, D. (2011). The imaginary of plasticity: Neural embodiment, epigenetics and ecomorphs. *The Sociological Review,* 59, 3, 432–456.

Parsons, T. (1951). Illness and the role of the physician: a sociological perspective, *American Journal of Orthopsychiatry*, 21, 452–60.

Partridge, B., Bell, S., Lucke, J., Yeates, S. & Hall, W. (2011). Smart drugs 'as common as coffee': Media hype about neuroenhancement. *PLoS ONE*, 6, 11, e28416.

Pasquinelli, E. (2012). Neuromyths: Why do they exist and persist? *Mind, Brain, and Education,* 6, 2, 89–96.

Patai, D. (1991). 'US Academics and Third World Women: Is Ethical Research Possible?'. In S. Gluck & D. Patai (Eds.), *Women's Words: The Feminist Practice of Oral History.* London: Routledge.

Peck, E. (2004). New Labour's modernization in the public sector: A Neo-Durkheimian approach and the case of mental health services. *Public Administration*, 82, 1, 83-108.

Peck, E., & Hills, B. (2000). Provider arrangements for mental health services in 'The New NHS,' *Health and Social Care in the Community*, 8, 5, 325-335.

Peeters, H. (1996). The historical vicissitudes of mental diseases: Their character and treatment. In C. F. Graumann & K. J. Gergen (Eds.), *Historical dimensions of psychological discourse*, pp. 204-226. New York: Cambridge University Press.

Pescosolido, B., Martin, J., Long, J., Medina, T., Phelan, J. & Link, B. (2010). 'A disease like any other'? A decade of change in public reactions to schizophrenia, depression, and alcohol dependence. *The American Journal of Psychiatry*, 167, 11, 1321–1330.

Petersen, A. (2011). Authentic self-realization and depression. *International Sociology*, 26, 5-24.

Petersen, A. & Lupton, D. (1996). *The new public health: Health and self in the age of risk*. Sage Publications, Inc.

Phelan, J., Bromet, E. & Link, B. (1998). Psychiatric illness and family stigma. *Schizophrenia Bulletin*, 24, 115–126.

Phelan, J., Cruz-Rojas, R., & Reiff, M. (2002). Genes and stigma: The connection between perceived genetic etiology and attitudes and beliefs about mental illness. *Psychiatric Rehabilitation Skills*, 6, 2, 159-185.

Phelan, J. (2005). Geneticization of deviant behavior and consequences for stigma: The case of mental illness. *Journal of Health and Social Behavior*, 46, 307–322.

Phelan, J., Yang, L. & Cruz-Rojas, R. (2006). Effects of attributing serious mental illnesses to genetic causes on orientations to treatment. *Psychiatric Services,* 57, 382–7.

Pickersgill, M., Cunningham-Burley, S. & Martin, P. (2011) Constituting neurologic subjects: Neuroscience, subjectivity and the mundane significance of the brain. *Subjectivity*, 4, 3, 346–365.

Pilgrim, D. (2007). The survival of Psychiatric Diagnosis. *Social Science & Medicine,* 65, 3, 536-547.

Pilgrim, D. (2009). Recovery from Mental Health Problems: Scratching the Surface Without Ethnography. *Journal of Social Work Practice*, 23, 4, 475-487.

Pinel, P. (1809/2008) Medico-Philosophical Treatise on Mental Alienation (Trans G. Hickish, D., Healy, D. and Charland, L.), Wiley-Blackwell, Chichester.

Pirutinsky, S., Rosen, D., Safran, R., & Rosmarin, D. (2010). Do medical models of mental illness relate to increased or decreased stigmatization of mental illness among orthodox Jews? *The Journal of nervous and mental disease*, 198, 7, 508-512.

Pitts-Taylor, V. (2010). The plastic brain: Neoliberalism and the neuronal self. *Health*, 14, 6, 635–652.

Pitschel-Walz, G., Bäuml, J., Bender, W., Engel, R., Wagner, M., & Kissling, W. (2006). Psychoeducation and compliance in the treatment of schizophrenia: results of the Munich Psychosis Information Project Study. *The Journal of Clinical Psychiatry, 67, 3, 443-52.*

Pomerantz, A. (1986). Extreme case formulations: A way of legitimizing claims. *Human studies*, 9, 2-3, 219-229.

Potter, J. & Edwards, D. (1990). Nigel Lawson's tent: Discourse analysis, attribution theory and the social psychology of fact. *European Journal of Social Psychology*, 20, 405-424.

Potter, J. (2002). Two kinds of natural. *Discourse Studies*, 4, 4, 539-542.

Quirk, A., Chaplin, R., Lelliott, P. & Seale, C. (2012). How pressure is applied in shared decisions about antipsychotic medication: A conversation analytic study of psychiatric outpatient consultations. *Sociology of Health and Illness*, 34, 1, 95–113.

Rabinow, P. (1992). Artificiality and enlightenment: From sociobiology to biosociality. In J. Crary & S. Kwinter (Eds.), *Incorporations* (pp.234–252). New York: Zone Books.

Racine, E., Waldman, S., Rosenberg, J. & Illes, J. (2010). Contemporary neuroscience in the media. *Social Science & Medicine*, 71, 4, 725–733.

Raison, C. & Miller, A. (2011). Is Depression an Inflammatory Disorder? *Current Psychiatry Representation.* 13, 6, 467–475.

