

MOVEMENTS OF MOODS

Interplay Between
Science, Clinical Practice and Patient
in Psychiatry



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MOVEMENTS OF MOODS: INTERPLAY BETWEEN
SCIENCE, CLINICAL PRACTICE AND PATIENT IN
PSYCHIATRY

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ACADEMIC DISSERTATION

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Chapter 1

Introduction

In the last two or three decades, mental disorders have become a major public health problem throughout the western world (Kessler et al., 2009). This has challenged the professionals in the field to more effectively research and treat mental disorders. The scientific understanding of the interplay between the human mind, brain and body has advanced significantly via high-tech neuroscientific research designs from neuroimaging and molecular genetics to animal models. Clinicians are able to treat patients with a whole range of new pharmaceuticals and psychosocial treatment practices. At the same time, knowledge is spread, used and moulded by media, patient organisations, education, celebrity biographers or lay people in the discussion forums in the Internet. The scope of psychiatric knowledge and practices has expanded having implications for the society, culture and the very ways anyone of us can understand the relationship between mind, brain, body and personhood (e.g. Dumit, 2004; Helén, 2011b; Rose, 2006; Rose & Abi-Rached, 2013).

Nevertheless, the challenge of translating and applying research results into clinical practice still persists. Despite the advances in understanding the mechanisms of mental disorders, there are no biomarkers in psychiatry and a certain amount of diagnostic uncertainty is inherent in psychiatry. The open question is: how to distinguish the normal thoughts, feelings and behaviour of a human being from the pathological? This fundamental problem in psychiatry is at the heart of this research.

In this research I am using bipolar disorder in Finland as a case study, allowing an empirical analysis of psychiatry as a complex and changing assemblage of interdependent economic, political, social and scientific endeavours (Collier & Ong, 2005; Pickersgill, 2012d). I am focusing on the interplay between scientific knowledge, clinical practice and patients' experiences, as well as the mundane practices of both mental health professionals and patients in getting along with the diagnostic uncertainty inherent in psychiatry. This research is an ethnographic analysis drawing from a diverse set of empirical material consisting of scientific and educational texts, observations on scientific gatherings and patients'

discussion forums online, as well as interviews with both experts and patients.

1.1 Investigating the social and the biological

SOCIAL IN SOCIAL SCIENCES

In the course of doing this research, I have often found myself in a situation where I have to explain what am I, as a sociologist, doing studying bipolar disorder and psychiatry? A common assumption is that as a sociologist I would be studying the social factors relating to bipolar disorder such as socio-economic status, gender and education. Another common assumption was, that a sociologist would be studying the social aspects in the illness experiences of the patients diagnosed with bipolar disorder. This research is about none of these, because I have adopted a different approach to what 'social' actually means.

In his book *Suicide* (1952 (1897)) the french sociologist Emilé Durkheim argued that suicide was best explained by social factors and the coherence or anomy in society, not psychological or biological differences in individuals. This novel way of approaching a phenomenon like suicide, marked the object of sociology as a science, the social fact, that should be studied independently from the psychological, physiological, biological, chemical or physical forces affecting human beings in their conduct of living. The 'social' can, however, be seen differently. Bruno Latour takes a critical stance towards this kind of sociology and suggests that the 'social' is not "*some glue that would fix everything... it is what is glued together by many other connections*" (Latour, 2005, 5). Latour is challenging the traditional boundaries of what 'social' as the object of social sciences is. 'Social' is not a factor explaining the world, but more the outcome of a complex set of connections between different actors (Latour, 2005; Lehtonen, 2009).

In this research, I approach psychiatry as a heterogeneous assemblage of intersecting material, symbolic and social elements (Pickersgill, 2012d). Therefore the 'social' has meaning only in relation to the sother elements and my interest is in the mediation and connections between these elements. Although I am trained as a sociologist, I draw from the multidisciplinary approach of science and technology studies (STS). For me, STS provides a disciplinary umbrella, where different and intersecting perspectives can be utilised in the analysis. I this research I have taken inspiration from, and discuss with, writings and analyses from the fields of sociology, medical anthropology, medical humanities, history of science and philosophy.

SOCIAL IN NATURAL SCIENCES

The 'social' is an important aspect of bipolar disorder as a mental disorder and an object of biomedical research. Bipolar disorder is a medically opaque

entity, something that cannot be detected in biomarkers like a blood sample or rendered visible by an imaging technology like x-ray. The standard view of the pathogenesis of mental disorder portrays actually a quite nuanced condition. For instance bipolar disorder, is seen as a consequence of genetic susceptibility, life experiences, acute stress, hormonal changes, as well as the neurochemical and structural changes in the brain. The human brain is plastic, and the synaptic connections in the brain are formed and reshaped throughout the life course and affected by pharmaceuticals, therapies, meditation, exercise and diet (see Rubin, 2009; Rees, 2010). Mental disorders are not either social, biological or psychological; they seem to be made up of all these factors.

In the beginning of the previous century, philosopher A. N. Whitehead (1920) emphasised that the western thought is a victim of, what he calls, *the bifurcation of nature*. This means the tendency to divide the world into two kinds of things, subjects or objects. There are things that constitute the universe; things that are real and known to science. Then there are other things that human minds add to these fundamental things to make sense of them; things that are subjective and unreal (see Halewood, 2011; Latour, 2014).

The bifurcation of nature repeats itself in the more mundane dichotomies attached to human beings as objects or subjects in psychiatry. For instance, it is possible to think that human beings are either creations of their genes or consequences of their upbringing and environment, or that the personhood is inscribed either in the brain or in the mind. Likewise it is possible to think that human beings must be either mentally ill or perfectly sane, or that the mentally ill should be treated with either psychotherapies or pharmaceuticals (see e.g. Martin, 2007, 1-30).

PROCESSES AND PRACTICES

As an answer to the problem of bifurcating the nature, Whitehead (1978) proposes a philosophy of organism. In his process ontology, all living are seen as organisms in *concrecence* with other organisms. A human being, the cells in a body, a stone, the sun, carrots and the soil; all these are in interaction with each other, affecting each other and changing in a constant process of becoming those things. Inspired by Whitehead's thinking, anthropologist Tim Ingold (2013) argues that humanity is neither pre-given through biology, nor learned through culture, but instead formed through the processes of life itself – interactive processes between genes, cells, organs, skin, nutrition, family, education, environment, politics, culture. These processes of life itself are constantly going on, and the human being is becoming slightly different through every single biological or social interaction. Hence, Ingold suggests that human beings are essentially *biosocial becomings* (see also Debaise, 2013; Stenner, 2008).

In line with both Whitehead's and Ingold's thinking, I argue, that considering

life and human beings through these kinds of processes can help social scientific analysis to overcome the common dichotomies. In particular this is helpful in understanding how human beings are always somewhere in between health and illness or disease, not clearly normal nor pathological (c.f. Canguilhem, 1978; Fraser, 2001; Greco, 2008a; Mol, 2002, particularly the subtext on pages 33-50).

I suggest that the processes of life can be brought into the analysis by concentrating on mundane practices where objects, like bipolar disorder, are put into effect. The quite ordinary practices in conducting research, treating patients and living life with bipolar disorder are intercepted snapshots of various processes. In the snapshots bipolar disorder is being *enacted* as certain kind of thing. Bipolar disorder is slightly different in every snapshot, but still coordinated into an object that can be researched by the scientists, treated by the clinicians and experienced by the patients (Mol, 2002). In this research my aim is to see the processual nature in the interplay between science, clinical practice and patient: to see in the snapshots how the processes of life shape the way psychiatry as a science works, how patients are treated and especially how the patients experience their daily lives with bipolar disorder.

1.2 Research design and objectives

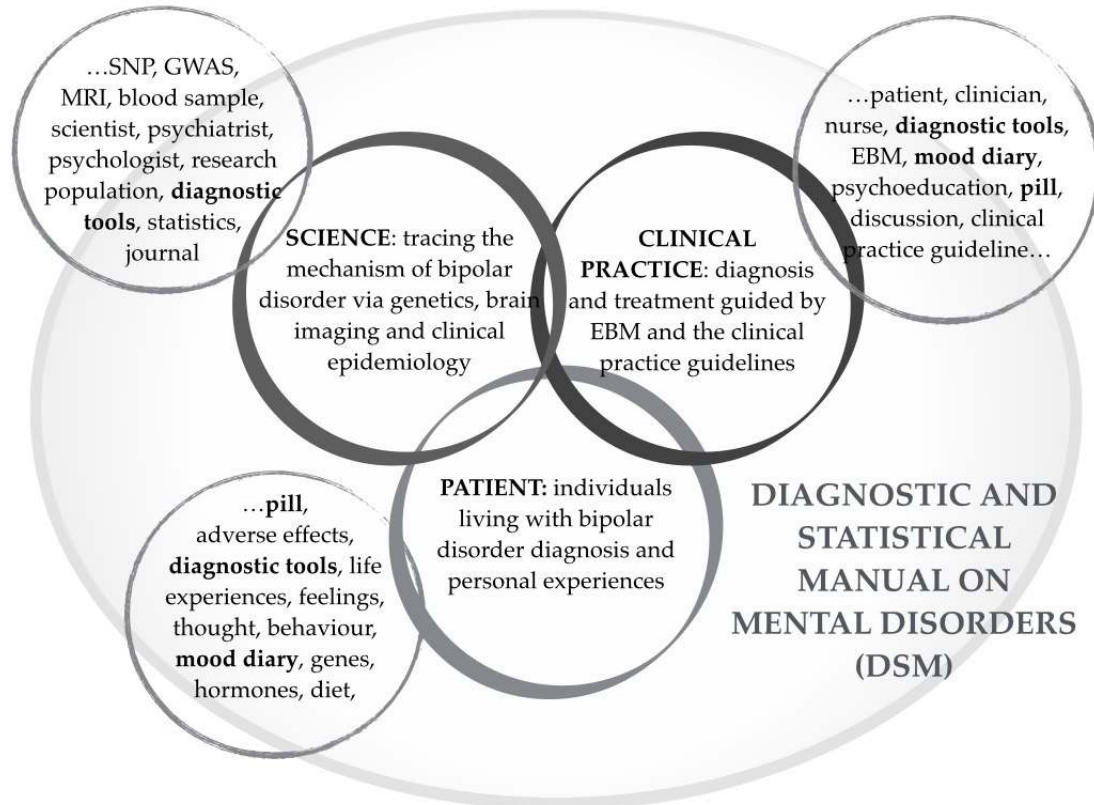
This research is about psychiatry seen through the lens provided by bipolar disorder. Bipolar disorder, as the case example of this research, limits the empirical material so that it is possible to analyse the complexities of how psychiatry works. The empirical material consists of scientific and educational texts about bipolar disorder, observations on scientific gatherings and bipolar disorder patients' discussion forums online, as well as interviews with both experts researching and treating bipolar disorder and patients living with the disorder.

The empirical material informed the choices I made in designing the research to be an analysis of the interplay between *science*, *clinical practice* and *patients' experiences* in psychiatry. These three perspectives into bipolar disorder are sites constructed from the empirical material.

Following Annemarie Mol's (2002) example I am focusing on the mundane practices, within these three sites, where bipolar disorder is being *enacted* as slightly different but still coordinated into an object that can be researched, treated and experienced. The diagnostic categorisation of bipolar disorder in the Diagnostic and Statistical Manual of Mental Disorders (DSM) is a technology that coordinates what is understood as normal or pathological moods, thoughts and behaviour within psychiatry. It is thus the technology that coordinates psychiatry and mediates between science, clinical practice and the patients' experiences. The first objective for this research is to analyse how this coordination happens in practice:

- what is being enacted, *put in to effect*, in the coordination process within science, clinical practice and patients' lives?

The following picture introduces the research design and portrays the three sites under investigation: science, clinical practice and patients' lives. In addition the picture introduces some of the human and non-human actors I have identified in the empirical material. The DSM holds this assemblage together:



The actors represented in the image are mediating within and between science, clinical practice and patients' lives and there are different looping effects between the sites (Hacking, 2007; Latour, 2005). The second objective for this research is to analyse the mediations and loopings:

- what kinds of mediations form between science, clinical practice and patients' lives in the coordination process?

In addition to the actors and practices introduced in the above image, there are actors like pharmaceutical industry, as well as mental health administration and law, which are important in the assemblage of psychiatry. I have omitted these actors or sites from this research so that the empirical material would be manageable and so that the analysis would not spread out too much. Pharmaceutical industry, in particular, does come forth in the empirical material and this is why I introduce the actor with the help of literature.

Some of the actors are globally encompassing and others more local. My objective has been to take a snapshot of the globally active and changing assemblage of psychiatry by taking one disorder and one national setting as a

case example. By concentrating on bipolar disorder in Finnish psychiatry, it becomes possible to empirically analyse this complex assemblage. However, my objective is not to provide information about global psychiatry as a whole, nor do I attempt to generalise knowledge from the case to the whole. Instead, this kind of research design provides analysis of the interplay between the global structures of psychiatry and the mundane practices of researching, treating and living with bipolar disorder in the local settings.

In Chapter 2, I will present the research process, as well as the theoretical concepts and the methodological choices in more detail. Next, I am introducing three discussions, which have informed the design and objectives of this research.

The first discussion concerns the DSM and what bipolar disorder is as a diagnostic categorisation. The question of what is normal and what is pathological frames every interaction between a psychiatrist and a patient in research settings and clinical practice, as well as troubles the patients living with bipolar disorder. The second discussion addresses the globalised nature of psychiatry, the pharmaceuticalisation of mental health care and evidence-based medicine as a medical technology governing the treatment of mental disorders. The third discussion is about the relationship between mind, brain, body and personhood.

1.3 What is normal and what is pathological?

BIPOLAR DISORDER AS A PSYCHIATRIC DIAGNOSIS

A psychiatric diagnosis is about ordering and measuring the thoughts, feelings and behaviour of a human being. A diagnosis is steered by various human and non-human actors, such as diagnostic questionnaires, clinicians, nurses, manuals and clinical practice guidelines. This is not a straightforward process of medical decision making. The diagnostic uncertainty stems from the fact that despite the advances in understanding the mechanism of mental disorders in the human organism, there are no biomarkers to validate the diagnosis. Also, what is considered as pathological instead of normal moods, thoughts and behaviour varies both historically and culturally (Giosan, Glovsky & Haslam, 2001; Healy, 2002; Kleinman, 1977; Lakoff, 2005a; Martin, 2007). A psychiatric diagnosis is based on discussions between the patient and the clinician. The discussions take place in consulting rooms of psychiatric hospitals and out-patient clinics, where the patient and the expert try to find a mutual language to speak about the moods, thoughts, emotions and behaviour of the patient. The mutual language is provided by the diagnostic manuals guiding the decision making in clinical practice.

In current psychiatry bipolar disorder is determined in manuals providing the standard criteria of symptoms and classification of mental disorders, the

Diagnostic and Statistical Manual of Mental Disorders (DSM) published by the American Psychiatric Association (APA) and the International Statistical Classification of Diseases and Related Health Problems (ICD) by World Health Organization (WHO).¹ The DSM defines bipolar disorders as follows:

“There are three types of bipolar disorder:

1. *Bipolar 1 Disorder*, in which the primary symptom presentation is manic, or rapid (daily) cycling episodes of mania and depression.
2. *Bipolar 2 Disorder*, in which the primary symptom presentation is recurrent depression accompanied by hypomanic episodes.
3. *Cyclothymic Disorder*, a chronic state of cycling between hypomanic and depressive episodes that do not reach the diagnostic standard for bipolar disorder” (APA (American Psychiatric Association), 1994, 388-392, emphasis added)

Bipolar disorders encompass severe psychotic mood swings and milder but chronic states of mood cycling, where the episodes of depression and mania or hypomania fluctuate in different durations from hours to years.

Depressive episodes are characterised by low mood, poor self-esteem and loss of interest or pleasure in life activities, as well as suicidal thoughts and actions. Mania and hypomania are states of abnormally and persistently elevated, expansive or irritable mood combined with increased self-esteem and interest in pleasurable activities. I will return to the specific symptoms of both depression and mania in more detail in Chapter 3 from the perspective of science and in Chapter 5 as experienced by the patients living with these symptoms.

The conditions we know as bipolar disorders are the result of a convergence of certain words, concepts and behaviours – like ‘mood’ or ‘affect’ – which as words, concepts and behaviours have their own history. Hence, the current notions of depression and mania are not in any unambiguous way transformations from the old notions of melancholia and mania dating back to Ancient Greek. German E. Berrios and Roy Porter (1995) have pointed out, that since there is no reason to assume that bipolar disorders have converted to the current diagnostic categorisations by something “written in the nature”, it would be anachronistic to say that the clinical conditions the words mania and melancholia refer to have remained the same throughout time.

¹Today the DSM is used both in research and in clinical practice. The DSM is the standard used in research to produce consistent results, but in many European countries, Finland included, the ICD classification is used in official medical documents and in the health administration. The definitions of most mental disorders are convergent between the two manuals and after the third edition of the DSM, the manuals have been updated in concordance. (Furman, Huttunen & Lönnqvist, 1985) But the use of the manuals in clinical practice varies and because the ICD-10 does not clearly differentiate bipolar 1 and 2 disorders, the use of both manuals is recommended in the clinical practice guideline for bipolar disorder (*Käypä hoito -suositus. Kaksisuuntainen mielialahäiriö.*, 2013).

A concept of bipolar disorder more akin to the modern definition has its origins in the nineteenth century France, where Jean-Pierre Flaret and Jules Bailarger independently presented descriptions of patients with what they called *folie circulaire* and *folie à double forme* respectively. Then, in the early 20th century the German psychiatrist Emil Kraepelin coined the term manic–depressive psychosis to separate the disorder from dementia praecox, a condition now known as schizophrenia. Kraepelin's term *manic-depression* was used until the 1980s and bipolar disorder is still commonly known by this term (Angst & Sellaro, 2000; Angst & Marneros, 2001; Craddock & Owen, 2005; Marneros, 2001; Moncrieff, 2014).

These early psychiatrists and researchers of mood disorders did not distinguish depression and bipolar disorder as separate conditions. The distinction between depression and bipolar disorder dates back to the 1960s, but was largely implemented into use in 1980 in the third edition of the DSM. This new version of the manual categorised the mood disorders for the first time as two distinct disorders *major depression* and the three types of *bipolar disorders*. DSM-III was also the first manual to introduce the milder bipolar disorder 2 with hypomania (Angst & Sellaro, 2000; Angst & Marneros, 2001; Craddock & Owen, 2005; Compton & Guze, 1995; Marneros, 2001).

In this research I have had no reason to make a strict distinction to the more severe bipolar 1 disorder and the milder bipolar 2 disorder. All the forms of the disorder occur in my empirical material. However, there is a slight emphasis on the milder end of the spectrum, because the emergence of bipolar disorder into Finnish research and mental health care in the beginning of the 2000s was propelled by the concern about the unrecognised bipolar 2 disorder.