Ramcharan, P. & Cutliffe, J. (2001). 'Judging the Ethics of Qualitative Research: Considering the "Ethics as Process" Model'. *Health and Social Care in the Community* 9, 6, 358–66.

Rampton, B. (2006). *Language in Late Modernity: Interaction in an Urban School.* Cambridge, UK: Cambridge University Press.

Rapp, R. (2011). A child surrounds this brain: The future of neurological difference according to scientists, parents and diagnosed young adults. In M. Pickersgill & I. van Keulen (Eds.) *Sociological Reflections on the Neurosciences* (pp.3-26). Bingley: Emerald.

Read, J., Haslam, N., Sayce, L., & Davies, E. (2006). Prejudice and schizophrenia: A review of the 'mental illness is an illness like any other' approach. *Acta Psychiatrica Scandinavica*, 114, 303–318.

Read, J. & Harré, N. (2001). The role of biological and genetic causal beliefs in the stigmatisation of 'mental patients'. *Journal of Mental Health*, 10, 2, 223–235.

Read, J., Bentall, R., & Sanders, P. (2010). *A straight-talking introduction to the causes of mental health problems*. PCCS Books.

Regier, D., Farmer, M., Rae, D., Locke, B, Keith, S., Judd, L., & Goodwin, F. (1990). Comorbidity of mental disorders with alcohol and other drug abuse. Results from the Epidemiologic Catchment Area (ECA) Study. *JAMA*, 264, 19, 2511-8.

Regier, D., Kuhl, E. & Kupfer, D. (2013). The DSM-5: Classification and criteria changes, *World Psychiatry*, 12, 2, 92–98.

Richardson, S., & McMullan, M. (2007). Research Ethics in the UK: What can sociology learn from health? *Sociology*, 41, 6, 1115-1132.

Riley, S., Thompson, J., & Griffin, C. (2010). Turn on, tune in, but don't drop out: The impact of neo-liberalism on magic mushroom users'(in) ability to imagine collectivist social worlds. *International Journal of Drug Policy*, 21, 6, 445-451.

Rodriguez, P. (2006) Talking brains: A cognitive semantic analysis of an emerging folk neuropsychology. *Public Understanding of Science,* 15, 3, 301–330.

Rogers, A. & Pilgrim, D. (1997). The contribution of lay knowledge to the understanding and promotion of mental health. *Journal of Mental Health*, 6, 1, 23-35.

Rogers, A. & Pilgrim, D. (2010). A sociology of mental illness. Berkshire, UK: McGraw-Hill.

Rose, N. (1996). Power and subjectivity: Critical history and psychology. *Historical dimensions of psychological discourse*, 103-124.

Rose, N. (1998). *Inventing Our Selves: Psychology, Power and Personhood*. Cambridge: Cambridge University Press.

Rose, N. (2007). *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the twenty-first century.* Princeton: Princeton University Press.

Rose, N. & Abi-Rached, J. (2013). *Neuro: The New Brain Sciences and The Management of The Mind*. Princeton: Princeton University Press.

Rosecrance, J. (1985) Compulsive Gambling and the Medicalization of Deviance, *Social Problems*, 32, 3, 275–84.

Rosenberg, C. E. (2002). The tyranny of diagnosis: Specific entities and individual experiences. *Milbank Quarterly*, 80, 2, 237–260.

Rosenberg, C. E. (2006). Contested Boundaries. Psychiatry, Disease, and Diagnosis, *Perspectives in Biology and Medicine,* 49, 3, 407-424.

Roth, J. & Douglas, D. (1983). *No Appointment Necessary: The Hospital Emergency Department in the Medical Services World.* New York: Irvington.

Roy-Chowdhury, S. (2003). Knowing the unknowable: What constitutes evidence in family therapy? *Journal of Family Therapy*, 25, 64–85.

Royal College of Psychiatrists and National Institute for Mental Health in England (2005). *New Ways of Working for Psychiatrists: Enhancing Effective, Person-centred Services through New Ways of Working in Multidisciplinary and Multi-agency Contexts. Final Report 'But Not the End of the Story'*. London: Department of Health.

Royal College of Psychiatrists (2011). *Ethics of psychiatric research.* Executive of the Faculty of Academic Psychiatry of the Royal College of Psychiatrists Position Statement PS02/2011. London: Royal College of Psychiatrists.

Rubin, H. & Rubin, I. (1995). Qualitative interviewing: A method to the madness. Thousand Oaks: Sage.

Rüsch, L., Kanter, J., Brondino, M., Weeks, C. & Bowe, W. (2010). Biomedical stigma reduction programs produce negative but transient effects on a depressed low-income community sample. *Journal of Social and Clinical Psychology*, 29, 1020–1030.

Rüsch, N., Todd, A., Bodenhausen, G. & Corrigan, P. (2010). Do people with mental illness deserve what they get? Links between meritocratic worldviews and implicit versus explicit stigma. *European Archives of Psychiatry and Clinical Neuroscience*, 260, 8, 617–625.

Saldana, J. (2009). *The Coding Manual for Qualitative Researchers*. London: Sage Publications.

Schnittker, J. (2008). An uncertain revolution: Why the rise of a genetic model of mental illness has not increased tolerance. *Social Science & Medicine*, 67, 9, 1370–1381.

Schomerus, G., Matschinger, H. & Angermeyer, M. (2006). Preferences of the public regarding cutbacks in expenditure for patient care. *Social Psychiatry and Psychiatric Epidemiology*, 41, 5, 369-377.

Schomerus, G., Matschinger, H., & Angermeyer, M. (2013). Continuum beliefs and stigmatizing attitudes towards persons with schizophrenia, depression and alcohol dependence. *Psychiatry Research*, 209, 3, 665-669.

Schrader, S., Jones, N. & Shattell, M. (2013). Mad pride: reflections on socio-political identity and mental diversity in the context of culturally competent psychiatric care. *Issues in Mental Health Nursing,* 34, 1, 62–4.

Schulze, B. *(2007).* Stigma and mental health professionals: a review of the evidence on an intricate relationship. *International Review of Psychiatry*, 19*, 137–155.*

Schwartz, B. (2004). The Tyranny of Choice, *Scientific American*, 290, 70-75.

Scott, M. & Lyman, S. (1968). Accounts. *American Sociological Review*, 46-62.

Scott, W. (1990). PTSD in DSM-III: A case in the politics of diagnosis and disease. *Social problems*, *37*, 3, 294-310.

Sears, P., Pomerantz, A., Segrist, D. & Rose, P. (2011). Beliefs about the biological (vs. nonbiological) origins of mental illness and the stigmatization of people with mental illness. *American Journal of Psychiatric Rehabilitation*, 14, 2, 109-119.

Severus, E. & Bauer, M. (2013). Diagnosing bipolar disorders in DSM-5, *International Journal of Bipolar Disorder*, 1, 14.

Shaw, I., Smith, K., Middleton, H. & Woodward, L. (2005). A letter of consequence: referral letters from general practitioners to secondary mental health services. *Qualitative Health Research*, 15, 1, 116-128.

Shepherd, D., Insole, L., McAllister-Williams, R. & Ferrier, I. (2009). Are specialised affective disorder services useful? *Psychiatric Bulletin,* 33, 41-43.

Shorter, E. (2009). *Before Prozac. The Troubled History of Mood Disorders in Psychiatry.* Oxford: Oxford University Press.

Shorter, E. & Tyrer, P. (2003). Separation of anxiety and depressive disorders: Blind alley in psychopharmacology and classification of disease, *British Medical Journal*, 327, 158-160.

Schweitzer, N., Saks, M., Murphy, E., Roskies, A., Sinnott-Armstrong, W. & Gaudet, L. (2011). Neuroimages as evidence in a mens rea defense: No impact. *Psychology, Public Policy, and Law*, 17, 3, 357.

Silverman, D. (1993). *Interpreting Qualitative Data Sage Publications*. London: Sage.

Simpson, A., Miller, C. & Bowers, L. (2003). The history of the Care Programme Approach in England: where did it go wrong? *Journal of Mental Health*, 12, 5, 489-504.

Sin, C. (2005). 'Seeking Informed Consent: Reflections on Research Practice', *Sociology,* 39, 2, 277–94.

Singh, I. (2011). A disorder of anger and aggression: Children's perspectives on attention deficit/hyperactivity disorder in the UK. *Social Science & Medicine,* 73, 6, 889–896.

Smith, D., Jones, I. & Simpson, S. (2010). *Psychoeducation for bipolar disorder*. Advances in Psychiatric Treatment, 16, 2, 147-154.

Soal, J. & Kottler, A. (1996). Damaged, deficient or determined? Deconstructing narratives in family therapy. *South African Journal of Psychology*, 26, 123–134.

Soobrayan, V. (2003). 'Ethics, Truth and Politics in Constructivist Qualitative Research', *Westminster Studies in Education,* 26, 2, 107–23.

Snowden, C., Garcia, J. & Elbourne, D. (1997). Understanding randomization: parental responses to the allocation of alternative treatments in a clinical trial involving their critically ill newborn babies. *Social Science & Medicine*, *45*, 1337-1355.

Spitzer, R. (2011). Psychological warfare: The DSM-5 debate. *HCPLive*, 25, 248-250.

Spivak, G. (1996 [1985]) "Subaltern Studies. Deconstructing Historiography", in D. Landry & G. MacLean (Eds.). *The Spivak Reader.* London: Routledge.

Spivak, G. (1990). The Post-colonial critic: Interviews, strategies, dialogue. In S. Harasym (Ed.). New York: Routledge.

Stone, B. (2004). Towards a writing without power: notes on the narration of madness. *Auto/Biography,* 12, 16-33.

Stone, M. (1985). Shellshock and the psychologists. In W. Bynum, R. Porter, M. Shepherd (Eds.), *The Anatomy of Madness*. Tavistock: London.

Strauss, A. & Corbin, J. (1990). 'Open coding', in *The Basics of qualitative research: Grounded theory procedures and techniques* (pp. 101-121). Newbury Park: Sage.

Sulzer, S. (2015). Does "difficult patient" status contribute to de facto demedicalization? The case of borderline personality disorder. *Social Science & Medicine*, 142, 82-89.

Szasz, T. (1972). *The Myth of Mental Illness*. Granada: St. Albans.

Taylor, V. (2016). *Rock-a-by baby: Feminism, self-help and postpartum depression*. London: Routledge.

Tekin, S. (2014). The missing self in Hacking's looping effects. In H. Kincaid & J. Sullivan (Eds.), *Classifying Psychopathology: Mental Kinds and Natural Kinds* (pp. 227-256). Cambridge, MA: The MIT Press.