The DSM categorisations have raised discussion in the scientific community about the clinical validity of the distinction, because in reality, the patients seem to fall more diversely into a *spectrum of mood* ranging from mild depressions and occasional energetic periods to psychosis. A similar idea of a spectrum has been used to characterise schizophrenia and autism. Molecular genetic research also suggests that actually there are similar genetic changes in all three disorders, yielding discussion about the usefulness of the DSM categorisation of mental disorders in general (see e.g. Lee et al., 2013).

THE CRITIQUED DSM

The DSM has been evolving from a collection of hospital statistics to the standardised manual of mental disorder it is now. The first version was published in 1952, but the third version has been seen as a shift in the paradigm of psychiatry. This new way of understanding and classifying mental illnesses rapidly transformed the theory and practice of mental health care in the western world (Mayes & Horwitz, 2005).

The new diagnostic approach aimed to categorise mental disorders according to descriptive criteria used in research, instead of clinicians' practical knowledge. The main task was to thus improve the validity and reliability of psychiatric diagnosis. The novelty of the DSM-III was that it was based solely on the observation of symptoms, signs and the course of the disorder without theoretical and etiological assumptions as to where these symptoms stemmed from (Kirk & Kutchins, 1997).

The new classification system yielded discussion on the ontological, epistemological, social and political problems and advantages of the system, both within psychiatry and in humanities (see e.g. Compton & Guze, 1995; Cooper, 2004; Faust & Miner, 1986; Kirk & Kutchins, 1997; Mayes & Horwitz, 2005; Murphy, 2006). Instead of rendering psychiatric diagnosis into an objective and reliable system for differentiating the normal from the pathological, the DSM has been a tool to *standardise* psychiatric diagnoses. It serves as a mutual language for all the actors to communicate mental disorders as distinct disease entities.

In Chapter 3, I demonstrate how the DSM works as a tool for standardising scientific knowledge. Science needs the DSM categories to screen the appropriate research subjects and to render research results comparable with other research. The DSM also works as a tool for health insurers and governments to allocate benefits and assess the effectiveness of mental health care. Moreover, the symptom-based categorisation allows pharmaceutical companies to develop drugs targeted to treat the specific disease entities. In clinical practice the DSM and the diagnostic questionnaires serve as a mutual language between the patient and the clinician. In Chapter 5, I show how the symptoms listed in the DSM provide a point of reference for the patients to reflect their individually experienced symptoms.

The latest version, DSM 5, was released in 2013 after years of development.² The launch was preceded and followed by an increasing critique about the abilities of the DSM system to differentiate normal and pathological mental states (see e.g. Angst, 2013; Callard, 2014; Hacking, 2013; Insel, 2013; Pickersgill, 2013). The problems of the DSM system lie in its medicalising effect when new categories convert new modes of human feelings, thoughts and behaviours into mental disorders. Moreover, the DSM system can hinder scientific advances in understanding the mechanism of mental disorders. The DSM system allows the scientists to work only within the limits of the symptom based categories.

This limits neuroscience to fully engage in creative basic research outside the symptom based categories. So much so, that the National Institute of Mental Health in the US deems the DSM system not valid enough and has declared

²In this research, I am referring to the DSM-IV categorisations of bipolar disorder, because that is the version of the manual mostly used in my empirical material and there are no substantial differences between the fourth and the fifth version in how bipolar disorders are defined (see Angst, 2013).

a radical shift in the paradigm. The NIMH states that it does no longer fund research, where subjects are selected using the DSM categories and instead fosters basic research “*to transform diagnosis by incorporating genetics, imaging, cognitive science, and other levels of information to lay the foundation for a new classification system*”, as the director of the NIMH Thomas Insel (2013) describes.

In his review of the DSM 5 in *London Review of Books*, the philosopher Ian Hacking comments on the DSM system as a whole and the criticism of the systems validity by Insel (2013). I think Hacking summarises the problems in the DSM system very eloquently:

“The DSM is not a representation of the nature or reality of the varieties of mental illness, and this is a far more radical criticism of it than Insel’s claim that the book lacks ‘validity’. I am saying it is founded on a wrong appreciation of the nature of things. It remains a very useful book for other purposes. It is essential to have something like this for the bureaucratic needs of paying for treatment and assessing prevalence.” (Hacking, 2013)

In this research, I am analysing the DSM as one of the key actors in the circulation of knowledge between science, clinical practice and patients’ lives. The DSM encompasses the assemblage of psychiatry and provides the shared description of what bipolar disorder is. In Chapter 3, I will introduce and discuss the categorisation in more detail.

1.4 Global assemblage and the local case

THE CASE OF FINLAND

While on the one hand psychiatry is a global assemblage, it is on the other hand situated in local practices. This requires empirical analysis of the complex global phenomena in local settings. For example, Andrew Lakoff (2005a) has analysed the globalisation of current biomedical psychiatry by following how bipolar disorder is implemented in the psychoanalytically oriented practices of Argentine psychiatry. Emily Martin (2007), in turn, has analysed bipolar disorder in American culture, concentrating more on the ways the worlds of patients, psychiatrists, pharmaceutical industry and mental health support groups intersect with each other and the wider popular culture. In Finland, especially Ilpo Helén (Helén, 2007b, 2011b, 2011a) has tackled the implications of life sciences and biotechnology, for example, by analysing the co-production of an assemblage of mental health management and depression as an object of knowledge.

Finland is a small but research- and innovation-oriented country, and therefore provides an especially fruitful locale to grasp the assemblage of psychiatry. In Finland, the history of psychiatry has followed in the footsteps of anglo-american

psychiatry in adapting thought styles guiding the research and organising mental health care. The welfare state context does not bring out any obvious differences in this respect. This means that the developments in Finland reflect the changes in Western world and Finland is not an exceptional case like, for instance, Argentina (Lakoff, 2005a). Ilpo Helén's (Helén, 2007b, 2011b, 2011a) analyses on Finnish psychiatry show how depression has been the core of research and mental health care and become one of the most salient public health problems in Finland.

Over the past ten years bipolar disorder has very rapidly tagged along: the research has been intensive, treatment guidelines has been created, clinicians are educated to recognise the disorder, support groups for patients are established, patient guidance is promoted and celebrities are coming out in public with their experiences of the disorder. This intensive development provides an excellent case to do STS oriented research. Bipolar disorder is a particularly interesting case because it falls in between a severe mental illness and milder community mental disorder. It is also treated in all the levels of mental health care from primary health care to hospitals and thus highlights many aspects of Finnish mental health care, although the health administration and mental health law are not in the focus of this research.

PHARMACEUTICALISATION OF SOCIETY

Pharmaceuticalisation is a term used to frame the complexities of the interdependence of national economies, individual patients and the pharmaceutical industry (Abraham, 2010; Hautamäki, Helén & Kanula, 2011; Williams, Martin & Gabe, 2011). Simon Williams, Paul Martin and Jonathan Gabe define pharmaceuticalisation as:

“a dynamic and complex heterogeneous socio-technical process that is part of what we might call a pharmaceutical regime. This can be understood as the networks of institutions, organisations, actors and artefacts, as well as the cognitive structures associated with the creation, production and use of new therapeutics.” (Williams, Martin & Gabe, 2011, 711)

They suggest that a *pharmaceutical regime* has been forming from the 19th century around the chemistry-based technology embodied in the pill and the regime is in a continuous process of commercial, clinical and geographical expansion.

The clinical expansion of the pharmaceutical regime refers to the proliferating use of drug treatments in various diseases and illnesses, as well as the expanding scope of what kinds of things can and should be treated as diseases and illnesses. This marketing strategy is sometimes referred to as *disease mongering*, where the illnesses are marketed and branded instead of the pharmaceutical products. Examples, such as the branding of erectile dysfunction and the Viagra (sildenafil

citrate) as its cure, show how the selling of sicknesses widens the boundaries of what is understood as normal and pathological or health and illness (e.g. Lexchin, 2006; Moynihan & Cassels, 2005; Moynihan, Doran & Henry, 2008, see theme issue on Disease Mongering in PLoS Medicine 2006).

The geographical expansion then refers to the globalisation of both diseases and the pharmaceutical solutions to them. It is no longer only the ageing western world where the use of pharmaceuticals is proliferating, but also other parts of the globe enter the orbit of the pharmaceutical regime. The rich and ageing western world has provided a fertile ground for launching new therapeutic markets, whereas the poorer parts of the world and the epidemics of, for instance, tropical diseases like malaria are not the in the core of the industry's research and development. However, the markets are opening up outside the western world, as the pharmaceutical industry is launching its products in new markets (Applbaum, 2006a, 2010; Helen, 2009; Petryna & Kleinman, 2006).

The commercial expansion is related to both the clinical and geographical expansions and refers to the fact that the Big Pharma, as pharmaceutical industry is nicknamed, is a multi billion dollar global business with expanding markets. One indicator is the proliferation of the costs drugs cause national economies and consumers: in Finland, similar to all western industrialised countries, the drug expenses have grown on an average of 10 percent yearly from the 1960s. This is mostly because new more expensive drugs replace old and cheaper ones (Helen, 2009; Vuorenkoski, 2004; Klaukka, Idänpään-Heikkilä, Helin-Salmivaara & Huupponen, 2007).

The problem is, that the new drugs are not necessarily better in clinical use. The estimation is that circa 80 percent of all new drugs provide few or no clinical advantages for the patients. This is mostly because the research and development focus on minor variations in existing drugs. The pharmaceutical industry invests less in research and development and ever more in marketing and creating brand loyalty. The few genuinely new compounds in the market are usually developed outside the industry (Helen, 2009; Klaukka, Idänpään-Heikkilä, Rajaniemi, Helin-Salmivaara & Huupponen, 2005; Vuorenkoski, 2004).

The clinical, geographical and commercial aspects of the pharmaceutical regime form a complex and expanding assemblage. Williams, Martin and Gabe(2011) also point out, I think wisely, that in its complexity, the pharmaceutical regime is best investigated empirically case by case. These kinds of analyses of all the aspects of the pharmaceutical regime have proliferated. The activities of the pharmaceutical industry have been on the agenda of investigative journalism that provides scoops about the unethical practices of the industry. Academic research, in both social sciences and medicine, has also been mostly critical towards the expansion of the pharmaceutical regime and its effects on health care and the societies more generally (Abraham, 2010; Angell, 2004; Appl-

baum & Oldani, 2010; Hautamäki et al., 2011; Healy, 2002; Vrecko, 2010b). The Finnish medical profession has, for instance, been concerned about the problem of biased evidence from the industry sponsored clinical trials of new drugs and the problems of regulating the pharmaceutical markets and the economic pressure the current situation puts on the health care (Hemminki, Toiviainen & Vuorenkoski, 2010; Idänpään-Heikkilä, 2006; Idänpään-Heikkilä & Klaukka, 2007; Klaukka et al., 2005; Klaukka, 2006; Klaukka et al., 2007; Palva, 1999; Toiviainen, Vuorenkoski & Hemminki, 2004; Toiviainen, 2007; Vuorenkoski, 2004)..

The facts point towards an unhealthy relationship between the Big Pharma and global health care. Nevertheless, the interconnections between the various actors are very complex and there are no simple answers untangling the relationship. The literature is vast and it is impossible to cover all the nuances of this complex regime here, but I will analyse these problems in more detail in Chapter 4 in the context of bipolar disorder treatment.

EVIDENCE-BASED MEDICINE

Evidence-based medicine (EBM) is a practice of organising and disseminating knowledge and providing the best evidence about the efficacy of different treatment options. EBM also guides the ways the best evidence is currently used in making decisions about the care and treatment of individual patients (Sackett, Rosenberg, Gray, Haynes & Richardson, 1996; Tonelli, 1998).

At the core of EBM is the evidence hierarchy, designed to reflect the methodological strength of medical research methods. The methods of gaining medical knowledge are weighed so that Randomised Controlled Trials (RCT) of new treatment options are above any other method, such as quasi-experimental designs, cohort studies, comparative studies, case-controls studies or case studies stemming from clinical experience. The use of evidence hierarchies as the principles of EBM has been criticised of allowing RCTs too much authority over the other methods of producing knowledge about how and why treatments do or do not work, because the RCTs provide answers only to certain kinds of clinical questions (Borgerson, 2009; Cartwright, 2007; Knaapen, 2013).

Clinical judgement and expert opinion used to be the authority in choosing the right treatment option for the right patients. This authority has now, into some extent, been reassigned to the hallmark of EBM, the *clinical practice guidelines*, compiling the bits of evidence gathered from the RCTs about which treatments are not only clinically effective but also cost-efficient. Therefore EBM is a strategy to reduce the uncertainty that has always been present in doctor-patient encounters, and to help regulate the costs of different treatment options (Armstrong, 2007; Healy, 2009).

EBM is the medical technology defining what is acceptable knowledge in assessing the most successful treatments for discretely defined medical conditions.

The clinical practice guideline is a technology through which the EBM works in practice. In psychiatry, however, EBM causes difficulties in at least three ways.

First, mental disorders are not entities as discretely defined as many other medical conditions are and the diagnostic uncertainty is a problem in evidence-based psychiatry. Secondly, EBM works through the idea that the RCTs are a gold standard for objective knowledge of whether a treatment works or not. This puts an emphasis on interventions that are easily evaluated in the RCT design, such as pharmaceutical treatments, and the different therapeutic approaches used in psychiatry are therefore easily considered as less evidence-based interventions. Third, EBM fosters evidence, which, particularly in psychiatry, is not directly translatable into clinical practice, because the variability of patients and their symptoms does not easily match the statistical generalisations of the RCTs. (Healy, 2009; Lakoff, 2007; McGoey, 2010).

In Chapter 4, I show how the EBM heaves into sight in Finnish psychiatrists' discussions about bipolar disorder from the 1960s onwards. I also show how the psychiatrists in the working group developing the clinical practice guideline for bipolar disorder negotiate the acceptable knowledge and in some ways resist the demands of the EBM by putting more emphasis on clinical decision making.

1.5 Discussions about the human mind, brain and body

IS PERSONHOOD INSCRIBED IN HUMAN MIND OR BRAIN?

This question has occupied the minds (or brains?) of philosophers and other scholars for at least as long as such organised modes of thinking have existed. Most scholars and scientists today agree that the mind is somehow embodied and mental processes do not take place in an ethereal entity somewhere outside the body. Yet the tendency to bifurcate the nature echoes in the arguments of both the philosophers and the empirical scientists observing the human being from the perspectives of both natural and social sciences. The scholars have flagged for either the 'biological' brain functions, the 'psychological' subjectivity or perhaps the 'social' and 'cultural' environment as the incubator of the personhood of a human being. (Bennett & Hacker, 2003; Rose & Abi-Rached, 2013).

In western thought an individual personhood has been a fundamental aspect of being human. The personhood is individualised and bounded, with interior depth and biographical continuity, autonomous and free to choose, conscious and intentional. Psychology and psychiatry as scientific disciplines emerged at the end of the 1800s to observe and to care for the ailments of this kind of personhood, and were playing a key role in fostering such subjectivity (Rose, 1998). In the 1960s, the social, historical and cultural context characterized by political change, faith in scientific and technological progress, and the advances

in molecular science, paved the way for the modern neurosciences. What characterises neurosciences today are high-tech methods such as brain imaging, animal models and behavioural genetics, and the aim to observe molecular processes and structure of the brain in order to locate human cognition, behaviour and emotions in the brain (Abi-Rached & Rose, 2010; Rose & Abi-Rached, 2013).

The range of modern neurosciences encompasses many scientific disciplines, including many aspects of psychology and psychiatry. Moreover, disciplines like neuropsychanalysis or neuroanthropology, merge the perspectives of neuroscience and humanities. Thus, it becomes more and more difficult to differentiate between the sciences studying the subjectivity of a human being and the sciences studying the molecular function of the brain. This research focuses on psychiatry as a discipline interested both in tracing the brain-related processes behind mental disorders, and in understanding and treating the patients' subjectivities in clinical practice. In Chapter 3, I will introduce the endeavours of the Finnish scientist in tracing bipolar disorder with the methods of molecular genetics, brain imaging, and neuropsychology of the endophenotypes, as well as the clinical epidemiology attempting to map the clinical reality of bipolar patients in Finland.

ACTING ON HUMAN MIND, BRAIN AND BODY

What is salient in the changes I outlined above is that the sciences around human personhood at the same time reflect and foster an ethos of *acting on* one's mind, brain and body. The sciences of the brain broaden the scope from the clinical practice of treating mental disorders to everyday life and to all kinds of technologies of the self, in which individuals act on their "*bodies and souls, thoughts, conduct, and a way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality*", as Michel Foucault (2000, 225) has pointed out.

Along with technologies targeting the subjectivity, there is a wide range of technologies attempting to mould and enhance the brain. Pharmaceuticals are perhaps the most obvious case of neurotechnologies, but we are also urged to enhance our cognition with the help of various brain excersises, eat brain foods or play brain games from crossword puzzles to mobile apps. But the brain is also targeted through the mind and the body. The most clear examples are meditation, particularly mindfulness practices commercialised all over from education to business and yoga (Rose & Abi-Rached, 2013, 219-244). All these technologies of the self are premised on the fact, fully discovered in the middle of 1990s, that the human brain maintains the plasticity of both creating new synaptic pathways and changing in structure throughout the life course up to neurodegeneration in old-age (Rees, 2010; Rubin, 2009).

In Chapter 5, I analyse the education on bipolar disorder and the ways this information mediates patients' processes of becoming a patient and being with

the bipolar disorder diagnosis in their daily lives. I argue that minds, brains and bodies of the patients become a somewhat different each time they try different cocktails of psychopharmaceuticals, connect with others in therapeutic situations in mental health care, meditate, write their daily mood diaries, periodically take up drinking or change their dietary and exercise regimes. The patients are shaped and moulded by their condition and by the interventions attempting to cure, alleviate or control that condition as *biosocial becomings* (Ingold, 2013).

THE CRITIQUED NEUROSCIENCES

The rise of the neurosciences has led critics to worry about the ways that both the technologies and the rhetorics of neurosciences have sought to reduce every aspect of humanness to a definable structure or function of the brain, transmuting personhood into *brainhood* (Vidal, 2009; Ehrenberg, 2009; Ortega & Vidal, 2011). This critique is often premised on maintaining a bifurcation of social and biological. between the realms of social and biological. The critique thus might not fully acknowledge the complexity of what is at stake in neuroscience and psychiatry, which nevertheless are practices thinking through, and acting on, the connections between bodies, brains, subjectivities and lived experiences (Fitzgerald, 2012). Nikolas Rose and Joelle Abi-Rached convincingly argue that:

“In this new neuro-ontology, it is not that human beings are brains, but that they have brains. And it is in this form – that our selves are shaped by our brains but can also shape those brains – that neuroscientific arguments are affecting conceptions of personhood and practices of self-fashioning.”(Rose & Abi-Rached, 2013, 22)

The empirical analyses have brought up the ways the neurosciences fail to fill the translational imperative of producing knowledge for the clinical practice and the consequences the expanding scope of the neurosciences have on the forming of identities of the mentally disordered (see e.g. Dumit, 2004; Littlefield & Johnson, 2012; Martin, 2007; Pickersgill & Keulen, 2011). This critical literature has been very important in showing the ways neurosciences and psychiatry work in the society and mould both our understandings and ourselves. However, the concerns of the critics sometimes miss what is interesting and novel in the ways the different thought styles converge and coexist. In this research I aim to see the productivity as well as novelty in the many ways social, cultural and neurobiological actually are in alignment.

1.6 The reading instructions for this research

TERMINOLOGICAL CHOICES

There are a few terminological choices I want to clarify before introducing the structure of this research. First of all, *bipolar disorder*. I am using the term the term bipolar disorder in its singular form to refer to the whole spectrum of different bipolar disorders because there is no reason to analytically distinguish between bipolar 1 disorder and the milder bipolar 2 disorder in this research, but in those cases where either of the forms is specifically mentioned in the empirical material, I obviously use the terms accordingly.³ I will also use the expression *hypo/mania* in this research to refer to both the manic and the hypomanic episodes or symptoms.

The second term that needs clarification is the *patient*. The individuals I have observed in this research have been diagnosed with bipolar disorder and are in one way or another in treatment because of the diagnosis. I do acknowledge that these are in the end individuals “under the description of manic depression”, as Emily Martin(2007) puts it in her research on manic depression. She uses the term to avoid the idea that there is something pathological rather than normal in these individuals. I fully share her stance that words like patient can be labels indicating something pathological. However, the word patient is mostly used in my empirical material by the scientists, the clinicians, the nurses and the individuals with the diagnosis alike. Therefore I think it is plausible to use the same term.

I will use the generic term *scientist*, when referring to the professionals conducting bipolar disorder research. The scientists have different educational backgrounds from psychology to molecular genetics, and their research interests vary according to different projects. This is why I have not wished to call these professionals, for instance, neuroscientists, even though some of them are indeed studying the human brain and all of them seem to share the understanding that mental disorders are in one way or another related to the human brain.

THE STRUCTURE OF THIS RESEARCH

The structure of the research continues as follows. After this introduction, I will continue by describing the intermingled processes of making the theoretical, methodological and empirical choices of this research in Chapter 2. In the subsequent three Chapters 3,4 and 5 I observe, describe and analyse the empirical material. The chapters are roughly divided according to the three sites I have constructed for analytical purposes: science, clinical practice and patients’ experiences. I have also used specific parts of the empirical material in these chapters

³In some of the extracts the two types of disorders are written using roman numerals according to the original form in the cited texts.

and each starts with a brief description of how I have used my diverse material in the respective chapters. However, because the objective of this research is to analyse indeed the interplay between science, clinical practice and the patients' lives, the themes do intermingle.

Chapter 3 follows two research projects: one tracing the biological mechanism, and the other mapping the clinical epidemiology of bipolar disorder. I show how the epistemological premises and mundane practices together direct the ways the scientists approach their research object. I am also observing, how the process of selecting the research subjects into the projects forces the scientists to work through and adjust the diagnostic standards of bipolar disorder.

Chapter 4 considers the processes of consolidating bipolar disorder as a treatable mental disorder in Finnish mental health care. In the chapter I follow how the object, bipolar disorder, is being coordinated and the knowledge strengthened amongst the clinicians, psychiatrists and other professionals by translating and disseminating knowledge, raising awareness and educating. This chapter also follows the forming an evidence-based treatment standard and the clinical practice guideline of bipolar disorder.

Chapter 5 turns to the patients' experiences with bipolar disorder by following the site where patients share information and peer support about their daily lives and experiences with bipolar disorder. The analysis show how their experiences overcome the dichotomies of, for instance, mind and brain or pharmaceuticals and psychotherapies. The treatment processes affect the patients moods, emotions and behaviour, as well as metabolism, libido, sleep rhythm and energy. Bipolar disorder patients are in a life long process of becoming, when fluctuating mood episodes come and go as the patients go through different phases of living their life with this disorder.

Chapter 6 is the conclusion of this research where the observations from the previous chapters are rounded-up. This chapter argues that the most integral balancing and coordinating task for psychiatry is to tackle the inconsistency between the universal knowledge and the variety of the particular patients.

Chapter 2

Research processes

This research has been a process where the theoretical, methodological and empirical choices have fed each other. The research questions and objectives have changed accordingly. My initial theoretical interests pointed towards certain kinds of questions and certain kind of data, but when the empirical reality provided surprises, new theoretical insights provided novel perspectives, the research questions changed and more data was collected. I have taken on and developed an ensemble of theoretical perspectives, concepts and literature. Therefore, I will not provide a profound introduction of all the discussions, but rather discuss the theoretical choices as part of gathering the empirical material. In this chapter, I describe the research process as a whole.

2.1 Theoretical insights

HISTORICAL ONTOLOGY AND THE LOOPING EFFECTS

This thesis originates from my previous research: master's thesis and three articles (Hautamäki, 2006, 2007; Hautamäki et al., 2011) analysing guidance and education for lay people about depression from the 1970s to the 2000s in Finland. In this project I showed how knowledge about a specific mental disorder is mediated, to anybody concerned about his or her mental health, through patient education and guidance. I was interested in the ways scientific knowledge and classifications, formed within certain styles of reasoning, was *making up people* as objects of medical knowledge and interference, as well as the various looping effects between science and its objects, the human beings (Hacking, 1995, 2002a, 2007; Lehtonen, 2003; Kuorikoski & Poyhonen, 2012). Inspired by Michel Foucault's (Foucault, 1984, 2000) writings on the technologies of the self, I concluded in the Master's thesis that the education on depression aimed at an ethical work on the self towards balance and happiness.

These thoughts formed a backdrop for this doctoral dissertation project. I decided to widen the scope in two ways. First, I chose to have bipolar disorder

as a case for this research because I found the fluctuating nature of this mental disorder interesting, particularly in the context of determining what is normal or pathological, when both the ups and the downs in life can be considered as symptoms of a mental disorder.

Another way I chose to widen the scope was to dig deeper into history. I wanted to conduct a more thorough genealogical analysis of bipolar disorder by retracing the discourses, concepts and practices evolving in relation to the mental health care apparatuses through which bipolar disorder became *problematized* as a health problem in Finland (Foucault, 1984; Helén, 2005, 2007b).

I collected a corpus of historical documents (medical journal articles, textbooks, education), but it turned out that the discourses about manic depression or bipolar disorder took place mostly from the 1990s onwards. This lack of historical depth in the material I had collected, and coincidences by which I became aware of an ongoing bipolar disorder research project in psychiatry, directed me to shift the focus of the research.

However, the foucauldian idea of analysing the interplay of problematisations and practices has affected my analysis (Helén, 2005). I have particularly benefited from Ian Hacking's dynamic nominalism, which refers to the idea that whenever social, medical and biological sciences create new classifications and new knowledge, new possibilities for certain kinds of human beings emerge (Hacking, 2002a, 2007; Lehtonen, 2003). Even though my empirical material does not cover historical changes, my analysis is based on the presumption that mental disorders as classifications of human beings seem to emerge and sometimes disappear from the world in loopings between science and its objects (Hacking, 1995, 1998, 2007; Kuorikoski & Poyhonen, 2012; Lehtonen, 2003).

THE ASSEMBLAGE OF PSYCHIATRY

The research process continued by collecting new empirical material using ethnographic methods. I attended the first psychiatric conferences, interviewed the first scientists from the two research projects I was following and collected the publications. Particularly the discussions opened my critical social scientist's eyes to the perspective of the scientists, and I started to take in the humane ethos in the scientists work in tracing and mapping bipolar disorder, as well as the profound complexity of the power relations in psychiatry. Simultaneously, I started to more familiarise myself with science and technology studies (STS) literature.

Among the ample and interesting theorising in STS, actor network theory (ANT) inspired me the most, and directed me to see new possibilities in my empirical material (Law, 2004, 2009; Latour & Woolgar, 1986; Latour, 2004, 2005; Lehtonen, 2000; Mol, 2002, 2004; Ylikoski, 2000). I identified actors like psychiatrists, pharmaceutical industry, patients, Internet, diagnostic manuals, neuroscience, diagnostic tools, pills, clinical practice guidelines or mental health

policies. I saw how the actors were interrelated and started to pay attention to the mediations between human and non-human actors in my empirical material. The inkactors formed an assemblage of psychiatry, a moving and an open-ended meshwork, as Tim Ingold puts it (Ingold, 2011, 89-95). The idea that psychiatry is an assemblage of different interrelated actors provided me with means to understand what psychiatry is in all its complexity.¹

The empirical material collected in Finland did, however, speak about globally encompassing actors like the pharmaceutical industry or the diagnostic classification. The idea that these shifting global chains of mediation, the assemblage of psychiatry, is best analysed in local settings and in everyday practices provided me with a useful approach to my empirical material (Collier & Ong, 2005; Collier & Lakoff, 2005). I started to see how the diverse empirical material provided snapshots of the global and changing assemblage so that it was possible to empirically analyse the interplay between the global structures of psychiatry, and the mundane practices of researching, treating and living with bipolar disorder in the local settings in Finland.

ENACTMENT IN PRACTICES

Annemarie Mol's book *The body multiple: Ontology in medical practice* (2002) helped me to understand how to analyse bipolar disorder as the case. The empirical philosophy Mol fosters uses ethnographic material to think through the questions of how to distinguish disease and illness or normal and pathological in the human body. Her thinking opened up a plausible way for me to analyse bipolar disorder as a moving object for psychiatry, which is nevertheless coordinated into something that can be researched, treated and experienced.

Mol (2002) conducts an ethnography of the practices of research, diagnosis, treatment and care of atherosclerosis in a Dutch hospital, and shows that the ontology of the diseased body becomes multiple *through* those medical practices.

This can be applied to bipolar disorder. Bipolar disorder is a slightly less stabilised medical object than atherosclerosis because it cannot be situated into a specific locale in the human organism, and when I thought through my empirical material, it was clear that the disorder seemed indeed to multiply in the practices where it was researched, treated and experienced. Bipolar disorder is one kind of object for the geneticist working with blood samples and SNPs, and quite another kind of object to be treated in the messy reality of clinical practice, and yet a different kind of object experienced in the patients day-to-day life.

Mol (2002) shows how the objects of medicine multiply in the practices they are *enacted* in, but are simultaneously coordinated into something that can be

¹ Although I do acknowledge the concept of assemblage in the joint work of Gilles Deleuze and Felix Guattari (Deleuze & Guattari, 2004), I am using the concept in a more vague sense as an heuristic tool useful for understanding my empirical material (c.f. Law, 2009).

called atherosclerosis and treated in the hospital. John Law (2004) defines the verb enactment as follows:

“The claim that relations, and so realities and representations of realities [...] are being endlessly or chronically brought into being in a continuing process of production and reproduction, and have no status, standing, or reality outside those processes. A near synonym for performance, the term is possibly preferable because performance has been widely used in ways that link it either to theatre, or more generally to human conduct.” (Law, 2004, 159)

For Mol (2002, 32-33) the word enactment has a similar meaning. It is a verb that depicts the process where different actors (surgeons, patients, hospitals, Doppler ultrasound scans, blood vessels) perform something, which in that process becomes real. She uses the word as a substitute to performing, because it “*suggest that activities take place - but leaves the actors vague*” (Mol, 2002, 33), and so does not exclude the non-human actors nor allude too much to acting.

The most important thing is that enactment happens within practices and it does not see human subjects and natural objects as distinct, but framed as “*parts of events that occur and plays that are staged. If an object is real this is because it is part of a practice. It is reality enacted.*” (Mol, 2002, 44, emphasis original).²

In this research I am using the verb enact in a slightly differently alluding more to the legal meaning of the word as *putting something into action or effect*. Bipolar disorder is something that is put into action in the interplay of the biological, the social and the cultural in a human being. It is possible to analyse this enactment without presupposing bipolar disorder to exist in any of these different realms, it is an object that takes shape in the processes of a given individual organism in interaction with various objects, social worlds and cultural understandings (Ingold, 2013; Whitehead, 1978). I am interested in what is put into effect in science, clinical practice and patients’ experiences and how the multiplied object is being coordinated into something that can be researched, treated and lived with.

The coordination takes place in the mundane practices in science, clinical practice and patients’ lives. I see practices as relatively stable wholes, where discursive and material, action and conduct settle down and the unstable object, bipolar disorder, becomes coordinated and stabilised. The objective of this research is to analyse how this coordination unfolds: what is being enacted, *put in to effect*, within science, clinical practice and patients’ experiences?

²Mol (2002, 33-44) discusses with Erving Goffman, Judith Butler and several STS scholars on the ways reality is acted, performed, constructed or made, but still real. See also the Special Issue in Social Studies on Science about the so-called ontological turn in STS (Woolgar & Lezaun, 2013).

2.2 Empirical material and methodological choices

EMPIRICAL MATERIAL

The empirical material has played the most important role in the process because it was the surprises in the empirical material that informed the theoretical and methodological choices. When most of the material was collected I started to see that I had material from three *sites*: science, clinical practice and patient's lives. At this point I also realised that I was conducting an ethnography. I acknowledge that ethnography is a term sometimes overused in social sciences to refer to almost any qualitative analysis, and indeed this research did not start as an ethnography (Ingold, 2014). However, I can not find any other academically shared terms for describing this research process from the collection of the material to the way I have written this research, and the. I have *observed* psychiatry as an outsider and, at times, as a participant for years (Ingold, 2014; Strathern, 1999).

I will return to the methodological questions in the next section after introducing in detail the material I have collected. The material consists of texts, observations and interviews and later on in this chapter I will describe in detail how the snowball rolled: how observations led to collect certain texts, and the texts led to interviews, and so on and so forth. The following table shows the material used and it is categorised according to the sites and the type of material:

	TEXTS	OBSERVATIONS	INTERVIEWS
SCIENCE	Original articles in medical journals (59), dissertation summaries (7)	In conferences for psychiatrists (5)	Thematic in-depth interviews with scientists (10)
CLINIC	Reviews and original articles in Finnish medical journals (54), Clinical practice guideline + suppl.material	In Finnish resident training days for psychiatrists (4)	Thematic in-depth interviews with medical doctors in primary health care (7), specialised nurses (2)
PATIENT	Education for patients, published in print and online (16)	In the discussion forums (3) and blogs (3)	Thematic in-depth interviews with patients (3)

Science

I followed two distinct research projects: one tracing the biological mechanism and the other mapping the clinical epidemiology of bipolar disorder. I collected a

corpus of texts consisting of 59 original articles produced within these projects and 5 summaries of article dissertations conducted in the projects. To gain more information about the ways research results are mediated and discussed within psychiatry, I attended, as a participant observer, 5 different conferences lasting up to two days. In addition, I interviewed 10 scientists in in-depth interviews lasting from 1 to 1.5 hours.

Clinical practice

I collected a corpus of 54 articles in Finnish medical journals from the 1940s to present, in which the research is popularised to a wider audience of medical professionals. In addition I analysed two versions (from 2008 and 2013) of the clinical practice guideline for bipolar disorder and its supplementary material consisting of different diagnostic questionnaires and other tools to be used in clinical practice. I observed the scientists educating psychiatry residents about the science and treatment standards of bipolar disorder during 4 training days. I have used previously collected interview data where 7 primary health care clinicians discuss the treatment of mood disorders in their practice.³ In addition, I conducted a joint interview with 2 specialised nurses organising psychoeducation groups for patients with bipolar disorder.

Moreover, I have collected a corpus of 22 articles from the Finnish medical journals which serve as a secondary material. These articles are about psychiatry in general, pharmaceutical markets in Finland and the history of evidence-based medicine in Finnish mental health care. I have also picked up all available brochures, program leaflets and hand-outs from the conferences I attended as a secondary source of information.

Patient

I analysed the patients' everyday practices by following 3 separate discussion forums online. On these forums bipolar disorder patients share information and peer support about their daily lives and experiences. I have also followed the flow of information about bipolar disorder online throughout this project by conducting regular searches. In addition, collected a corpus of 16 printed leaflets and websites directed to the patients or anybody interested. These leaflets and websites provide guidance and education about bipolar disorder. To complement the material about the patients' experiences, I have followed 3 personal blogs and interviewed 3 patients in in-depth interviews lasting for approximately 2 hours.

All text sources and the list and short descriptions of the interviewees can be found in separate appendixes. The anonymised interviews have been transcribed by myself or as an outsourced service. I have not found it necessary to transcribe

³These interviews were conducted by me in 2006 for another research project, but have not been used before.

my field notes, because I have not used qualitative analysis software. The hand written notes consist of two notebooks and during the process, every time when came across something interesting online, I either printed it out, copied it to a text processor (which is what I did for interesting discussion threads in the forums) or saved it for later use in the Evernote software (www.evernote.com). In addition, I have had several journals, where I have recorded my thoughts and observations during the several years I have been following psychiatry.

ANALYSIS OF THE SITES

Psychiatry is not a place, a distinct geographical area, rather it is in action everywhere. Therefore, the methodology I have applied can be characterised as *multi-sited ethnography* – a research design expanding from of the single field of conventional ethnography (Falzon, 2009; Hannerz, 2003; Marcus, 1995; Nadai & Maeder, 2005; Wittel, 2000). Multi-sited ethnography can mean that the researcher observes something in various places, but in this case psychiatry is not something that can be accessed directly and the sites also manifest themselves ‘virtually’ in the form of online discussion threads or scientific discussions in journals (c.f. Nadai & Maeder, 2005; ?, ?; Wittel, 2000).

I am studying psychiatry and using bipolar disorder as a case example, to analyse the situated practices in the case of Finnish psychiatry. I have had to focus on the question of units of analysis in this situation where I have a case within a case. Bipolar disorder has been the main unit of analysis, which has directed the collection of the empirical material and which I have followed within the three sites. I have analysed the sites inhabited with practices, where humans and non-humans together put into effect a certain version of bipolar disorder. Therefore, within the specific sites, I have used smaller units of analysis, such as the scientist, the patient, the diagnostic tools, the pill or the knowledge about bipolar disorder. Even though the three sites are analysed in their respective Chapters 3,4 and 5, all these actors circle through the sites and in my analysis. In the beginning of each chapter I explain in more detail the material and analysis used.

The human and non-human actors are not equally visible in the empirical material and the humans tend to stand out, if one is not alert. I have benefited from Bruno Latour’s (Latour, 2005) methodological critique and his guidelines of how to render non-human actors or agencies visible in empirical data. I have followed the simple advice and looked for accounts on agency in the interviews, field notes, online material and texts (c.f. Meskus, 2014; Woolgar & Lezaun, 2013).

I have been sensitive to the dichotomies inscribed in the practices within the assemblage of psychiatry by being attentive to the practical situations and processes where the dichotomies open up and likewise where something indeed seems to be dichotomous in the empirical material. However, I have omitted

the intersectional questions of sex, race or age in the assemblage of psychiatry. This has been choice mainly informed by the empirical material, where these kinds of distinctions have not surfaced as clearly as the ones concerning the human mind/brain/body, treatment with psychotherapy/pharmaceuticals or subjective/objective science. The case of bipolar disorder in children and the differential diagnosis between ADHD and bipolar disorder has been discussed in my material, but these discussions I have left out of the analysis in this research to be further analysed in the future (about the case see Healy, 2008; Moncrieff, 2014) .