The Lancet Psychiatry (2018). Breaking the ice. *The Lancet. Psychiatry*, *5*, 1, 1.

Tiefer, L. (1996). The medicalization of sexuality: Conceptual, normative, and professional issues. *Annual Review of Sex Research*, 7, 1, 252-282.

Tiefer, L. (2006) Female sexual dysfunction: a case study of disease mongering and activist resistance, *PLoS Medicine*, 3, 4, 178.

Timimi, S. (2009). Why diagnosis of ADHD has increased so rapidly in the West: A cultural perspective. In S. Timimi & J. Leo (Eds.), *Rethinking ADHD: From Brain to Culture* (pp. 133-159). Basingstoke: Palgrave Macmillan.

Timimi, S. (2014). No more psychiatric labels: Why formal psychiatric diagnostic systems should be abolished. *International Journal of Clinical and Health Psychology*, 14, 3, 208-215.

Tsuang, M., Farrone, S. & Fleming, J. (1985). Familial transmission of major affective disorders: is there evidence supporting the distinction between unipolar and bipolar disorders? *British Journal of Psychiatry*, 146, 268-271.

Tyrer, P. (2013). *Models for mental disorder* (5th Ed.). John Wiley & Sons.

Van der Sanden, R., Stutterheim, S., Pryor, J., Kok, G. & Bos, A. (2014). Coping with stigma by association and family burden among family members of people with mental illness. *Journal of Nervous and Mental Disease*, 202, 10, 1–9.

Van Os, J. (2016). " Schizophrenia" does not exist. *BMJ: British Medical Journal (Online)*, 352.

Van t' Veer, J., Kraan, H., Drosseart, S. & Modde, J. (2006). Determinants that shape public attitudes towards the mentally ill: a Dutch public study. *Social Psychiatry Psychiatric Epidemiology*, 41, 310–317.

Vidal, F. (2009). Brainhood, anthropological figure of modernity. *History of the Human Sciences,* 22, 1, 5–36.

Visser, J. & Jehan, Z. (2009). ADHD: A scientific fact or a factual opinion? A critique of the veracity of Attention Deficit Hyperactivity Disorder. *Emotional and behavioural difficulties*, 14, 2, 127-140.

Voronka, J. (2017). The Politics of "people with lived experience": Experiential Authority and the Risks of Strategic Essentialism. *Philosophy, Psychiatry, & Psychology*, 23, 3, 189–201.

Wagner, W., Holtz, P. & Kashima, Y. (2009). Construction and deconstruction of essence in representing social groups: Identity projects, stereotyping, and racism. *Journal for the Theory of Social Behaviour*, 39, 3, 363-383.

Wakefield, J. (2010). Misdiagnosing normality: Psychiatry's failure to address the problem of false positive diagnoses of mental disorder in a changing professional environment. *Journal of Mental Health*, 19, 4, 337-351.

Wakefield, J. & First, M. (2012). Validity of the bereavement exclusion to major depression: does the empirical evidence support the proposal to eliminate the exclusion in DSM-5? *World Psychiatry,* 11, 3–10.

Wakefield, J. (2016). Diagnostic issues and controversies in DSM-5: return of the false positives problem. *Annual review of clinical psychology*, *12*, 105-132.

Walker, I. & Read, J. (2002). The differential effectiveness of psychosocial and biogenetic causal explanations in reducing negative attitudes toward "mental illness". *Psychiatry: Interpersonal and Biological Processes*, *65*, 4, 313-325.

Walter, H. (2013). The third wave of biological psychiatry. *Frontiers in Psychology*, 4, 582.

Walsh, R. (2011). Lifestyle and mental health. *American Psychologist*, *66*, 7, 579.

Ware, N. (1992). Suffering and the Social Construction of Illness: The Delegitimation of Illness Experience in Chronic Fatigue Syndrome, *Medical Anthropology Quarterly*, 6, 4, 347-361

Ware, N. & Kleinman, A. (1992) Culture and somatic experience: The social course of illness in neurasthenia and chronic fatigue syndrome, *Psychosomal Medicine.* 54, 5, 546–560

Ware, N., Lachicotte, W., Kirschner, S., Cortes, D. & Good, B. (2000). Clinician Experiences of Managed Mental Health Care: A Rereading of the Threat. *Medical Anthropology Quarterly,* 14, 1, 3-27.

Welsh Assembly Government (2010). *The Role of Community Mental Health Teams in Delivering Community Mental Health Services: Interim Policy Implementation Guidance and Standards* (July, 2010). Cardiff: Welsh Assembly Government.

Weiner, B., Perry, R. & Magnusson, J. (1988). An attributional analysis of reactions to stigmas. *Journal of Personality and Social Psychology*, 55, 738–748.

Weiner, T. (2011). The (un) managed self: paradoxical forms of agency in self-management of bipolar disorder. *Culture, Medicine, and Psychiatry*, 35, 4, 448.

Werner, A. & Malterud, K. (2003). It is hard work behaving as a credible patient: Encounters between women with chronic pain and their doctors, *Social Science & Medicine,* 57, 8, 1409–1419.

Wetherell, M. (2007). A step too far: Discursive psychology, linguistic ethnography and questions of identity. *Journal of Sociolinguistics*, 11, 5, 661-681.

White, M. & Epston, D. (1990). *Narrative Means to Therapeutic Ends.* New York: Norton.