All in all, my main aim in this research has been to analyse those very practical and mundane situations where the multiple bipolar disorder is being coordinated into something the scientists can analyse, the clinicians treat and the patients live with in their everyday lives. Drawing on Mol's (2002) work I see these situations, the practices, as the snapshots where the complex reality in process can be intercepted and analysed. I am drawing conclusions about the assemblage of psychiatry as it emerges in the practices Finnish mental health care and psychiatric research on bipolar disorder.

HOW THE SNOWBALL ROLLED

As I already mentioned, I started to approach the possible empirical material for this research by mapping the historical documents. I went through the archives of the two major medical journals in Finland *Suomen Lääkärilehti* (The Finnish Medical Journal), published by the *Finnish Medical Association* (FMA) since the early 1920s, and *Duodecim* published by the *Finnish Medical Society Duodecim* founded already in the late 1800's. I quickly realised that the search engine of the online archives of these journals did not pick up all the articles, so I searched the archives of both journals systematically, volume by volume, via the online archives and the archives kept in the University of Helsinki Meilahti Campus Library from early 1900's onwards. Along the way, I also picked up interesting articles about psychiatry in general. I also conducted specific searches on topics like evidence-based medicine and clinical practice guidelines.

The most frequent hits concerning bipolar disorder emerged in the mid 1990s, and from the mid 2000s there were more and more articles, editorials and discussions about bipolar disorder. The archive work indicated that bipolar disorder, or manic depression, seemed to be quite a recent problematisation in Finnish psychiatry. At the same time I came across one of the ongoing research projects about bipolar disorder and started to notice the same researchers writing on the pages of the medical journals.

I was also interested in the educational texts provided for patients with bipolar disorder. I had used similar material on depression in my Master's thesis before. To map the printed material, I searched the archives of the National Library

of Finland. The oldest patient information leaflet I found was from early 1991, published by the Finnish pharmaceutical company Orion and addressing the specifics a patient should know in regard to Lithium treatment, but most of the material is published from the 2000s onwards. I have mapped the educational and awareness raising material about bipolar disorder from the beginning of this project and quite quickly I noticed how the material online proliferated during the process of this research.

So there seemed to be something going on as regards to bipolar disorder in Finland: increased research activities, writings in medical journals to educate the clinicians to recognise bipolar disorder, and increasing awareness-raising for lay people online.

Meanwhile, I came across an advert for a training day for resident psychiatrists on the web pages of the *Finnish Psychiatric Association (FPA)*, which was dealing specifically with bipolar disorder, and where most of the speakers were familiar names from the medical journals I had read. I attended the event, which proved to be very interesting and started to take notice of future training days. In addition I started to attend the biannual conferences of the FPA and the annual symposia organised by the pharmaceutical company *Eli Lilly*.

At this stage of the process, I had already familiarised myself with the field and next step was to interview the researchers. The interviews were partly structured, because I wanted to know what all my interviewees thought about science in general, the basic practices of psychiatric research in Finland and the research infrastructure. However, all in all the interviews were carried out as an informal chat between two researchers. I felt that the younger researchers treated me more as a peer, whereas the senior researchers tended to have a more educational approach when discussing with me. We discussed a great deal about each of their own field of research. I had mapped the publication profiles of the researchers beforehand so that I could direct my questions. We also discussed their career choices and identities as psychiatrists and clinicians. I also brought up the observations I had made during the training days or otherwise, and asked direct questions regarding things I found interesting in their work.

The interviews, the journal articles and observations in the conferences and training days started to constitute a web: an observation here led to a discussion with one psychiatrist there, which again led to other discussions with other researchers and again to new journal articles. At this point I systematically collected the corpus of research articles published in international scientific journals by these researchers and some others on the field I did not have a chance to interview.

One of the themes in the interviews that came as a surprise for me was the way these researchers were constantly referring to patients and clinical situations in their talk. It was not something I would have expected. The scientists talked

about the patients in length and it became clear to me that in addition to the scientific ambitions, the scientists were motivated by the patients' suffering. It was important for them to try to translate the research results into the clinical practice.

In 2008, the first clinical practice guideline for bipolar disorder was released in Finland. In an interview with a member of the working group compiling the guideline, the psychoeducation groups for bipolar patients came up. This interview led me to interview nurses who were responsible for leading the psychoeducation groups in a municipal outpatient clinic. With the nurses I discussed the practicalities and work in the groups, as well as the patients attending them.

Along the way, I was regularly surfing the online discussion forums for the patients and the personal blogs. This was a very rich source of material, which I continued to update until the very last stages of the research. The patients talked about their experiences with bipolar disorder from problems with the medication and the treatment system to the ways they coped with the disorder and experienced the symptoms themselves. Because I did not want to interfere in the discussions and some of the discussion threads were already closed, I felt I needed to complement this material by interviewing a few patients as well. With the patients I discussed their life histories, the way they became diagnosed with bipolar disorder and their experiences within the treatment system of the Finnish mental health care.

RESEARCH ETHICS

Regarding research ethics I have followed the principles laid by the Finnish National Advisory Board on Research Ethics and the Codes of Ethics of International Sociological Association. All interviews have been anonymised before transcription and the recordings are destroyed after the research is completed. During the research, the recordings have been stored on my personal computer and transcriptions in a locked storage.

I have used separate informed consent forms for the professionals and the patients I have interviewed, in which anonymisation and the right to refrain from participating in the research have been emphasised. I also explained the content of the consent forms and the use of the material in the research before the interviews. In the patients' interviews I was more sensitive and explained the consent in more detail, particularly as regards to their right to refrain from participating even during the interview, whereas for the scientists and other professionals, I emphasised the anonymisation and that I was going to pay specific attention to using quotations in a manner that would not directly reveal the speaker. The interviewees were not that particular on this issue. One of them gave a laugh and pointed out how in the small world everybody knows everybody and that she did

not really mind being recognised. In addition, I made two more choices to ensure anonymisation: I quote the patient interviewees using pseudonyms and I have anonymised the municipal hospital, where one of the research projects took place, so that it would not be directly identifiable. Apart from the formalities of research ethics, I found it important to foster an emphatic and understanding stance towards both the professionals and the patients, aiming more to understand them than question them. The interaction was effortless and none of the interviewees seemed to be irritated or anxious while we talked about their personal lives or when I asked naive questions about science.

In following the discussion forums and blogs online I could try to engage into empathic interaction, because I did not participate in the discussions. It was also not possible to get informed consents from all the participants, particularly because some of the threads were already archived. The use of online discussion forums as research data involves ethical issues regarding the publicity of the forums and the informed consent. The discussion forums I observed, were public and did not require registration, but it is of course possible that the participants in the discussion threads even on public forums are not fully aware of the publicity of their posts. This is more a problem in research that analyses the interaction of specific threads or the interaction of the participants on one forum (Kozinets, 2010, 136-156). I did not follow specific participants, nor did I analyse the interaction of the participants, I simply visited the forums from time to time and most of the individual participants with their nicknames were anonymous for me already when I observed the forums. Therefore I find it less of a problem to use individual posts without the consent. I asked for permission to use the material from the administrators of the forums and the heads of the patient associations running the forums (Kozinets, 2010, 136-156).

I have taken specific care in fully anonymising the quotations I have used from the patients' posts. The quotes have been translated from Finnish to English by myself, so that the translations are not direct, which unavoidably eliminates the possibility of finding the discussion threads in search engines. To further minimise the risk of identifying the quotes, I do not mention the name of the forums or the nicknames of the discussants, nor the time or titles of the discussion threads. These principles of anonymisation also applies to the personal blogs I have used as research material, but from the one blogger I have quoted in the research, I have asked for and received the consent. These principles of ethical conduct I have applied as advised by Robert Kozinets in his book *Netnography* (Kozinets, 2010).

The conferences and training days I attended, were open to anybody interested. In these settings, it was of course impossible to ask for permission from all the attendees. I did, however, inform the organising parties that I was interested in the conferences because of my research. I discussed the observations in the

conferences and training days with some of the interviewees, and also mentioned my role in the events to some attendees at lunch. Nobody seem to be bothered about my role as an ethnographer observing the events. In addition, I have not identified which conferences and training days I attended and avoided naming the events in the text as well.

The data management plan of this project follows the Finnish Social Science Data Archive (FSD) guidelines. The main responsibility for me has been to ensure the inaccessibility of confidential data, to manage the archiving of the data after the completion of this project, and to distribute the thesis to the participants if they wish for it.

Chapter 3

Bipolar disorder as an object of science

3.1 Introduction

In this chapter, I analyse the ways scientists trace and map bipolar disorder in human neurobiology and in the clinical reality. I show how epistemological premises, personal interests and enthusiasm, as well as research infrastructures and mundane practices *together* direct the ways scientists approach their research object. In addition, I show, how the process of selecting the research subjects forces the scientists to work through and adjust the diagnostic standards of bipolar disorder.

I have analysed bipolar disorder research within two research projects. One is a project where scientists are tracing bipolar disorder in the neurobiology of the human organism with the methods of molecular genetics, neuropsychology and brain imaging. The other project is a clinical epidemiology mapping the naturalistic manifestation of bipolar disorder and aiming to provide more information about the clinical picture and diagnosis of bipolar disorder.

A starting point for my analysis in this chapter, was the observation that the scientists themselves do not describe their work as a linear process, where science reveals the secrets of the brain functions, the hereditary mechanisms or the clinical features of patients with bipolar disorder. Science seems to be a more complex process, where the mundane practices, as well as the affective and enthusiastic side of science, play important roles (Fitzgerald, 2012, 2013, 2014; Pickersgill, 2011b, 2012a).

In this chapter, I will show what is put into effect when bipolar disorder is placed under the scrutiny of the scientists. I will analyse the ways the scientists deal with the diagnostic uncertainty and try to stabilise the multiple object in order to study it. The diagnostic uncertainty motivates the scientists' research and demands working through methodological problems. This is why I pay

specific interest to the ways the researchers reason through the gap between the DSM definitions of bipolar disorder and the clinical or biological reality.

THE MATERIAL USED TO ANALYSE THE SCIENTIFIC PRACTICES

In this chapter I have used material gathered within the two mentioned research projects. Both were joint projects of the National Institute of Health and Welfare (NIHW, formerly National Public Health Institute) and Department of Psychiatry in the Helsinki University Central Hospital (HUCH). The project on neurobiology of bipolar disorder was a more loose collaboration of smaller projects not limited to specific data or time period. The other project was a clinical epidemiology where the data was gathered from the population of a municipal hospital in the Helsinki metropolitan area. This hospital is anonymised as Hospital X. These projects were the sites where almost all bipolar disorder research in Finland took place during the time of my research and therefore provided excellent cases to analyse bipolar disorder research.

I have read all the research articles published within these projects and interviewed the researchers in thematic in-depth interviews. I had a thematic set of questions about the conditions of doing research in general in Finland, such as research infrastructures, funding and collaboration. However, because the interviewees all had slightly different research interests and career paths, we also discussed their research interests and personal motivations in the interviews. I had familiarised myself with the publications and research of each interviewee and tailored the themes according to the profile of the researcher.

The interviews proved out to be a very important source of insight into the mundane research practices, and to the clinical practice of treating patients as well. The latter aspect took me somewhat by surprise. Even though many of the researchers did clinical work, I did not expect the scientists to speak that much about the patients and the clinical reality, considering that I did not specifically ask about these themes. I use this aspect of the interviews in Chapters 4 and 5.

The publications produced within these two research projects were important in providing an overview of the research projects. I have read through all the journal articles and analysed parts of them more in-depth by paying attention to the data collected, the ways research process is described in the articles and the ways results are elaborated and discussed. As mentioned, the journal articles also provided information that I discussed with the authors in the interviews. In the same way, I also utilised observations from the conferences and resident training days, as well as the material from the domestic medical journal articles in the interviews.

THE STRUCTURE OF THIS CHAPTER

To begin this chapter, I will introduce bipolar disorder as it is defined in the diagnostic manuals. In the first part of this Chapter, I will introduce the scientists and the research infrastructure of the two projects followed in this research. I will then introduce the research projects tracing the neurobiology of bipolar disorder and analyse how the scientists balance between the hopes and disappointments of the difficulties in translating the results from neurosciences to clinical practice. This leads me to analyse the ways in which the scientists invest, not only their time and energy, but also their feelings in the research.

In the remainder of the Chapter, I will introduce the other research project mapping the clinical epidemiology of bipolar disorder. In this part of the chapter, I pay particular interest in the mundane processes of patient selection. The processes where the research population is formed show how the scientists need to balance between the demands of objective and valid research and the fuzzy clinical reality where patients do not exactly fit the diagnostic categorisations.

3.2 The object of research: bipolar disorder

DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS

As I already noted in the introduction to this thesis, what is meant by *manic depression* or *bipolar disorder*, varies both historically and culturally (Angst & Sellaro, 2000; Angst & Marneros, 2001; Craddock & Owen, 2005; Marneros, 2001; Moncrieff, 2014). The diagnostic manuals used in psychiatry, the Diagnostic and Statistical Manual of Mental Disorders (DSM) and the International Statistical Classification of Diseases and Related Health Problems (ICD), define the medical condition today known as bipolar disorder. The DSM categorisations are used in the research projects I studied, because it has become the international standard in neuroscience, as well as psychiatric and psychological research. Although the ICD is the official manual used in health care in Finland and it is the coding used in the patients files and records, the DSM is widely used in clinical practice as well (Furman et al., 1985).

As I noted in Chapter, in the 3rd edition of the DSM manual, released in 1980, the diagnostic criteria of a given mental disorder was based merely on descriptions of observed symptoms, signs, and course of the disorder. This change was supposed to increase the validity and reliability of psychiatric diagnosis, so that every clinician, regardless of the school of thought or clinical experience, would diagnose the same patient with the same disorder. This new way of understanding and classifying mental illnesses transformed the theory and practice of mental health care in western world and the section of mental and behavioural disorders in ICD was harmonised with the DSM (Compton & Guze, 1995; Furman et al.,

1985; Mayes & Horwitz, 2005).

However, in clinical practice the two manuals intermingle. The clinical practice guideline for bipolar disorder advises the clinician to use partly both manuals, because the ICD-10 manual does not recognise bipolar 1 and 2 as distinct diagnostic categories. The use of the manuals in day-to-day practice depends on the clinician. One of my interviewees told me that some colleagues refuse to use the DSM and related diagnostic questionnaires in their clinical practice because it is not the official classification, and because they feel the questionnaires impairs their clinical decision making.

In the DSM, the symptoms of hypo/mania consist of changes in mood and behaviour. The so-called mood symptoms are a period of elation or irritation. Either one of these mood symptoms is indispensable for a bipolar disorder diagnosis and must be combined with three or more of the so-called behavioural symptoms. The criteria for a hypo/manic episode are:

“A. A distinct period of abnormally and persistently elevated, expansive, or irritable mood, lasting at least 1 week [4 days in hypomania] (or any duration if hospitalization is necessary)

B. During the period of mood disturbance, three (or more) of the following symptoms have persisted (4 if the mood is only irritable) and have been present to a significant degree:

- (1) increased self-esteem or grandiosity
- (2) decreased need for sleep (e.g., feels rested after only 3 hours of sleep)
- (3) more talkative than usual or pressure to keep talking
- (4) flight of ideas or subjective experience that thoughts are racing
- (5) distractibility (i.e. attention too easily drawn to unimportant or irrelevant external stimuli)
- (6) increase in goal-directed activity (either socially, at work or school, or sexually) or psychomotor agitation
- (7) excessive involvement in pleasurable activities that have a high potential for painful consequences (e.g., engaging in unrestrained buying sprees, sexual indiscretions, or foolish business investments)”
(APA (American Psychiatric Association), 1994, 362)

At the other end of the fluctuating moods in bipolar disorder is depression. DSM uses the same criteria for depression in bipolar disorder as in the diagnosis of major depression. The criteria for a depressive episode are characterised in the DSM as follows:

“Depressed mood and/or loss of interest or pleasure in life activities for at least 2 weeks and at least five of the following symptoms

that cause clinically significant impairment in social, work, or other important areas of functioning almost every day:

- (1) Depressed mood most of the day.
- (2) Diminished interest or pleasure in all or most activities.
- (3) Significant unintentional weight loss or gain.
- (4) Insomnia or sleeping too much.
- (5) Agitation or psychomotor retardation noticed by others.
- (6) Fatigue or loss of energy.
- (7) Feelings of worthlessness or excessive guilt.
- (8) Diminished ability to think or concentrate, or indecisiveness.
- (9) Recurrent thoughts of death” (APA (American Psychiatric Association), 1994, 356)

The indispensable criteria for any mental disorder is that the symptoms are “*clinically significant*”, the term used to distinguish the mental disorder from normal mood swings in life. But the problem still exists: how exactly should these symptoms be interpreted? What does mild elevation of mood mean? How many hours per night represents decreased need for sleep? In the hypo/manic symptoms there are other questions of interpretation: in what kind of normative frame should the increase of sexual energy or sociability be defined?

These problems of interpretation are at the heart of the diagnostic uncertainty in psychiatry and DSM is not fully able to overcome the problems. However, in the context of science, the criteria is needed to compare and accumulate research results and to communicate the results to professional and wider audiences. The DSM provides a mutual language for the scientific community just like it does in clinical practice in the discussions between the psychiatrist and the patient.

The particular problem in diagnostic uncertainty and the interpretative nature of the symptoms of bipolar disorder for science is the fact that the selection of research subjects is based on the DSM categorisations. So the question remains: what is actually being researched as bipolar disorder? Are the research subjects representative of the bipolar disorder patients in real life or representatives of the DSM category? This is why, for instance, the scientists in NIMH argue that a symptom-based categorisation is not a valid way of conducting patient selection in basic research (Insel, 2013). The scientists I studied also needed to adjust the DSM standards in their research so that the research population would represent the patients with bipolar disorder in reality.

A MOOD SPECTRUM

It has been suggested that actually all the disorders under the category of mood disorders should be seen as a wide *mood spectrum* ranging from mild symptoms to psychotic states and avoiding a clear distinction between disease entities like depression or bipolar disorder. The DSM system, as it now is, fails to

grasp the clinical reality of different mood disorders and the sophisticated ways hypo/mania and depression can fluctuate and change (H. S. Akiskal, 1996; Angst, 2013).

There has been quite an influential discussion on mood disorders attempting to comprehend the disorders in a new way and challenge the DSM system by actually investigating the clinical reality of bipolar disorder and creating new classifications based on this research (H. Akiskal, Maser, Zeller & et al, 1995; H. S. Akiskal, 1996; H. S. Akiskal, Benazzi, Perugi & Rihmer, 2005; H. S. Akiskal et al., 2006). This discussion has been especially promoted by Armenian-American psychiatrist and bipolar disorder researcher Hagop Akiskal. He sees mood disorders as a spectrum ranging from depressive to manic, from agitated to stagnant and varying in the severity of the symptoms. The mood spectrum model also involves an idea of temperaments as *endophenotypes* behind the many different clinical manifestations of the mood spectrum. The concept of endophenotype refers to biological manifestations of the mood disorders that lie in between the genotype, the genetic coding of the individual, and the phenotype, the way bipolar disorder manifests itself in the moods, emotions and behaviour of the patient (H. S. Akiskal et al., 2006).

The researchers in the clinical epidemiology project needed to slightly adjust the DSM standards in their patient selection process and the mood spectrum model was used to justify the changes. The diagnostic uncertainty is indeed a practical issue, requiring “practical uncertainty work”, as the sociologist Martyn Pickersgill (2009) has described the mundane processes where scientists work through the problems of the DSM system. I will return to this important matter later on in this chapter, but first I will introduce the scientists and the research infrastructure in which they work in Finland.

3.3 Day-to-day bipolar disorder research in Finland

WHO ARE THE SCIENTISTS ENGAGED IN BIPOLAR DISORDER RESEARCH?

The scientists and clinicians I have followed and discussed with come from the educational backgrounds of genetics, psychology and psychiatry. These professionals represent different phases of professional career in both research and clinical work; from a PhD student and resident to a professor and leading clinician. Clear-cut distinctions between the disciplines of psychiatry, psychology, neuropsychology, neuropsychiatry or neuroscience is sometimes hard to make, because the research projects I followed were multi- or cross-disciplinary. Therefore, I have decided to use the more generic words scientist and researcher, when referring to the individuals in the research projects.

As a profession psychiatrists are usually physicians who specialise in treating

mental disorders during 5-6 years of training besides normal clinical work with the patients. So the expertise of a psychiatrist in Finland is built in residency training. This means working as an employee in a given hospital and regularly attending academic seminars and training days on various topics. The scientific expertise is gained in more academic settings by conducting a PhD research, and the clinical expertise by working with patients under supervision by a senior practitioner added with a possible psychotherapeutic training. The psychologists also specialise in a certain field in psychology, such as cognitive- and neuropsychology, and have their own residency period.

Many psychiatrists and psychologists are also trained psychotherapists authorised to treat patients by the National Supervisory Authority for Welfare and Health (Valvira). What differentiates the psychiatrists and psychologists as clinicians, is most significantly the permission to prescribe drugs of the former. The division into clinical work and research is by no means absolute; all the scientists I interviewed, spent some of their working hours in the clinic as well.

I discussed the residency training of young psychiatrists with one of the senior researchers, who was also responsible for the training in one of the hospitals in the Helsinki area. She portrayed the young residents as doctors who do know that they are engaging with a very peculiar medical discipline, which is not quite exact, but all the more interesting. She told me that the psychiatry residents know the limits of translating scientific knowledge into clinical practice and they acknowledge that this means hard work in terms of diagnosing and treating the patients.

I asked all the interviewees about their career choices and most of them mentioned that they had developed an interest in the human brain and mind early on in their medical studies. But then again, one of the scientists was first interested in quite another field in medicine, but ended up working part time in psychiatry after several years as a stay-at-home mother, and in the end became an active senior researcher and project leader.

The scientists had diverse paths for ending up conducting research particularly on bipolar disorder, ranging from personal interest or wanting a specific person's supervision to answering a job advertisement by chance. Consider how this scientist described her interest and enthusiasm in psychiatry:

“I am interested in the brain, the mechanism of the brain, the human mind, human action, and how to link the psychological concepts to the biological ones. Back in the day these things were from totally different theoretical worlds, but not anymore. We don't think that way anymore. Even the old school psychoanalysts today think that it is *neuropsychanalysis* they are doing.” (Scientist4)

In the career path stories of my interviewees the enthusiasm for the interplay or relation between the human brain and the mind was common. There was

something in bipolar disorder that seemed to be particularly interesting, even though one would not identify oneself as a bipolar disorder researcher, as this interviewee: *"It's not just bipolar disorder I'm interested in, it is more this data I happened to have. But it's like through bipolar disorder, I try to understand human behaviour and I think it is a really interesting thing right now."* (Scientist5).

MULTIDISCIPLINARY WORK AND NEW IDEAS

In a small country like Finland, the scientists usually know each other personally. The small circles make it easier to gather the expertise needed in a given research project and the research groups are more or less multidisciplinary. In addition to the scientists with their different academic and disciplinary backgrounds, there are also other experts in the research groups: such as statisticians, laboratory technicians and research nurses. For instance, a senior neuropsychologist told me that she found it impossible to do research without *"the psychiatrist, the geneticists, the biologists, the statisticians and us psychologists. We haven't even thought about us as a multidisciplinary group, because it is self-evidently so"* (Scientist3).

This brings up the different roles researchers with various backgrounds have in these groups. For example one of my interviewees had a double role as a trained molecular geneticist and psychiatrist. She told me that when she works with a team consisting mostly of psychiatrists, she is the "geneticist" in the group, but when she is in the laboratory doing genetic research, she is the "psychiatrist" in the team.

The multidisciplinary group does cause some challenges in communication. For instance, a young neuropsychologist, a PhD candidate, described how she at first had problems in finding a mutual language with the psychiatrists in the group: *"perhaps the way of thinking is simply different, like a more diagnosis-oriented thinking, it's like they are more straightforward than we in psychology tend to be"* (Scientist7). All in all, a multidisciplinary group means that the researchers need to be able to communicate with each other and this sometimes means that they have to adjust to non-familiar ways of thinking and speaking about bipolar disorder. However, as the geneticist/psychiatrist cited earlier explained to me, the difficulties can be overcome; the concepts and language translate through disciplinary boundaries:

"Multidisciplinary work challenges the way you use your own concepts and the way you discern your subject. You need to explain in words of one syllable, to yourself as well, what exactly was the point I had here. I have been writing an article with a biologist and it has been a one of a kind journey and I have lost faith many times just because of the linguistic reasons. But you also need to figure out for who's audience you are addressing and how you are supposed to direct the whole article." (Scientist1)

This excerpt also raises the idea that one needs to think of the audience when publishing research results, an important issue I will return to later on in this chapter. The individual scientists work in their respective fields and report the results from their data with different partners in the multidisciplinary group, but the groups of course also have regular meetings with everyone present. The meetings are for catching up with the members' individual projects, for planning the future research on the data and sharing news from conferences the group members have attended. Conferences provide networking and new ideas, which are then brought to the group meetings to discuss: *"In the conferences you hear what's going on in the field. But I find them a bit stressful, because I get so many ideas of new research, when the old ones are still on progress"* (Scientist4).

I asked all the interviewees what the research of their dreams was; what kind of bipolar disorder research they would like to conduct if there were limitless resources and they could fulfill their wildest ideas. The scientists in clinical epidemiology wanted to add genetic or imaging data into their frame and similarly the scientists working with genetics and imaging wanted to turn to the clinic. They wanted to solve the problem of translating scientific knowledge to clinical practice. The hypotheses the scientists dreamed of testing ranged from neural networks and autoimmune hypotheses to pharmacogenetics. One of the scientists wanted to change the diagnostic system altogether:

"The big dream would be to gather a large set of data, which would represent all the different kinds of people with different kinds of psychic suffering leading to specialised health care. Based on this data we could find completely new groups of people and clusters of symptoms never seen before. And then we could really renew the diagnostic categorisation based on the clinical reality. That would be the dream." (Scientist1)

RESEARCH FUNDING

A basic infrastructure for any research is obviously money and both the data collection and analysis need funding. The projects I followed in this research were mostly publicly funded. For instance, for the data collection of the genetic research, the funding came from the Academy of Finland and the actual analysis and reporting of the data was then funded by grants for the individual scientists. Another example was the clinical research project, funded the Academy of Finland and Helsinki and Uusimaa Health Care District's to collect the data. Individual researchers received their funding from private foundations and small grants from the pharmaceutical industry, in this case Eli Lilly's and H. Lundbeck's foundations.

This represents a common funding structure of a psychiatric research in Finland, where the role of pharmaceutical industry is rather small. As one

of my interviewees pointed out, apart from a few private clinics conducting pharmaceutical research on new drugs, there is relatively little industry funded research in Finland altogether. The main form of collaboration is the education, which I will return to in Chapter 4.

As the main funder of the bipolar disorder research in Finland, the state has its demands. The Ministry of Social Affairs and Health is directing the research done in the National Institute of Health and Welfare, which is a state funded research institute. One of the senior researchers told me, this meant more demands to produce knowledge that could be directly translated to clinical practice, as well as different kinds of reporting on the current situation in mental health care. This all of course diminishes the resources for basic research on mental disorders. She felt, however, that it was possible to hold up in the situation: *“we just have to find the time to do the basic research, because that knowledge is the only path to any translation to mental health care.”* (Scientist3).

A professor and a senior project leader described the situation as follows:

“There is of course a completely justified worry about the distorted results in industry funded research. But there is an opposite worry that if the industry is not at all interested in psychiatry, our discipline suffers. And this is actually a quite big problem at the moment, because there are only a few new molecules to be studied and the mechanism of the disorders is so difficult to grasp. It is a risky business for the industry. And then from our point of view they have huge resources compared to the academy. Like for decades we have talked about the problems and the urgent need for research funding, but this has not opened up any flow of money to psychiatric research. But you see the problem here? In the 1990s we talked about the suicides and depression and here we are. Today we have young people going untreated to disability pensions because of depression, but still nothing happens. It is so senseless.” (Scientist6)

The scientist has a point, when he states that psychiatry needs pharmaceutical industry funding in order to survive in the diminishing state funding and tightening demands for translatable research results. The public and private partnership models in mental health research and care are becoming more and more common in the industrialised West (Applbaum & Oldani, 2010).

PUBLISHING RESEARCH RESULTS

When I started reading the scientific articles published within the research projects in both domestic and international medical journals, my very first observation was that the audience mattered. The comparison of the ways scientists portray bipolar disorder in international medical journal articles, the applied domestic

medical journal writings, not to mention the presentations in the educational events, showed that the results were presented differently in different contexts. I discussed this observation with the interviewees and they talked about this discrepancy in terms of both publishing and educating colleagues with varying expertise in psychiatry. I will return to the latter aspect in Chapter 4.

There is an ample variety of medical journals, from the general medical journals covering wide-ranging topics in medicine to the ones dedicated to a respective medical speciality. The research results of the projects I followed, were published in medical journals specialised in the field of psychiatry, or even more specifically mood and affective disorders, as well as journals specialised in genetics or brain imaging. When the scientists talked about publishing, they usually noted that the way they write about the results depends on the journal they aim at: *“the policy and the readers of the journal direct the ways we set the preface and in a way justify the results”* (Scientist3).

As the researcher quoted above notes, the articles are usually framed differently depending on the context. For instance in an article published in a genetics journal, the writers need to start with a general introduction to bipolar disorder, whereas in the special journals for bipolar disorder research this is not needed. These differences stem from both the journals' publication policies and the differences in the supposed expertise of the readers.

What I found more striking was indeed the differences in representing the research results in various media. In the journal articles, the results are always positive, always confirming the hypothesis, but in the conference papers and more review articles in domestic journals, the same scientists are wary and do not state any definite results.

When I expressed my wonder about this to one of the interviewees, she told me this is due to the well known publication bias in science: *“the whole scientific community knows that only positive results are published”* and the interviewee continued to ponder the bias in her field, psychiatric genetics:

“But there is the problem that our negative results are not real exclusions, because the data doesn't have enough power. We do think that one specific gene has very little effect on the risk, so statistically we need large data sets. But when we have a heterogeneous disorder, like bipolar disorder, there is just not enough population to conduct the research and in different populations the environmental factors are changing, so we can't replicate the results. It is not a positive nor a negative result if the power of the data to validate the hypothesis is not enough. So it is not only a question of the tradition in science that the positive results are reported in the journals, there are also factors in the research object or the methodology at play.” (Scientist4)

Researchers are well aware of this bias. Scientific journals are not keen to publish

articles reporting of a phenomenon or treatment effect not existing, or results from researches using data that does not reproduce previously published work. In psychiatric science this, for instance, means that the DSM categorisations need to be used in every research so that the data is comparative with previous research. In medical sciences this publication bias is a problem also in clinical trials on pharmaceuticals and other treatments (Dickersin & Min, 1993; Chan & Altman, 2005), but it is obviously problem for basic research as well (Insel, 2013). One of the scientists summarised what this publication bias means for basic research:

“I think it would also be important to know which genes do not associate or to know that when we study this subject in this kind of model or frame, there are no findings. But these kinds of articles are not published in any journal, you need to have a finding in order to get your article through. I think this is a problem” (Scientist2)

The skewed traditions of scientific publishing have created a situation where scientists are not able to report results that prove certain hypotheses wrong or certain designs in certain subjects not useful. The academic world lives in the publish-or-perish economy where funding is dependent on publications. At the same time, the structures of the publication process can seriously hinder the accumulation of knowledge and the creation of novel research designs. I will return to the issue of clinical trials and evidence-based medicine in Chapter 4, because the publication biases in clinical trials are much more complex and do not limit to the pressure of publishing positive results.

3.4 Tracing the mechanism of bipolar disorder

I am using the word *trace* to describe the efforts of the scientists to untangle the pathophysiology of bipolar disorder. I take the metaphor of tracing from Des Fitzgerald’s (2012) dissertation, which is “*about neuroscientists’ on-going search for a brain-based biomarker for autism*”. I feel very much affinity with his analysis on the in-depth interviews with the neuroscientists doing autism research. He observes many of the exactly same dynamics in the scientists relation to objectivity and their research subjects, as well as the ways the scientists hold together their complex and moving target, as I do in reading my own interviews.

Fitzgerald (Fitzgerald, 2012, 2014) points out that the neuroscientists need to constantly place themselves within distinctions between, for instance, psychology and neuroscience, mind and brain, subjective and objective knowledge, biological and social, hard and soft science, as well as the biological and diagnostic definitions of what they are researching. One of the aspects in this active labour of the scientists is the way they balance the dynamics between the hopes and disappointments invested in cutting-edge neuroscience to be translated into clinical

practices of treating patients. In this section I will use this point in analysing how the scientists I interviewed take positions in studying bipolar disorder via molecular genetics and structural brain imaging.

THE GENETICS AND BIPOLAR DISORDER RESEARCH

In her illustratively titled article "*The century beyond the gene*" Evelyn Fox Keller (2005) separates the terms 'gene' and 'genetics' – the former referring to the entities historically assumed to be important in the process of heredity and the latter being the study of the processing of DNA in the construction of a phenotype.

This conceptual distinction points out that the hopes and promises invested in the sequencing of human genome were not met. In the so-called post-genomic era, the neuroscience research has focused on the search for single-nucleotide polymorphisms (SNP) associated with a given mental disorder or phenotype. To increase statistical power, the SNPs are studied in large genome-wide association studies (GWAS). The processes of genetic coding mechanisms in cells and in the whole organism have been studied in epigenetics (Kendler, 2005). The interplay between the genes and the environment, the nature-nurture problem, has been addressed in many kinds of designs studying the gene-environment interactions (Caspi & Moffitt, 2006; Moffitt, Caspi & Rutter, 2005) and the in the quest for the endophenotypes, which are intermediate components between a complex disease and the susceptibility genes, such as cognitive functions with a genetic connection (Gottesman & Gould, 2003).

The research conducted in the field of molecular genetics of bipolar disorder reveals the dynamics of high hopes and disappointments, because the heritability of bipolar disorder is a clinical observation made already by Emil Kraepelin in the 1800s. The fact that bipolar disorder runs in families has been grounded on twin, family and adoption studies in the 1970's. In Finland genetic epidemiology and other genetic research has been popular, because the Finnish population has been considered to be a genetically isolated population, the registers are accurate due to the welfare state health care system, and the individuals are willing to participate in research (Hovatta et al., 1997; Peltonen, Palotie & Lange, 2000; Meskus, 2009).

In early 2000s a sample of Finnish families and twin pairs with bipolar disorder was gathered, by enrolling the research population from different registers. This data was analysed and several chromosomal regions and SNPs were found in these association studies (Ekholm et al., 2002, 2003; Ollila et al., 2009; Palo et al., 2007, 2010; Pekkarinen, Terwilliger, Bredbacka, Lönqvist & Peltonen, 1995; Soronen et al., 2008, 2010). The same data was used to map the possible endophenotypes for bipolar disorder in the cognitive functions, such as executive functioning and psychomotor processing speed (Antila, Tuulio-Henriksson,

Kieseppä, Soronen et al., 2007). The data was also used to replicate the findings made earlier that a certain DISC1 haplotype (a sequence of chromosome, where multiple SNPs appear) was first associated with schizophrenia. This was one of the most prominent findings in psychiatric genetics, but when the study was replicated in other populations, including the Finnish data, DISC1 associated also with bipolar disorder and major depression (Hennah et al., 2009).

Nikolas Rose and Joelle Abi-Rached (2013, 107) point out that the DISC1 studies exemplify the general problems in psychiatric genetics. When it was first associated with schizophrenia, there were high hopes this anomaly could be a candidate biomarker by which to diagnose schizophrenia. But the future replications turned this hope into a disappointment, because the same biomarker could not serve as a diagnostic test for three different and distinct mental disorders. The promise of psychiatric genetics was, in particular, in the hope that the concrete biological laws of genetics would shed some light on the biological mechanisms of mental disorders and the results would be translatable at least into personalised drug treatments if not clear biomarkers. One of my interviewees put the disappointment in the field into words as follows:

“In these international conferences for psychiatric genetics, the terrible disappointment has been tangible. The scientists became frustrated when nothing ever replicates properly and it seems that all the findings are eventually just left floating in the air as promises never kept. But perhaps this disappointment has also introduced some new waves into the research.” (Scientist4)

She continued to elaborate on how molecular genetics could be beneficial in psychiatric research after the initial hopes had not come true:

“It would be important to fund and support diverse research. Like even though there are these fashionable trends in science or things that are just technically and methodologically possible right now, there should be other methods in use. And then when we reach some baby step advances, we would have diverse methods, which could provide novel results. You always get the answers you are asking for in science. It really is the hypotheses that determine the answer, yes or no.” (Scientist4)

The interviewee referred here to the possibilities in epigenetic research and the hopes of technological advances in gene sequencing which might widen the scope of genetics from the designs attempting to associate single genes or SNPs to multifactorial diseases. I am reading her account as hope for a more ideological than pragmatic way to do research; a paradigm where the hypotheses would be tested with novel methods suited for those hypotheses, not the other way around.

CAN YOU REALLY SEE BIPOLAR DISORDER IN THE BRAIN?

Like gene sequencing techniques, the new brain imaging techniques have also shaped the ways scientists form their hypotheses of what can and can not be studied within mental disorders and the human brain in general. Brain imaging provided a promise to actually see into the thinking and feeling brain when the technologies advanced considerably from the 1970s and 80s onwards (Rose & Abi-Rached, 2013).