White P., Rickards H. & Zeman A. (2012). Time to end the distinction between mental and neurological illnesses. *British Medical Journal*, 344.

Wiles, R., Heath, S., Crow, G. & Charles, V. (2005). *Informed Consent in Social Research: A Literature Review.* Southampton: ESRC National Centre for Research Methods.

Willig, C. (2012). *Qualitative interpretation and analysis in psychology*. UK: McGraw-Hill Education.

Wilson, M. (1993). DSM-III and the transformation of American psychiatry: a history. *American Journal of Psychiatry*, 150, 399-399.

Williams, B. & Healy, D. (2001) Perceptions of illness causation among new referrals to a community mental health team: ''explanatory model'' or ''exploratory map''? *Social Science & Medicine,* 53, 465–476.

Williams, G. (1984). The genesis of chronic illness: narrative re-construction. *Sociology of Health & Illness*, 6, 2, 175-200.

World Health Organization. (2013). *Guidelines for the management of conditions that are specifically related to stress*. World Health Organization.

Wulff, H. (1984). The causal basis of the current disease classification. In Nordenfolt, L. & Lindahl, B. (Eds.), *Health, Disease, and Causal Explanations in Medicine* (pp. 169-177). Dordrecht: Springer.

Yee, L., Korner, A., McSwiggan, S., Meares, R. & Stevenson, J. (2005) Persistent hallucinosis in borderline personality disorder. *Comprehensive Psychiatry*, 46, 2, 147–154.

Young, S., Bramham, J., Gray, K. & Rose, E. (2008). The experience of receiving a diagnosis and treatment of ADHD in adulthood. *Journal of Attention Disorders*, 11, 493-503.

Zachar, P. & Kendler, K. (2007). Psychiatric disorders: A conceptual taxonomy. *American Journal of Psychiatry*, 164, 4, 557–565.

Zachar, P. (2000). Psychiatric disorders are not natural kinds. *Philosophical Psychiatry & Psychology*, 7, 167-182.

Zaretsky, A., Segal, Z. & Gemar, M. (1999). Cognitive therapy for bipolar depression: a pilot study. *The Canadian Journal of Psychiatry*, 44, 5, 491-494.

Ziółkowska, J. (2011). The representation of illness manifestation during the first psychiatric interview with patients preliminarily diagnosed with depressive illness. *Polish Psychological Bulletin*, 42, 3, 123.

Zola, I. (1972). Medicine as an institution of social control, *Sociological Review*, 20, 4, 487-504.

Zola, I. (1983) Socio-Medical Inquiries: Recollections, Reflections, and Reconsiderations. Philadelphia: Temple University Press.

Appendix I: McPin Foundation Reviewer Feedback

Reviewer 1

What did you think of the proposal in general?
(e.g. Was it easy or not to understand? Is it an important area or not to research – and why? What is good about the proposal?)
The background for the research and motivation for conducting it is very relevant to the problems that exist in society today surrounding perception, communication and terminology of emotional breakdown/mental health issues. Gathering evidence from a number of secondary mental health sites and using a variety of types of settings should give researchers insight into any similarities and differences in the terminology and explanations used. The studies aim to gather information about how terminology/professional explanations is shaping the self-perception of the individual experiencing distress is important if professionals and society are to understand a bit more about patient's internal dialogue and self-talk. Not all people suffering mental health issues are able to articulate this information in a way that is easy for other's to understand. The study plans to gain the consent of both the professional and participant in the observations which is a valid ethical method. Interviewing the professional independent of the participant is also included so a different type of information can be gathered.

Specific queries for the research team
(e.g. What was unclear or did not make sense? What did you like about the proposal? Do you have any concerns?)
I do not see why it is limited to those diagnosed or suspected to have bipolar. Biploar has been likened by some to be a spectrum disorder (e.g. everyone is somewhere along the line or can identify with the symptoms of the disorder to some degree, it is just that those with a diagnoses or problem are towards the more severe end of that line).
Why is the method of recruiting participants limited to the professional's suggestion? Yes this more ethical for participants getting help from care settings but I am concerned about the long-term wellbeing of those that have a diagnoses of bipolar disorder or strongly think they might have it but are currently unknown or discharged from services. The study is in Wales. Will the findings be of benefit on a national scale? How will the research take into consideration the impact the professional environment is having on the behaviour and communication expressed by the participant?
Drawing on your lived experience perspective, is there anything you would have liked to have seen that was not in the proposal?
Yes if I was a participant I'd like the option of being independently interviewed by the researcher in my own setting e.g. home.
Is there anything you want to comment on from a research perspective (if you feel qualified to do so)

Reviewer 2

What did you think of the proposal in general?
(e.g. Was it easy or not to understand? Is it an important area or not to research – and why? What is good about the proposal?)

I like this proposal and think that this is both a valuable area of enquiry and potentially very helpful in teaching communications.

The proposal asks an intriguing and important question and researcher clearly understands context and why it is important.

Specific queries for the research team
(e.g. What was unclear or did not make sense? What did you like about the proposal? Do you have any concerns?)

Title: word involved is too weak and broad and has too many alternative meanings. If you look uo involved in thesaurus it leads to all sorts of interesting ideas about connection between explanations and identity. Need clearer wording such as "related to", "causal", contribute to shaping, etc.