The imaging techniques are simulations of the structure (CT, MRI) or the functioning (PET, fMRI) of the living brain. These imaging methods are currently used in diagnosing tumors and large injuries or the functional changes caused by Alzheimer's disease in the human brain. However, these technologies are indeed imaging the brain not picturing it. The technologies are complex models using x-rays, magnetic fields, radio waves, oxygenated blood, radioactively labeled chemicals and sophisticated statistical models to produce 'pictures' of the brain. These images are then thought to be interchangeable with the actual brain in the physical body, which they are not. This is particularly true in the popular discourses of brain imaging and certainly contributed to the idea that it is possible to actually see the thinking and feeling mind in the brain; to see the personhood in the brain (Beaulieu, 2002; Dumit, 2004; K. Joyce, 2005; K. A. Joyce, 2006; K. Joyce, 2011).

"Bipolar disorder and the brain - what can be seen?" is the title of a lecture on brain imaging, from one of the resident training days I attended, where the scientists were educating the junior clinicians about scientific approaches and research results on bipolar disorder. The lecturer, one of the researchers I interviewed, introduced bipolar disorder research using different structural and functional imaging techniques. Her lecture summarised the findings with a very cautionary tone and warned the junior psychiatrists not to expect too much translatable knowledge from the imaging technologies (c.f. Fitzgerald, 2012, 88-116).

The brain imaging studies conducted on the Finnish population have been based on a sample of twins diagnosed with bipolar disorder. The MRI scans from this sample of bipolar disorder twins, their co-twins and controls, was analysed in the early 2000s in several articles and meta-analyses where the basic findings suggested that there were alterations, myelination, of the left hemisphere white matter, as well as increased hippocampal and amygdala volume when the research subjects were treated with lithium.

White matter in the brain is involved in transmitting information from one part of the brain to the other, so the these findings in the structural anomaly in the brain of patients with bipolar disorder do not reveal anything specific about the biological background of bipolar disorder in the human brain. The results of the MRI imaging hinted to one direction in the structure of the brain, the white matter, for the future research to take use of. In an interview the scientist

discussed the limits of brain imaging:

“The results are not that sensational. If you look at the meta-analyses and try to find what it is they actually found, there is nothing that couldn’t be explained by pure chance. The methods are still so rough that they just can’t see the differences in the sophisticated activity of the brain. Like when we have research showing that the metabolism of the brain is activated in mania, this is hardly any news to a clinician. It is not that this wouldn’t be interesting thing to study, but we are in the very beginning of understanding the imaging technologies, as well as the brain itself, so we don’t know what might be found. Or perhaps there is nothing to be found in the imaging studies. It is also a possibility.” (Scientist5)

FEELINGS OF HOPE AND DISAPPOINTMENT IN BIPOLAR DISORDER NEUROSCIENCE

In one of the conferences I attended, an annual symposia organised by the pharmaceutical company Eli Lilly, a keynote speaker opened up his presentation with a telling slide: two identical pictures of mice, one named “*the depressive mouse*” and the other “*the bipolar mouse*”. The slide, presented to an audience of prominent scientists, was an anecdotal representation of the difficulties in using animal models to study bipolar disorder. Animal models are problematic in the research of mental disorders most notably because it is so hard to induce a complex set of emotion, thoughts, moods and behaviour in, for instance, a rodent (Nestler & Hyman, 2010; Rose & Abi-Rached, 2013). Animal models exemplify the problems of translation from the experimental models of neuroscience to the lived reality of mental disorders in the clinic. The same problems of translating concern any of the experimental models in neurosciences, also the research on molecular genetics and brain imaging.

The scientists I interviewed and observed were very aware of the problems of translating their research into clinical practice, as well as the mentioned problems of replicating the results of genome-wide association studies or finding significant results with the brain imaging technologies. Despite the disappointment with the power of the technologies and methods, the scientists were able to continue their work. The feelings of hope and enthusiasm are invested in novel ways of forming diverse hypotheses and new technologies to test these hypotheses. The scientists are still searching for a genetic mechanism to explain why some of us develop the symptoms of bipolar disorder, or a biomarker to help diagnose the condition.

This balancing act between the feelings of hope and disappointment is exactly what it means to *trace* bipolar disorder. The experimental scientists are indeed tracing an objective thing, which, for the scientists I interviewed and observed, is neurobiology of bipolar disorder. The expression illustrates the way the scientists are at the same time holding on to the idea that there is an objective thing to

be traced, and that the hypotheses, methods and technologies used to trace that objective thing have failed to fulfill the expectation invested in them (Fitzgerald, 2012).

The scientists work through this ambiguity in their own feelings in the context of the research infrastructure in a wider sense. The tracing of bipolar disorder takes place within the assemblage of actors shaping the research infrastructure. The scientists balance between the demands from the funders, the pressures to publish, the disciplinary and communicative boundaries of the multidisciplinary group. Moreover, the scientist's work is limited by the non-human actors, the technologies, methods and apparatuses by which the research is put into practice. The feelings of hope and disappointment intensify in the work of creating new ideas and hypotheses and understanding that in reality the scientist's dreams are not enabled by the research infrastructure.

The 'objective' neuroscience is indeed embedded in an assemblage of 'subjective' factors: the social and political context and infrastructure, as well as the feelings, orientations, educational backgrounds and personal choices of the scientists themselves (Despret, 2013; Fitzgerald, 2013; Pickersgill, 2012a; Svendsen & Koch, 2011; Wilson, 2010).

One of the aspects of the scientists disappointment in tracing the neurobiological bipolar disorder in the brain and the heredity was that their research did not benefit the patients. The lives of the patients were mediated to the scientists through the technologies and methodologies they used. Patients manifested themselves as blood samples or statistical variables in their data.

The other project I have followed in this research was more closely in connection to the patients. The project was mapping the clinical picture of bipolar disorder in a naturalistic research design, aiming indeed to produce results that could be directly translated into the clinical practice of diagnosing and treating patients. In what remains of this chapter, I will introduce this research project and focus on the ways the DSM criteria of bipolar disorder was adjusted to meet the aims of the research. In addition, I will show how the important the process of patient selection is in psychiatric research in general.

3.5 Mapping the clinical reality of bipolar disorder

PLANNING A RESEARCH PROJECT

This project took its first steps in the late 1990s on a backseat of a bus in Croatia: two scientists were traveling back home from a conference, where they had been presenting a joint study on the clinical epidemiology of depression, investigating the naturalistic outcome of depression to develop more rational clinical practices to treat depression. One of these researchers described the discussion they had

on what could be the next subject to investigate:

“So the question of suicidal behaviour and depression we had been studying seemed to always bring along the fact that many patients had something one could call ‘speed’ in their life before. At the end of the 90’s, we didn’t know much about bipolar disorder, and in Finland there was hardly any research.” (Scientist2)

At this time depression and suicidality were the main targets of Finnish psychiatric research and mental health care. The tradition of psychiatric epidemiology and social psychiatry has been strong in Finnish psychiatric research (Helén, 2007b). The initial interest to set up a research project on bipolar disorder stemmed from observations from another research that in a naturalistic sample of depressive patients in the Helsinki metropolitan area, there were many patients, who seemed to have periods of elevated mood, energy or agitation in their lives as well (Holma, Melartin, Holma & Isometsä, 2008; Melartin et al., 2002; Vuorilehto, Melartin, Rytsälä & Isometsä, 2007)

The idea was to collect a data using a similar naturalistic design and the hypothesis was that many bipolar patients could actually be wrongly diagnosed as depressed and this was a problem. The research was thus designed as a prospective, naturalistic, cohort study. The stated goals of the project were to obtain more information on the clinical picture of bipolar disorder, to analyse the differential diagnosis, and to provide information on the long term treatment outcomes. The more implicit goal for the project was to translate the results into clinical practice, as one of the senior researchers in the project told me:

“I had the interest in this project to gather information from the perspective of the patient, what works and what doesn’t, and then to implement the results back into the work in the clinics and develop our practices.” (Scientist2)

The patients were selected to become research subjects through a systematic screening process from the general population within a geographically defined catchment area i.e. the population in the Hospital X area. Hospital X encompasses three cities in the metropolitan Helsinki area and provides medical treatment in many other areas of expertise as well. Hospital X has a relatively small inpatient ward for only 55 patients and two distinct outpatient clinics, the other one with a day hospital, and separate clinics specialised in adolescent psychiatry. The psychiatry clinics of the Hospital X are representative of secondary level mental health care in Finland. The patients usually attend the clinics of Hospital X on referral from primary health care in the area, but in emergencies patients are also taken straight to the inpatient ward. Treatment in Hospital X is, at least in principle, available to everyone in the area, and, because it is public service, the treatment is almost free of charge for the patients.

THE RESEARCH PROCESS FROM DATA TO FINDINGS

The research design was naturalistic, which means that the researchers initially screened all patients taken into the clinics of Hospital X during a certain period of time and no patients were especially recruited to the study. The patients attending the clinics were screened to become research subjects as they were; subjects were not excluded because possible comorbidities of other mental disorders, somatic symptoms or substance use problems, and there were no age, sex, race or socio-economic exclusion criteria. The only exclusion criteria for the research subjects was that they were not clearly psychotic.

All in all, the patients came to Hospital X to seek help not to attend a research, and they were included in the research population as part of their treatment. The research was also designed as a prospective cohort study, meaning a longitudinal observation of the patients over time at regular intervals. The patients were and are to be followed after the initial diagnostic interview after 6 months, after 18 months and again after 5 and 10 years. Prospective cohort studies are usually used to determine risk factors, progress and treatment outcomes of a given illness. In this case the follow-ups were and are executed to investigate the predictors of chronicity of bipolar disorders, recurrences of the manic or depressive states, and suicidal behavior of the patients. In addition the aim was to investigate the work disability and overall functional disability of the patients and the adequacy of treatment they received.

After the cohort of patients had been screened and put through a very thorough diagnostic process, they received normal treatment in Hospital X, as any other patients attending the clinics. They had individually tailored medication, psychoeducation with trained nurses and meetings with the treating psychiatrists.

The bipolar 1 and 2 patients selected as research subjects were measured in terms of their previous illness history, life events and treatments, family history of mental disorders, current symptoms and situation, psychiatric and somatic comorbidity, demographic characteristics and suicidality. After the data collection, the research progressed from the clinics of Hospital X into the workrooms, computers, literature searches, notes, and minds of the researchers. The patients and nurses were excluded from the research process and the scientists started to work with the data outside of Hospital X.

The most important findings from this project were that both bipolar 1 and 2 disorders are poorly recognised even in psychiatric hospitals and out-patient settings in Finland, the suicide risk is high in both types of the disorder, and that the treatment is inadequate especially because of the poor recognition, but also maintenance treatment is commonly compromised (Arvilommi et al., 2007, 2010, 2014; Mantere et al., 2004, 2006; Mantere, Suominen, Arvilommi et al., 2008; Mantere, Suominen, Valtonen et al., 2008; Mantere, 2008; Mantere et al., 2010; Suominen et al., 2007; H. Valtonen et al., 2005; H. M. Valtonen et al., 2007, 2008;

H. M. Valtonen, Suominen, Sokero et al., 2009). In Chapter 4, I will show how the scientists in this project communicated the message and translated their results for a wider audience of medical professionals.

In the next section, I will analyse the process screening and selecting the research subjects forming the representative population of the research. This is a process where the scientists need to balance between the diagnostic uncertainty and the demands of proper research design. The patient selection is a practice where bipolar disorder is defined as an object of science, because it determines what kinds of individuals, with what kinds of symptoms, are included in the research data. I will use mostly the clinical epidemiology project as an example, because in this project the scientists pondered the limits of the diagnostic categories and adjusted the category to the needs of the research.

3.6 Patient selection and the diagnostic uncertainty

SCREENING THE ELIGIBLE RESEARCH SUBJECTS

In the research project of Hospital X the eligible research subjects were screened from all the patients attending the clinics and the scientists chose to use a screening questionnaire called Mood Disorder Questionnaire (MDQ). This is a self-rated screening instrument designed especially to screen bipolar disorders from the general population. The MDQ was developed by Dr. Robert M.A. Hirschfeld and a committee of psychiatrists, researchers and consumer advocates in 2000 in the US (Hirschfeld, 2001).

The questionnaire is a brief, single page, paper-and-pencil questionnaire, asking 13 yes/no questions about the patients hypo/manic symptoms or 'risky' behaviour. The questions address things like activity, sociability, foolish and excessive behaviour, use of money, interest in sex, troubles of concentrating, self-confidence, talkativeness – all derived from the DSM-IV symptoms of a hypo/mania. This is the MDQ (Hirschfeld, 2001):

APPENDIX 1. The Mood Disorder Questionnaire

1.	Has there ever been a period of time when you were not your usual self and...	YES	NO		
	...you felt so good or so hyper that other people thought you were not your normal self or you were so hyper that you got into trouble?	<input type="checkbox"/>	<input type="checkbox"/>		
	...you were so irritable that you shouted at people or started fights or arguments?	<input type="checkbox"/>	<input type="checkbox"/>		
	...you felt much more self-confident than usual?	<input type="checkbox"/>	<input type="checkbox"/>		
	...you got much less sleep than usual and found you didn't really miss it?	<input type="checkbox"/>	<input type="checkbox"/>		
	...you were much more talkative or spoke faster than usual?	<input type="checkbox"/>	<input type="checkbox"/>		
	...thoughts raced through your head or you couldn't slow your mind down?	<input type="checkbox"/>	<input type="checkbox"/>		
	...you were so easily distracted by things around you that you had trouble concentrating or staying on track?	<input type="checkbox"/>	<input type="checkbox"/>		
	...you had much more energy than usual?	<input type="checkbox"/>	<input type="checkbox"/>		
	...you were much more active or did many more things than usual?	<input type="checkbox"/>	<input type="checkbox"/>		
	...you were much more social or outgoing than usual, for example, you telephoned friends in the middle of the night?	<input type="checkbox"/>	<input type="checkbox"/>		
	...you were much more interested in sex than usual?	<input type="checkbox"/>	<input type="checkbox"/>		
	...you did things that were unusual for you or that other people might have thought were excessive, foolish, or risky?	<input type="checkbox"/>	<input type="checkbox"/>		
	...spending money got you or your family into trouble?	<input type="checkbox"/>	<input type="checkbox"/>		
2.	If you checked YES to more than one of the above, have several of these ever happened during the same period of time? <i>Please circle one response only.</i>	YES	NO		
3.	How much of a problem did any of these cause you — like being unable to work; having family, money, or legal troubles; getting into arguments or fights? <i>Please circle one response only.</i>	No problem	Minor problem	Moderate problem	Serious problem

The choice of the instrument used in the initial screening is important, since it is a way to address the symptoms of a given mental disorder with the patient and it provides words for the otherwise unspecific or confusing feelings. A self-reported screening questionnaire provides a mutual language for the patient and the clinician to speak about the mood swings.

In the case of bipolar disorder, the patient usually seeks help when depressed, not in the hypo/manic state, when life only seems to be amazingly productive and active, at least from the point of view of the patient. So the questionnaire is a tool for the clinician to dig up and identify the possible past manic episodes of the patient. However, the problem of diagnostic uncertainty remains: how to distinguish the symptoms of a mental disorder from normal feelings, traits or behaviour?

The scientists in the project translated the MDQ screen into Finnish and conducted a pilot study to see how the screen worked in the Finnish population. The pilot study found the MDQ to improve the recognition of bipolar 1 disorder, but not bipolar 2 disorder. The tricky part was the third question in the screen asking whether the symptoms had caused any problems in the patients' lives: *"How much of a problem did any of these cause you - like being unable to work; having family, money or legal troubles; getting into arguments or fights?"*

This is actually the very question that in this screen is distinguishing normal

mood swings from the disordered ones. In clinical practice the main objective is to determine the patient's *ability to function*. The researchers in Hospital X, however, wanted to interpret this question differently and adjust the standard use of the screen and one of the interviewees explained to me why:

"One of the questions is about the ability to function and in that question the MDQ is too strict if you want the screen to catch the hypomanic patients as well. If the patient has hypomanias it does not necessarily worsen her ability to function enough. So if you use the Hirschfeld screen as such, it leaves some of the patients negative. This is why we took a bit more sensitive screening approach and included patients with only minor problems in the ability to function to our research" (Scientist2)

The scientists in the project interpreted the crucial question differently, because the sensitivity of the screen determines what kind of patients will end up as the actual research subjects. Hence, the screen was modified because the scientists in Hospital X wanted to catch especially the bipolar 2 patients in the depressive end of the spectrum.

Altogether 1630 non-schizophrenic psychiatric in- and outpatients in the Hospital X area were screened for bipolar 1 and 2 disorders with the MDQ. The modified screen caught 490 patients who went through a diagnostic interview process and from these patients, altogether 191 were then included as actual subjects into the research.

DIAGNOSTIC TOOLS

The MDQ screen was used when the patients came to the clinics for the first time, straight to the ward as inpatients or to the outpatient clinic with a referral from the primary health care. After a positive screen, the patients were thoroughly diagnosed using an apparatus of 7 different screens, questionnaires, rating scales and clinical interviews I call *diagnostic tools*.

The first step was to conduct a *Structured Clinical Interview* (SCID) – a standardized diagnostic interview guided by the DSM-IV. The interview procedure included two phases. SCID-I is a few hours' semi-structured interview, assessing the basic mental disorders, like bipolar disorder in DSM-IV, whereas SCID-II is a personality assessment measuring personality traits or possible personality disorders in the patient. In Hospital X, the diagnostic interviews were conducted by the researching psychiatrists of the project. The researchers also tested the so-called inter-rater reliability, i.e. whether individual diagnosticians really ended up with the same diagnosis by using videotaped interviews, which were blindly assessed by another diagnostician. In addition, there were weekly meetings amongst the project team to solve diagnostic problems. In order not to reveal the

diagnosis made by the first interviewer, all items were asked and neither hints of inclusion or exclusion, nor the diagnosis, were allowed on the tape. When a patient is diagnosed outside a research project, these precautions to ensure the validity of the diagnosis are not used, and the patient is interviewed only by the treating psychiatrist.

The current phase and severity of the depressive, manic or hypomanic and anxiety symptoms of the patient was then measured by yet another set of diagnostic devices. To determine the gravity of the manic or hypomanic symptoms, the scientists used the *Young Mania Rating Scale* (YMRS), an eleven-item, multiple-choice questionnaire filled in by the interviewing psychiatrist. Then the depressive symptoms were measured by using the *Hamilton Depression Scale* (Ham-D-17), a seventeen-item questionnaire used again by the interviewing psychiatrist. The patient filled in the 21-item *Beck Depression Inventory* (BDI) to measure the depressive symptoms with a set of self-reported questions. Then possible anxiety symptoms of the patient were assessed using the *Beck Anxiety Inventory* (BAI).