Just a reflection on immediate response to introduction but I was left wondering if "stigma" needed deeper probing. How does a service user or carer experience stigma and is it the same experience for everyone. What is relationship between stigmatising behaviour and one's perception of being stigmatised? "and thus the amount of stigma they carry" is a problematic statement for me as I don't carry stigma I perceive that I have just experienced it. This perception may be skewed by my own locus of control and identity.

Drawing on your lived experience perspective, is there anything you would have liked to have seen that was not in the proposal?

There is still an issue around diagnosis. Although proposal discusses models it doesn't refer explicitly to those attributes of current models (biopsychosocial) that are based on service user centred approaches and actively reject diagnostic labelling. This causes immense distress in some circumstances to both servicer user and carer and is seen as both a power issue and a control of information issue.

Proposal discusses class, gender and ethnicity but I suspect age is a major variable as SMI, especially as onset is often in late teens early 20's, delays and distorts identity development. There may be a distinct difference between 20-25yr olds and 40-45 year olds. Age of onset and age of diagnosis may also need to be considered.

There is also an implicit assumption that it is service user/professional interaction that is the most powerful element in influencing. However, in an inpatient setting (if this study is about secondary care this will be most common setting) the most time is spent with other service users. As much stigmatisation can arise from attitudes of other service users as can from staff, carers and other associated professionals. Those further along pathway of a condition can attempt to "fill in" information communicated by professional care team. Sometimes it seems as if "the guy in the next bedroom" is more believable and a greater influence in terms of information giving than the more circumspect and cautious professional staff.

Is there anything you want to comment on from a research perspective (if you feel qualified to do so)

I didn't see anything in this proposal about analysis of data. For this study it is not safe to assure interviewing is a valid data collection technique until much more work is done on theoretical and analytical framework. For example this study looks, on the face of it as an ideal candidate for Phenomenological Analysis. This approach would encompass and deal with the researchers own bias. Sources of (research) bias do need to be explored (what are the biases in a study about bias!). For example audiotaping or videotaping interactions between research subjects and care team may provide much richer data. Interviewing and focus groups, without a pre-cursor framework, would be a waste of time and effort at the beginning of the study but may be useful later to test interim conclusions.

The data theory needs a little work to strengthen the whole proposal at the outset (even if it is just to propose a way to decide on theoretical approach at this time). Refer to "data collection" rather than "interviewing" and include exploration of two or three possible theoretical approaches for analysis within early stages of study.

Appendix II: Letter of Unfavourable Opinion from REC

08 October 2015

Dear Miss Lane

Study title:	**Exploring how explanatory models are framed, interpreted, and shape client identities within secondary mental health care settings**
REC reference:	**15/WA/0343**
Protocol number:	**1453-15**
IRAS project ID:	**179629**

The Wales REC 1 reviewed the above application at their meeting held on 06 October 2015. Thank you and Professor Hedgecoe for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Mrs Jagjit Sidhu, jagit.sidhu@wales.nhs.uk. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

The members of the Committee present decided to issue an unfavourable opinion for the following reasons:

The Committee noted that this was huge piece of work involving potentially vulnerable participants. The Committee discussed the application and all members were concerned as they were of the view that you were relatively inexperienced to conduct this study and raised concerns for your safety and wellbeing.

The Committee agreed that the application form and supporting documents were unnecessarily complex and lengthy, making it very difficult to understand the study.

The Committee was of the view that you should discuss the study with your supervisors and any resubmission should be less complicated and thoroughly thought out. Furthermore the Committee will be looking for an assurance from your supervisor that you are able to undertake the study without putting yourself or potential patients under undue distress.

The Committee was of the view that it was important that all potential participants are aware of their diagnosis prior to being contacted by yourself, as it would be very distressing to learn of their diagnosis from a third party. The Committee was not convinced by your clarification that all potential participants would be aware of their diagnosis prior to being recruited into the study and agreed that any resubmission should make this explicitly clear.

The Committee noted that the application did not provide information on how the research will be undertaken at the various Bipolar Education Programme Cymru groups throughout Wales and that you were also unsure of how the research will be undertaken at these locations. If you wish to carry out research at these locations in any future application, you should seek advice on how to do this and be clear on what you would be doing.

The Committee noted from Section A43 of the application form that data will be stored for 6-12 months? The Committee was of the view that this did not comply with the Data Protection Act and asked that this be considered in any resubmission.

The Committee was of the view that the patient names should not be included in the audio recording and that this should be confirmed in any resubmission.

The Committee was of the view that the title did not reflect the study and should be revised on all study documents.

The Committee agreed that the application form and supporting documents had not been provided as required using language easily understood by lay reviewers and should be revised.

The Committee made reference to the information documents and noted the following points:

The Committee was of the view that the whole of the information sheet was making assumptions about patient's knowledge and there was too much jargon. The information sheet should be rewritten in lay language. The Committee agreed that you should ask a service user and friend/colleague to read the information sheet for ease of use and clarity. Further guidance on producing information sheets can be found at http://www.hra.nhs.uk/documents/2013/09/information-sheet-and-consentform-guidance.pdf

The Client information sheet – What will happen if I don't want to carry on with the study – (part 2) should be revised to read '*It is up to you to decide to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive*'.

The Committee noted that point 4 of the consent form referred to data being shared with third parties. The Committee noted that the data will be deposited at the UK Data Archive (UKDA) as per agreement with ESRC regulations. The Committee was of the

view that the consent form should allow potential participants to opt out of allowing their data to be shared. The Committee also asked that point 3 of the consent form be amended to read 'anonymised data'.