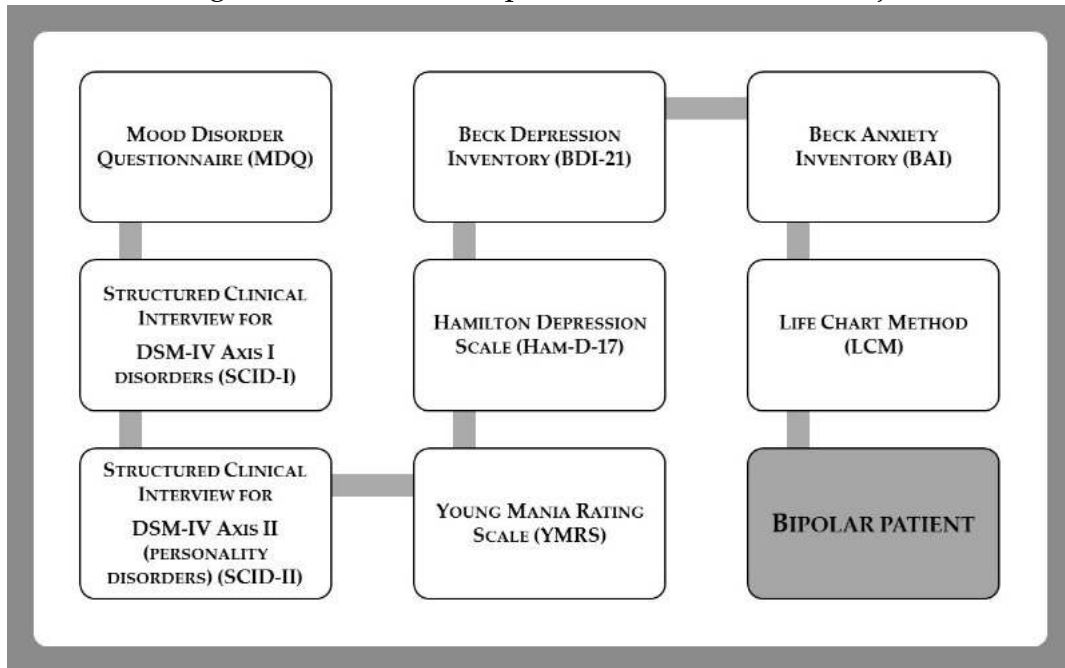
These tools are all similar to the MDQ in that they address questions on the symptoms of hypo/mania, depression and anxiety; only the phrasing, amount of the questions and the execution varies: some are self-reported and some are interviewed by the clinician. In addition to these standardised diagnostic tools, the scientists in the project had their own questionnaire about possible family history of bipolar disorder, substance abuse, somatic health, and demographic variables like age, sex and socio-economic status.

The scientists in Hospital X collected information on the patient's prior illness history, life events and preceding treatment using yet one tool called Life Chart Methodology (LCM). The LCM charts the patient's mood episodes, medications, hospitalisations, alcohol abuse, comorbid symptoms and life events for the past five years. These are considered factors that might have influenced the onset of hypo/manic, depressive or mixed episodes in the patient's life. The mood swings are differentiated from mild to severe mania and depression.

The LCM was created in the NIMH in the US in the 1990's, but the same methodology of charting the previous episodes of mania and depression, and assessing the severity of the episodes is as old as the concept of manic depression. A similar methodology was used already by Emil Kraepelin in his clinical work in the late 1800s (Leverich & Post, 2002; Livianos-Aldana & Rojo-Moreno, 2006; Martin, 2007, 180-181). In Finland the use of the LCM is recommended in the clinical practice guideline for bipolar disorder to be used in the diagnostic process of bipolar disorder patients, although the translated version is a bit simplified (*Käypä hoito -suositus. Kaksisuuntainen mielialahäiriö.*, 2013). The daily mood diary is a similar method of tracking, measuring and visualising the mood swings for a shorter period of time. This methodology is used in the psychoeducation groups I will analyse in Chapter 5.

BECOMING A PATIENT AND A RESEARCH SUBJECT

This is an overview of the process of diagnosing the patient from the screening phase to becoming at the same time a patient and a research subject:



From the point of view of the patient, identification as a bipolar patient has been a process of filling in or answering dozens of questions on moods, feelings, behaviour and personality. This must be quite an ordeal for the individual, especially if facing the mental health care system for the first time. The diagnostic process is also a starting point for the patient to become conscious of the symptoms and the construction of an illness identity starts in the process of reaching the diagnosis. But in the same process the individual patient also becomes a research subject – a variable N in the statistical data.

From the point of view of the research this thorough diagnostic procedure is a process of data collection. All possible information on the patient’s previous illness history, previous treatment, current symptoms, psychiatric and somatic comorbidity and family history is needed for the research. The tick-the-box questionnaires are efficient diagnostic tools in the clinical practice, they are easy and quick to use and designed to aid the diagnostic process. In addition these kinds of questionnaires are easy to render into statistical data. Using a certain questionnaire, a researcher is communicating with others in the scientific community, investigating entities like “BDI-depression” or “Ham-D-17-depression”.

In this way the diagnostic classification is *making up people* as objects of medical knowledge and interference (Hacking, 1995, 1999, 2002a, 2007). The concurrent process of making up the research population and the bipolar patient is an interplay between the individual patients particular life and the needs of the research to generalise knowledge. The classification system is needed to tame the diagnostic uncertainty and the *diagnostic tools* are psychiatric technologies

mediating this process. The diagnostic tools are crucial for the assemblage of psychiatry to work, because they mediate between science, clinical practice and the everyday practices of the patients. I will return to the use of these tools in the clinic and in the patients lives the following chapters, but the DSM categorisation is an important mediator also inside science.

“DSM-IV BIPOLAR DISORDER”

In the introduction of a journal article reporting research results, the scientists usually state their object of research: “*Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) bipolar disorder (BD)*”. This means that the research is about bipolar disorder as it is defined in the DSM-IV manual. Even though the scientists in Hospital X wanted to study bipolar disorder in the naturalistic setting in the clinical reality, they still needed to use the the DSM-IV categorisation of bipolar disorder to be able to extract something from the fuzzy clinical reality, and, most importantly, to be able to communicate their results plausibly to the scientific community. An entity named “*DSM-IV bipolar disorder*” is needed to maintain coherence, comparability and accumulation of knowledge inside the scientific community.

As I noted previously in this chapter, the scientists in Hospital X adjusted the MDQ screen in order to have more diverse research population including more patients with milder symptoms of bipolar disorder. The scientists also adjusted the DSM-IV categorisation in order to maintain their ideal of grasping bipolar disorder as it naturally occurs in the patients attending the clinics of Hospital X. The scientists were aware of the discussion about the mood spectrum model and used that literature in outlining the interpretations they made in the process of diagnosing the research subjects. In a journal article produced in the project, this adjustment is put as follows:

“[...] The soft bipolar spectrum was excluded, but our bipolar II patients included DSM-IV bipolar NOS subjects (a hypomania of 2–3 days, or depressive mixed states). Excluding them would have had little if any influence on our findings. We deliberately accepted the concept of depressive mixed states in bipolar II as defined by Benazzi and Akiskal; in the DSM-IV these episodes are otherwise rated as major depressive episodes.” (The clinical characteristics...2004)

This means that the scientists included subjects with DSM-IV bipolar NOS (Not Otherwise Specified), the catch-all-category in the diagnostic system for those patients who do not exactly fit in the actual categories of bipolar 1 or 2 disorders. The patients included were the ones who were more on the depressive end of the spectrum or had depressive mixed states and only short periods of hypomania. This means that the patients were suffering from moderate to severe

depression most of the time and had only short periods, 2-3 days, of hypomania, or that the patients were suffering of mental states where the depressive and manic symptoms mix and there are no clear-cut episodes of either depression or hypo/mania.

The scientists deliberately, as they themselves state, stretched the DSM-IV categories to be more sensitive in including also those bipolar 2 patients with more depressive than hypomanic symptoms into their research population. This kind of selection criteria was more fitted to the scientists' original hypothesis derived from their previous clinical experience with depressive patients who did not quite fit the DSM-IV category of depression. Hence, the scientists needed to open up, at least slightly, the black box of "*DSM-IV bipolar disorder*", because the real-life bipolar disorder encountered in daily clinical work was more complex than the categorisation. One of the scientists in the project explained the reasons for the adjustments made in the patient selection:

"All the psychiatrists working with bipolar patients know for a fact that bipolar disorder is usually not properly diagnosed. We wanted to thoroughly scan what happens to those patients who do not get the right diagnosis. It is of course clear that when a patient becomes part of the research population, the treating clinician's diagnosis can be challenged by the research diagnosis. So obviously our research has these kinds of consequences to the research subjects as well. But we were all informed by our clinical experience and we all had the understanding that this is the way the research population should be formed." (Scientist2)

The project of mapping the clinical reality of bipolar disorder in Hospital X is bound to the same assemblage of actors shaping the research infrastructure I introduced in the beginning of this chapter. The scientists in this project also balanced between the demands from the funders and the pressures to publish, the disciplinary and communicative boundaries of the multidisciplinary group. In addition, their work of mapping the clinical reality required them to balance between the strict diagnostic category of the "*DSM-IV bipolar disorder*" and the patients in real life, with their distinct life histories, families, problems in work, substance abuse, personality disorders, socio-economic situations, hormones, genes and neurotransmitters. They needed to balance between the certainties and uncertainties of psychiatric diagnosis and the demands of 'objective' science and the patients' 'subjectivity' (Helén, 2007b; Pickersgill, 2012b).

The choice and use of the diagnostic tools defines *what kind of bipolar disorder* is actually analysed in the research. As I noted in the beginning of this chapter, the particular problem in diagnostic uncertainty for science is the fact that the selection of research subjects is based on the DSM categorisations and the categories do not always match the clinical reality. In the research projects I have

analysed here, there was also the problem of how to deal with the use of both the ICD and the DSM categorisations of bipolar disorder.

3.7 What kind of bipolar disorder does the data represent?

THE NUMBERS ARE FOR REGISTERS

As I have already noted, the two diagnostic manuals, the DSM and the ICD, are used concurrently in diagnosing bipolar disorder. The DSM categories are usually used in research, so that it is in concordance with other research. The ICD is used as the official categorisation in the medical reports and hospital records. This concurrent use of the diagnostic coding causes problems in an untrained clinicians use, as one of my interviewees pointed out:

“I have a firm understanding that the bipolar disorder diagnostics by the non-researching clinicians is fuzzy. Practically, they don’t even know what the damn DSM-IV is, so they don’t know how to use the F31.8 code, which is the diagnostic code for bipolar 2 disorder in the ICD. Then they usually code the patient as having major depression.”
(Scientist1)

This scientist takes up another problem: the ICD manual does not differentiate bipolar 1 and 2 disorders clearly enough. The patients that would, according to the DSM-IV, be diagnosed with bipolar 2 disorder, receive the ICD-10 code “F31.8”, which refers to an undefined bipolar disorder. The clinicians need to be aware of the DSM categorisation to be able to acknowledge that bipolar 1 and 2 disorders are two distinct disorders. However, as our interview continued, the same scientist concluded that:

“But, it doesn’t really matter, it doesn’t guide the treatment, what number you have there. Psychiatrists are a bit bohemian, you know, they do consider what they are treating. The numbers are then in a way only for the registers. And that’s why the register based research data can be tricky.” (Scientist1)

Part of the clinical experience of a psychiatrist is to be bohemian enough to differentiate between diagnosing a patient and writing the code of the diagnosis in the medical report.

What I find interesting in the interviewees comment are the consequences this double book-keeping has for the hospital registers and therefore for research using these records in patient selection. The numbers and codes are not irrelevant in research, because research subjects can be identified from the hospital discharge

registers. These identified research subjects are then contacted via their treatment unit to enrol them to a research population.

In the research projects tracing the neurobiology of bipolar disorder with the methods of genetics and brain imaging, the research patients were selected in this manner from the hospital discharge registers. The register-based approach to patient selection is an often used method to identify patient groups easily and reliably. This is a completely different patient selection process from the one I introduced earlier, where the research subjects were screened from the general population attending the clinics of Hospital X. Before analysing the different methods of enrolling research subjects, I will introduce the process in the register-based method in more detail.

A DAY WITH THE TWINS

The research projects tracing the neurobiology of bipolar disorder used, among others, a data sample of twins and their families from the Eastern part of Finland. This was in sampling this data, the National Hospital Discharge register was used to identify the bipolar patients. Then the twins and families of these individual patients were identified in the National Population Register of Finnish citizens. This obviously means that the probands selected into the data were already diagnosed elsewhere using the ICD codes in the hospital discharge registers.

The patients selected for the research population were then diagnosed again. The so-called best-estimate diagnosis was conducted, where the diagnosis is based on the expert analysis of the previous medical records (Kousten & Rou-sainville 1992). The best estimate analysis was conducted by two psychiatrists separately using the DSM-IV categories for bipolar disorder. Then the patients were contacted and interviewed using the SCID I and II procedures I introduced earlier in this chapter. This procedure transformed the patients to a research population representing the “*DSM-IV bipolar disorder*”. In the process of collecting the data for the twin and family study, the scientists reported the accuracy of using register- and record-based diagnoses in bipolar 1 disorder was 92% (Kieseppä, Partonen, Kaprio, Lönnqvist et al., 2000).

When the sample of patients was selected, the patients were interviewed in terms of family and illness history, they were tested with neuropsychological questionnaires, they filled-in questionnaires concerning circadian rhythm and finally they provided blood samples and the MRI scans were taken. Here is how the scientist responsible for the data collection described her data:

“We have three levels of information from the patients, we have the register-based information from the patients’ previous hospitalisations, the medical records and patient files, we have information from the initial interviews where the research nurses enrolled the patients in the research, and then we have the diagnostic interviews. And of course

all the biological data, the neuropsychological tests and questionnaires about the circadian and seasonal rhythms. (Scientist5)

In our interview, the scientist who used this data in her dissertation told me how the process went with the patients. This is the schedule for the research days taken from one of the articles reporting the findings:

- 9:00 am - Coffee or tea: Study introduction: Informed Consent
- 9:30 am - Either the SCID.interview with other questionnaires or neuropsychological testing + blood sample collection
- around 12:00 - Lunch
- 1:00 pm - Either the SCID.interview or neuropsychological testing
- around 16:30 Brain MRI at Teslamed in Helsinki

The twin pair were asked to take part in the research at the same time and they switched pairs during the parts of the research and in the afternoon the scientist drove the patients to the laboratory where the brain scans were taken. These are not just mundane details of a research process. It was important to collect the data in a standardised manner so that the process is exactly the same to all the patients to ensure that, for instance, the blood samples were taken at the same time of the day. The scientist responsible for the data collection pointed out that the clinical patient samples, for instance in Hospital X, are somewhat problematic, because the examinations are conducted non-systematically here and there and need to be fitted into the Hospital schedules.

THE 'RIGHT' BIPOLAR DISORDER

All in all, in the interviews I heard a certain friendly juxtaposition between the scientists using the register-based and the naturalistic clinical data. Both seemed to think their own research design and method of patient selection was better in reaching the 'right' bipolar disorder patients. I am not aiming to judge which data was methodologically more solid and obviously different research designs call for different research populations. What I have wanted to point out by introducing the patient sampling of the research projects, is how these processes highlight the ways the scientists have to balance between the diagnostic uncertainty and the needs to conduct valid and reliable research about the "*DSM-IV bipolar disorder*".

In the Hospital X research project, the hypotheses stemmed from their previous clinical and research experience and the clinical epidemiology was conducted to map the occurrence of particularly bipolar 2 disorder in the general population. The scientists in the project attempted to reach the real-life bipolar disorder patients with all sorts of comorbid disorders – the ones that did not exactly fit the DSM-IV category:

"I think one problem in the research on bipolar disorder, is the fact that so much of the research is based on selected patient samples. Especially the research executed in fancy university clinics or tertiary-level centres is too selected. Those places don't treat ordinary patients, the ones who are short of money, addicted, personality disordered and whatever. But from these selected patient populations they draw huge conclusions and generalisations." (Scientist2)

Whereas in the genetic and brain imaging research, the 'right' bipolar disorder patient was someone who would be interesting in the context of heredity, because the aim was to study bipolar disorder candidate SNP's and endophenotypes. This is why the twins and their family members were chosen from a particularly interesting pedigree in the Eastern Finland, which the scientist had previously used to study schizophrenia. These patients were not at all "ordinary patients", but indeed particularly and carefully selected.

In addition, the two research projects I have analysed here seize the individual patient in different phases of the usually lifelong illness. The projects tracing the neurobiology of bipolar disorder enrolled the patient to the research population long after their diagnosis was first reached. Whereas the project mapping the clinical epidemiology diagnosed the patients at the same time they became part of the research population.

In both cases, an individual patient becomes a research subject: a sample or proband in a research population, representing a *certain kind of bipolar patient*. In enacting their research in practice the scientists needed to coordinate the diagnostically unstable bipolar disorder into an object that they could analyse. In the two different projects, the epistemological bases by which the hypotheses were formed, the methodology used and the processes of enrolling the research subjects varied. I would argue, that actually the scientists were not doing research on exactly the same disorder even though the object in both cases was the "*DSM-IV bipolar disorder*".

3.8 Conclusion: Multiplied bipolar disorder

I started this chapter by introducing the definition of bipolar disorder in the DSM and pointed out that despite the standardised categorisation, a certain diagnostic uncertainty is inscribed in psychiatric diagnosis. The DSM attempts to stabilise this uncertainty and render bipolar disorder so that the diagnosis would be the same regardless of the psychiatrist or the context. What I have shown in this chapter is, that even in science, the psychiatrists need to adjust the categories and balance between this uncertainty and what is understood as 'objective' science.

The chapter consisted of two parts. In the first part, I showed how the day-to-day of doing bipolar disorder research in Finland is balancing between

the realities of research infrastructure and the ambitions and enthusiasm of the scientists to conduct their research. The demands from the funders, the structures of scientific publishing, disciplinary and communicative boundaries of a multidisciplinary group, as well as the limitations of the methods in genetics and brain imaging force the researchers to adapt to the situation. The scientists in the project were disillusioned about the ability of neurosciences to actually produce research results that could be translated into the clinical practice. At the same time, the scientists worked through the ambiguous feelings of disappointment and remained optimistic of advances in genetics and brain imaging methods (c.f. Fitzgerald, 2012).

In the second part of the chapter, I introduced another research project, which was mapping the clinical epidemiology of bipolar disorder. I showed how the scientists in the project balanced between the the certainties and uncertainties of psychiatric diagnosis and adjusted the DSM-based categorisation of bipolar disorder to fulfil their aim to map the real-life bipolar disorder in the clinics of Hospital X. I also analysed and compared the processes of patient selection in the two different research projects discussed in this chapter.

I argued that actually the two projects are investigating different kinds of bipolar disorders. One bipolar disorder is understood through the neurobiology of the human organism: the blood samples, SNPs, brain structures and MRI scans. This bipolar disorder is analysed using carefully selected patient populations. Where as the other bipolar disorder is understood through the observations of patients' symptoms in clinical practice: the real-life patients with substance abuse problems, anxiety, personality disorders or family issues. This kind of bipolar disorder is analysed using a patient population of the ordinary patients encountered in the clinics of Hospital X. These example show, that the object of research is multiplied into many, but at the same time coordinated into one (c.f. Mol, 2002). The diagnostic uncertainty requires practical uncertainty work (Pickersgill, 2011b), where the scientists need to coordinate the diagnostically unstable bipolar disorder into an object that they can analyse: "*DSM-IV bipolar disorder*"

In this chapter I also introduced a set of *diagnostic tools*: the screens, questionnaires and rating scales, which the are the manifestations of the DSM. The diagnostic tools are medical technologies mediating in the assemblage of psychiatry, and travelling from research use to the clinical practice and to the patients' lives as online tests by which to conduct a self-diagnosis. The diagnostic tools do standardise the "*DSM-IV bipolar disorder*", but eventually this does not help to overcome the diagnostic uncertainty, since the tools are ultimately just check-lists of symptoms and leave the interpretation open (Hacking, 2013; Healy, 2009; Pickersgill, 2009, 2011b). Based on my analysis of how bipolar disorder takes form as an object of science, I conclude that bipolar disorder seems to be a multiple object

under the scrutiny of different ways of doing science with different hypotheses, research populations, methods and research practices.