The Committee was of the view that as the observation and interview were two separate procedures and that separate consent should be sought for each procedure.

The Committee asked whether anyone else would be present during the interview i.e. friend/relative and if so their consent should also be sought and an additional consent form provided.

The letter for Professionals, the Committee was of the view that the letter talks to Professionals as if they were patients and should be revised.

The Who has reviewed the study section of the information sheet should be revised to read that the study has been reviewed by Wales REC 1.

I regret to inform you therefore that the application is not approved.

If you would find it helpful to discuss any of the matters raised above or seek further clarification from a member of the Committee, you are welcome to contact Mrs J Sidhu, REC Manager on 02920 376823

Options for further ethical review

You may submit a new application for ethical review, taking into account the Committee's concerns. You should enter details of this application on the application form and include a copy of this letter, together with a covering letter explaining what changes have been made from the previous application.

We strongly recommend that you submit the new application to this REC. In order to arrange for the new application to be reviewed by this REC, please contact **Mrs J Sidhu, REC Manager on 02920 376823** when you have prepared the new application in order to book a slot at the meeting. If you prefer, you may submit the application to a different REC by contacting the Central Booking Service. Please note, you must be able to submit the application on the same day as making the booking.

Alternatively, you may appeal against the decision of the Committee by seeking a second opinion on this application from another Research Ethics Committee. The appeal would be based on the application form and supporting documentation reviewed by this Committee, without amendment. If you wish to appeal, you should notify the relevant Research Ethics Service manager (see below) in writing within 90 days of the date of this letter. If the appeal is allowed, another REC will be appointed to give a second opinion within 60 days and the second REC will be provided with a copy of the application, together with this letter and other relevant correspondence on the application. You will be notified of the arrangements for the meeting of the second REC and will be able to attend and/or make written representations if you wish to do so.

The contact point for appeals is:

Catherine Blewett

HRA Improvement & Liaison Manager

Health Research Authority

Email: hra.appeals@nhs.net

Summary of discussion at the meeting (if appropriate)

Social or scientific value; scientific design and conduct of the study

The Committee noted that the study would involve potentially vulnerable participants. The Committee discussed the application and all members were concerned with the limited experience of the researcher. The Committee agreed that the application form and supporting documents were unnecessarily complex and lengthy, making it very difficult to understand the study.

Recruitment arrangements and access to health information, and fair participant selection

The Committee noted in discussion that the research is being undertaken by the student as part of doctoral research. The student will be designated as the Chief Investigator and will be responsible for conducting all research and analysing the data produced.

The Committee noted the researcher's clarification that all potential participants will initially be identified and approached by healthcare professionals involved in their care.

The Committee noted that the project will involve both participant observations (and audio recordings) of professional client interactions within diagnostic and therapeutic interventions taking place within three mental health settings: the CUPS second opinion clinics based in the Hayden Ellis Buildings, Cardiff University, various Bipolar Education Programme Cymru (BEPCymru) groups throughout Wales, and various community mental health teams (CMHTs) within Cardiff and Vale.

The Committee asked for details of how the research will be undertaken at the various Bipolar Education Programme Cymru groups throughout Wales. The researcher explained that she was not completely sure on how to manage this part of the study and would have to consider this further. The Committee was of the view that it would be informative for the researcher to visit one of the Bipolar Education Programmes and

experience a session, this would provide her with an insight into how the sessions are run.

The Committee noted that only adults able to consent will be included in the study and that patients who have a limited capacity will be excluded from the study. However, it was not completely clear to the Committee how the researcher would assess capacity.

Favourable risk benefit ratio; anticipated benefit/risks for research participants (present and future)/Care and protection of research participants; respect for potential and enrolled participants' welfare and dignity

The Committee was of the view that it was important that all potential participants are aware of their diagnosis prior to being contacted by the researcher, as it would be very distressing to learn of their diagnosis from a third party. The Committee was not convinced by the researcher's clarification that all potential participants would be aware of their diagnosis prior to being recruited into the study.

The Committee asked whether the audio recording will include patient names? The Committee noted the researcher's clarification that they felt that even if the name is not on the tape the information can be identifiable and because of the concerns around accuracy of the tapes they cannot be destroyed and must be retained for a certain length of time.

The Committee noted from Section A43 of the application form that data will be stored for 6-12 months? The Committee was of the view that this does not comply with the Data Protection Act and contradicts the above information.

The Committee was of the view that the patient names should not be included in the recording.

Informed consent process and the adequacy and completeness of participant information

The Committee was of the view that the whole of the information sheet was making assumptions about patients knowledge and there was too much jargon. The Committee agreed that the information sheet should be rewritten in lay language avoiding jargon. The Committee agreed that the researcher should ask a service user and friend or colleague to read the information sheet.

The Committee was of the view that as the observation and interview were two separate procedures separate consent should be sought for each procedure.

The Committee asked whether anyone else would be present during the interview i.e. friend/relative and if so their consent should also be sought.

The Committee made reference to the client information sheet – What will happen if I don't want to carry on with the study – (part 2) and agreed that it should be revised to read 'It is up to you to decide to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive'.

The Committee noted that point 4 of the consent form referred to data being shared with third parties. The Committee noted the researcher's clarification that the data will be deposited at the UK Data Archive (UKDA) as per agreement with ESRC regulations. The Committee was of the view that the consent form should allow potential participants to opt out of allowing their data to be shared. The Committee asked that point 3 of the consent form be amended to read 'anonymised data'.

The Committee discussed the letter for Professionals, the Committee was of the view that the letter talks to Professionals as if they were patients.

The Who has reviewed the study section of the information sheet should be revised to read that the study has been reviewed by Wales REC 1.

Suitability of the applicant and supporting staff

The Committee was concerned that the researcher could be emotionally impacted by the study and asked what experience she has had with this type of study and interfacing with this type of patient. How is the potential emotional impaction viewed and what practical steps were being taken to prevent this.

The researcher explained that she would follow the Cardiff University's Lone Worker' guidance and Cardiff University 'Health and Safety in Fieldwork' policy for advice. The researcher further explained that she had experience of working with the Samaritans.

The Committee was of the view that the researcher was relatively inexperienced and raised concerns for her safety and wellbeing.

Furthermore the Committee was of the view that as patients have bipolar disorder, would it not be safer to conduct interviews on NHS premises or as standard have a second interviewer present if conducted at patient's home.

Suitability of supporting information

The Committee agreed that the application form and supporting documents had not been provided as required using language easily understood by lay reviewers and should be revised.

The Committee was of the view that the title did not reflect the study and should be revised on all study documents.

Suitability of the summary of the research

The Committee could not confirm that the summary of the research was suitable for publication as it had not been provided in lay language.

Other ethical issues were raised and resolved in preliminary discussion before your attendance at the meeting.

Documents reviewed

The documents reviewed at the meeting were:

Document	Version	Date
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of Sponsor insurance]	1.0	20 July 2015
Interview schedules or topic guides for participants [Interview Schedule Mental Health Clients]	1.0	01 August 2015
Interview schedules or topic guides for participants [Interview Schedule Mental Health Professionals]	1.0	01 August 2015
IRAS Checklist XML [Checklist_04092015]		04 September 2015
Letter from sponsor [Sponsor letter]	N/A	24 August 2015
Letters of invitation to participant [invitation letter]	1.0	15 August 2015
Letters of invitation to participant [Contact letter BEPCymru]	1.0	15 August 2015
Participant consent form [consent form]	1.0	15 August 2015
Participant information sheet (PIS) [Patient Information Sheet]	1.0	01 August 2015
Participant information sheet (PIS) [professional information sheet]	1.0	01 August 2015
REC Application Form [REC_Form_04092015]		04 September 2015
Research protocol or project proposal [Research Written Protocol]	1.0	15 August 2015
Summary CV for Chief Investigator (CI) [CV]	1.0	19 August 2015
Summary CV for supervisor (student research)		

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

15/WA/0343	Please quote this number on all correspondence

Yours sincerely

<u>Appendix III: Interview Schedule for Patients</u>

INTERVIEW SCHEDULE (CLIENTS)
Version 3.0, March 2016

Brief to interview: This interview will explore your thoughts about your diagnosis and the explanations that you have encountered for your mental health difficulties. The questions provided here are meant as a broad outline of what will be discussed, and you may be asked other questions based on what answers you provide. Your answers may be as long or as short as you wish. You may also refuse to answer certain questions without explanation. The interview is expected to last between 30 minutes and 1 hour.

Establish consent:
Everything you say will be treated as completely confidential and you will remain anonymous in any report that may result from this research. This interview will be tape recorded so that I can type out exactly what was said during the interview. At any time during the interview, you may stop the tape recorder if you wish. If you would still like to proceed with the interview, you will now be required to sign a consent form.

Questions

Background Information and Diagnosis

1. Could you describe the process that led to you being diagnosed/ being considered for your current diagnosis? *You can talk about who diagnosed you/ how/ when and why you were diagnosed, how long after you started experiencing mental health problems did you get diagnosed etc.*

2. How were you told about this diagnosis and did you understand why you received the diagnosis?

3. What does your diagnosis mean to you and how do you feel about it? *E.g. How helpful do you find the diagnosis?*

4. Has your mental health diagnosis impacted on how you see yourself? If so – how?

5. Has the diagnosis impacted on the way you imagine your future? If so –how?

Questions on causal explanations

6. Can you describe what led you to be in contact with mental health services? *e.g. the circumstances under which this happened/ what events or feelings led to this? Who was involved in the decision to refer you to mental health services?*

7. What do you think has caused you to develop mental health difficulties? *i.e. what led to you having these particular issues?*

8. How were the causes of your mental health problems discussed with the mental health professionals you have spoken with, if at all? *E.g. How were the causes of your symptoms explained to you?*

9. If particular explanations were suggested by the professionals, how did these explanations effect the way you view yourself? *i.e. how did they impact/change the way you perceived yourself or your own difficulties?*

10. What different ways of explaining your difficulties have you come across? Which have you found most helpful? (e.g. medical vs. more social explanations).

11. During your mental health assessments, how was information relating to possible causes used to explain your current difficulties? *Were you asked questions relating to possible causes, i.e. life history and family history, immediate life circumstances and current relationships?*

12. What treatments did you receive for you mental health difficulties?

Concluding questions

13. Is there anything else you would like to add or say?

14. If I wanted to conduct a second interview, would you be interested in taking part in this? Do not feel pressure to say yes to this. This would only happen if I felt that there were issues needing further exploration following the first interview.

Interview End