On the whole, what is put into effect in the practices of doing science within these two research projects is objective and translatable knowledge about bipolar disorder. The scientists are balancing between the 'objectivity' of science and an array of 'subjective' factors: the social context and the structures of the research infrastructure, the variability of the patients in clinical reality, and the scientists own feelings, orientations, educational backgrounds and personal choices.

In the next chapter I will continue by analysing how this unstable object is consolidated as a mental disorder that can in the end be diagnosed and treated in mental health care.

Chapter 4

Consolidating bipolar disorder

4.1 Introduction

In this chapter, I show how the multiple object, bipolar disorder, is being consolidated as a treatable mental disorder in Finnish mental health care system.

To consolidate means both to solidify and strengthen something, and to connect and combine something. According to the Oxford English Dictionary (OED Online) to consolidate is: *“to make firm or strong; to strengthen (now chiefly power, established systems, and the like) and to combine compactly into one mass, body, or connected whole (territories, estates, companies, administrations, commercial concerns, and the like; rarely, things material)”*.

Consolidation is not a series of procedures and actions producing a single outcome, but an ongoing process where the object, bipolar disorder, is being coordinated and the knowledge strengthened amongst the clinicians, psychiatrists and other professionals by translating and disseminating knowledge, raising awareness and educating. The researchers working in the projects I introduced in Chapter 3 are among the actors translating and disseminating the knowledge for a wider audience of professionals. In this chapter I analyse how the knowledge is being disseminated into the Finnish mental health care and professional discussion, and how this process problematises bipolar disorder in a new way in Finnish mental health care.

Part of the process of consolidating bipolar disorder is the way evidence-based knowledge of how to diagnose and treat bipolar disorder is compiled to form a clinical practice guideline. In this chapter I analyse the process of compiling this guideline, and show how the principles of evidence-based medicine become part of the treatment standard of bipolar disorder.

Pharmaceuticals are in the heart of the standard treatment of bipolar disorder. So to set up the analysis of the treatment standard, I will also discuss the pharmaceutical regime and the ways new drugs are developed and marketed by the pharmaceutical industry.

THE MATERIAL USED TO ANALYSE THE CONSOLIDATION OF BIPOLAR DISORDER

Translating and disseminating knowledge of bipolar disorder for the professional audiences in Finnish mental health care happens through different media: publishing in domestic medical journals, resident training days and satellite symposia within the biannual conferences of Finnish Psychiatric Association (FPA).

The two major medical journals in Finland are *Suomen Lääkärilehti* (The Finnish Medical Journal) published by the Finnish Medical Association (FMA) and *Duodecim* published by the Finnish Medical Society Duodecim. Both associations are stating to take responsibility for the continuous professional development of doctors and advance medical expertise via many forms of education. The respective medical journals are one medium to actualise these aims. Both *Suomen lääkäri-lehti* and *Duodecim* publish peer-reviewed original articles and research reviews as well as short news flashes and commentaries on various topics.

FMA is an influential professional association for Finnish doctors, safeguarding the ethics and rights of the profession, whereas the Duodecim is more concentrated on education and publishing. In addition to their own scientific journal, the society has a wide range of products from traditional medical textbooks, handbooks and practical guidebooks to up-to-date medical databases published on the internet. The participation in both associations is of course voluntary, but almost all medical students join both associations in the fourth year of their graduate studies, when they receive the right to practice medically. The membership in the associations serves as an initiation to the profession. Hence, the circulation of both of these medical journals covers almost all practitioners in Finland: 90% are members of the Finnish Medical Society Duodecim and 94% members of FMA (FMA & Duodecim websites).

Both journals, *Suomen lääkäri-lehti* and *Duodecim*, are therefore a medium for Finnish researchers to disseminate their research results to wider professional audiences of practitioners with limited expertise in psychiatry and educate them on relevant topics in psychiatry (as well as other specialities, of course). Hence, the basis of my analysis of the medical journal articles in this Chapter is that they form an 'applied' discourse, writing about bipolar disorder in a way that differs from the research reports in international medical journals analysed in the previous Chapter. (Helén, 2011b; Jauho, 2007; Meskus, 2009, using similar material in analysing health care discourses)

Medical journals are not only a form of dissemination of applied knowledge, but also represent the changes in psychiatry as a science and a medical practice. I searched the archives of both *Duodecim* and *Suomen lääkäri-lehti* systematically from the early 1900's onwards to map the discussion around bipolar disorder in order to find out: when and how did bipolar disorder actually become problematised as a medical problem salient enough to appear on the pages of the medical journals?

In the process of mapping the discussion about bipolar disorder, I quickly

came across familiar names from the research projects I had been familiarising myself earlier. These were scientists whose research reports and articles in international medical journals I had been reading and who I was about to be interviewing as well. Moreover, whilst collecting the journal articles, I also attended one of the first resident training days about bipolar disorder and in these events, again, the same actors were educating their colleagues.

During 2009-2011, I attended several resident training days, the biannual conferences of the FPA, and general psychiatry symposia organised by pharmaceutical company Eli Lilly. I will return to the specifics of these educational events later on in this chapter, but all in all I observed the events and took notes on many aspects, such as the setting and sponsors, but mostly I concentrated on the actual substance the educational events were about. In the lectures about bipolar disorder, I took particular notice on the way bipolar disorder was portrayed in the educational setting.

This set of empirical material, combining different ways of disseminating knowledge, provided me with an opportunity to compare the ways the scientists wrote and talked about bipolar disorder to different audiences, and I discuss these questions of translating the knowledge with them in the interviews. All in all, in this chapter I will analyse the web of consolidating bipolar disorder in Finnish mental health care through the combination of these types of empirical material.

THE STRUCTURE OF THIS CHAPTER

I will start by briefly introducing the ways the scientific knowledge needs to be *translated* in order to be taught to different audiences of medical professionals. I will then take an overview of the writings in the Finnish medical journals, by which bipolar disorder awareness was raised amongst the medical profession and knowledge disseminated. Then, I will make a slightly longer exploration into the global pharmaceutical regime. Based on previous research, I will provide an overview of the effects of pharmaceutical development and marketing on mental health care and societies. Although I take an detour from my own empirical material, this exploration is essential, because it contextualises my further analysis of how the bits of knowledge provided by the clinical trials are coordinated into an evidence-based treatment practice. I will then analyse the process of compiling the first clinical practice guideline for bipolar disorder and go through the details of the treatment standard for bipolar disorder.

4.2 Disseminating knowledge

TRANSLATING THE KNOWLEDGE FROM AND FOR DIFFERENT EXPERTISES

As I already mentioned in Chapter 3, in the context of publishing research results, the comparison of the ways scientists portray bipolar disorder in different media from international medical journal articles to training days, provided me with one of the first observations: the way the knowledge is presented to professional audiences with different levels of expertise in psychiatry varies a great deal. The researchers write in a more popularised manner in the domestic medical journals directed for the medical professionals in general, than they do in research reports in international medical journals for colleagues in psychiatry. For instance, when I read the result sections of peer-reviewed articles, the results seemed to me to be represented as the objective truth about the matter, emphasising the new knowledge and the significance of the results brought about by this research. Whereas, when reading review articles in domestic medical journals or, in particular, listening to the lectures during the training days for psychiatry residents, the same results were presented with much caution and words of warning about the generalisability of the results.

I discussed this discrepancy in disseminating the knowledge with the interviewees and asked about their ways of adjusting knowledge for different audiences. A senior researcher elaborated his ways of translating the knowledge to general practitioners:

“When we talk about these neural issues, they are so complex, difficult to grasp for yourself and of course we do not have any final knowledge about anything. But you need to first figure the mess out yourself, so that you are able to convey the knowledge to others. When you try to grasp the essential and most reliable knowledge, it is necessary to reduce, to simplify. And then you forget to even mention that this is simplified knowledge. But that is how the story goes in all communication and of course when you talk to a general practitioner, it is, like, you need to search for the right level, like, mmm, the level of knowledge. It is hard to find the right words because general practitioners are such a heterogeneous bunch. There are some who really know psychiatry and then there are varying attitudes that make the communication challenging. The people in the training events are of course somewhat more interested and the ones who really needed the education are not attending. It is a difficult and challenging task and I am bothered by the feeling that I have to oversimplify, it would be nice to have time to discuss and introduce the issues more comprehensively and demandingly.” (Scientist6)

He continued by adding that then again, general practitioners are practice oriented people, who have concrete problems and limited time with the patient. When the patient enters the consulting room, the clinician has 20 minutes to decide whether to treat the patient as depressive, refer her to secondary mental health care as a bipolar patient or just monitor the patients situation. The general practitioners are not that interested in philosophical finesses, but rather they need information that is important in making the clinical decisions and they are usually relieved if one can provide them with a clear rule: *“act on this and do this”*, as the interviewee put it. This is just where the clinical practice guidelines and medical journal articles and research reviews are needed: to disseminate knowledge in a simplified form, but so that the bases of the knowledge are visible.

As the senior researcher points out in the above excerpt, the level of expertise within the general practitioners varies, some are more interested in psychiatry and some are less. However, the level of expertise varies amongst the trained psychiatrists as well. The knowledge gained from neuroscience on bipolar disorder genetics or imaging, is not in the core expertise of every psychiatrist. One of the interviewees, a geneticist and a psychiatrist, discussed the ways all the tests, sequencing and analysing is summarised in the results of a single article *“this is not simple even for an expert reader”* and continued by pondering the expert audience in general:

“Well this is the point where the problem arises: what actually is an expert audience? It is not psychiatrists, because the psychiatrists very easily think that, ok, an association has been found [between the gene and the mental disorder]. And they are like there it is, the answer to all the questions! This is why I am always overcautious when I’m giving a presentation and emphasise that the results are not significant, because usually people are overoptimistic towards genetics.”(Scientist4)

I continued by asking the interviewee if she had an idea why even professionals in psychiatry are so overoptimistic towards particularly psychiatric genetics, as she pointed out. She said that it is typical that non-experts in a certain matter assume more than know. She thought that the allure of genetics is that it obeys laws, biological laws, and that when one is not an expert in the diversity of the questions of inheritance, one likes to think genetics is simple and logical, providing simple results.

In one of the resident training days I attended, a few of the lectures handled genetics and brain imaging research in bipolar disorder. The methods of genetics and brain imaging, as well as the results in bipolar disorder research attained by using these methods, were presented in a very cautious manner to the audience. For instance, the genetics lecture started from the basics of genetics and the speaker explained what it actually means when scientists talk about monogenic

heritability and multifactorial inheritance, what are the limitations of genome wide association studies and psychiatric genetics in general. Respectively, the lecture on brain imaging started by introducing the basic methods of imaging the brain and pointed out the limitations in both accuracy and sensibility of this method for actually identifying differences and disorders in the human brain. Hence, the scientists needed to translate their specific area of expertise for the audience of clinicians.

Neuroscience has been seen as prone to misinformation, oversimplifications and inaccurate reporting in translating and disseminating new knowledge to the public through media and science popularisations. This research also shows, how dissemination of scientific knowledge is one-way communication from experts to lay people and public stakeholders, not multidirectional communication and open dialogue between the actors (Illes et al., 2010; Racine, Bar-Ilan & Illes, 2005). These problems in science communication can also be seen in the ways the Finnish neuroscience experts educate medical professionals and their colleagues in psychiatry. The expertises of the professionals vary and the psychiatrists not trained in neuroscience research are not immune to the allure of neuroscience explanations and imagery, because the promise is that neuroscience provides, indeed, the simple and logical explanations that could tame the diagnostic uncertainty in psychiatry (Weisberg, Keil, Goodstein, Rawson & Gray, 2008; McCabe & Castel, 2008).

The problematics of applying research results and knowledge in general for the use of different expertises was brought up by many of the interviewees, regardless of their own area of research. For instance, a researcher from the research project in Hospital X, introduced in Chapter 3, emphasised the difficulties in combining the roles of an educator and an expert. The expertise one gains from clinical work and research are different. Her experiences uncovered that scientific knowledge is not obviously relevant to the clinical practice and the daily experience of the psychiatrists with their patients. The interviewee used the term “*clinicalise*” to describe the process where the expert needs to work the knowledge and indeed translate it to fit the needs and know-how of the clinicians. The scientists need to use their expertise from both clinical work with patients and research, in order to clinicalise their message.

The task of translating knowledge from one register to another is not easy, because of both the complex nature of the neuroscientific knowledge and the varying applicability of the knowledge to clinical practice. The dissemination of knowledge in both the medical journals and the educational events happens from scientist to clinicians with various expertise in psychiatry, therefore the translation also requires sensitivity to the needs of different audiences from general practitioners to senior psychiatrists.

Along with the educational events, the medical journals provide another

media for the experts to translate neuroscientific knowledge for a wider audience of professionals. While mapping the writings about bipolar disorder in the Finnish medical journals, the first observation I made was that the bulk of the articles and research reviews were about the inadequate diagnosis and proper treatment of bipolar disorder. This worry came from the researchers and fell upon the clinicians in primary and secondary mental health care, whose awareness about these issues needed to be raised. In the next section I will provide an overview from the medical journal writings and concentrate particularly on this educational aspect and its effects.

4.3 Raising awareness on a public health issue

WHAT IS THIS MENTAL ILLNESS CALLED?

Ilpo Helén (Helén, 2007b, 2011b, 88-116) has analysed how depression emerged as the main target of Finnish mental health care at the turn of the 1990s. There were four main triggers to the awakening of depression awareness. First, the increased research activity, in particular clinical epidemiology in Finnish population; second, the adopting of the DSM classification and diagnostic thinking inherent in it; third, awareness-raising amongst the mental health professionals and fourth, the increasing marketing efforts and use of SSRI medication (Helén, 2007b). The process by which bipolar disorder became consolidated some ten years later in Finnish mental health care shared many of these triggers. I find it interesting, that not only did the depression-awakening form a fertile ground for bipolar disorder discussion, but also brought out the need to rethink the relationship between depression and bipolar disorder.

The first writings about bipolar disorder in the Finnish medical journals appeared in the late 1940s and the discussion started to increase in the late 1990s and proliferated in the 2000s. The overview on the writings across several decades display the change in diagnostic classification. In the early writings mania, depression and manic depression were the terms used. The latter was also referred to as 'mania' and 'cyclic depression' and depression was referred to as 'unipolar disorder' in contrast to manic depression (see also Helén, 2007b). This terminological muddiness was cleared when 'bipolar disorder' was introduced in DSM-III in the early 1980s.

DSM-III was really put into operation in Finnish psychiatry in 1989, when the DSM-III classification was implemented in psychiatric use. In an article introducing this new classification system to the Finnish medical profession, the term 'bipolar disorder' was used in its modern meaning. The article covers the theme from various perspectives, from the fine line between sickness and health, and the role of society and families in individual's suffering to the biological

basis of mental disorders.

In 1999 a Special Issue appeared in *Duodecim* titled “*Has bipolar disorder been forgotten?*”. In the introductory article of the Special Issue, the writer, a prominent Finnish psychiatrist, anticipated the future: “*The latest observations point to the direction that bipolar disorders are being found in Finland again.*” (Hypomanioita ja masennustiloja...1999) The Special Issue consisted of separate articles covering bipolar disorder from many perspectives from new guidelines for drug treatment to therapeutic treatments and the possible pathogenesis of bipolar disorder. However, the main message of the theme-issue was to stress the importance of recognising bipolar 2 disorder and differentiating it from bipolar 1 disorder more likely to be known to the audience as manic depression: “*Type II bipolar disorder is not as well known as the proper manic-depression (type I bipolar disorder). It is characterised by the fluctuation of serious depressions and hypomanic episodes.*” (Hypomanioita ja masennustiloja...1999)

In this theme issue, bipolar 2 disorder was covered in its own article, a thorough review of international research on the clinical picture, differential diagnostics, treatment and outcome of this ‘new’ disorder. The main educational goal seemed to be to provide the medical professionals means to understand this milder form of manic depression and to recognise that the severely depressed patient could have had hypomanic episodes. To be able to differentiate the manic and the hypomanic states in a patient, the latter was vividly described:

“A hypomanic state can be experienced as pleasant and it can include euphoric feelings of exaltation and happiness. Many patients describe the mild acceleration of thoughts in hypomania as a pleasingly intensive feeling of overpowering fastness, sharpness and clearness of thought. Many also have more intensive and strong sensory experiences. Then again, the mood can also be dysphorically irritable and the tone of the feelings agitative and tense. Simultaneous riotous substance use along with a lively social life makes the hypomanic state difficult to recognise.” (Hypomanioita ja masennustiloja...1999)

The fact that hypomania can be experienced as a pleasant state of mind causes the main problem in recognising bipolar 2 disorder patients from the depressed patients, because the patients usually find their way to the mental health care only during the depressive episode when they feel they need help.

DIAGNOSTIC UNCERTAINTY: DEPRESSION OR BIPOLAR 2 DISORDER?

The differential diagnosis between depression and bipolar 2 disorder is the key to the problematisation of bipolar disorder as a public health issue in the medical journals. The writers in the theme issue of 1999 assume that perhaps the increasing rush of patients with depressive symptoms in health care centres and

occupational health care might actually hide populations of unrecognised bipolar 2 patients. Ilpo Helén (Helén, 2007b) notes how Finnish mental health experts in the early 1990s were almost unanimous in their assessment that depressive symptoms and disorders were underdiagnosed and therefore inadequately treated. This same problematisation arose especially, when the writings on bipolar disorder multiplied in both journals from the early 2000s onwards. The alert for better recognition, more accurate diagnosis and right treatment became more and more salient in the articles.

In 1999, when the first bipolar disorder Special Issue started the discussion in the medial journals, there was very little epidemiological evidence to back up the assumptions that there might be a hidden bipolar disorder group in the increasing populations of depressed patients treated in primary health care. The research project in Hospital X provided this needed epidemiological information. The baseline findings of the research highlighted that in particular bipolar 2 disorder was inadequately diagnosed and often misdiagnosed as depression, indeed because the presentations of a full manic episode were absent in the patient. Thus, these findings strongly suggested a need to educate practitioners in both primary and secondary mental health care. The problems of recognising patients' depressive symptoms as a phase in bipolar 2 disorder were summarised in an article as follows:

"Most likely bipolar disorder, in particular, type II, remains unrecognised in health care. Type II bipolar disorder patients seek help mainly during a depressive episode. A hypomanic episode rarely leads to treatment contact with the patient and the incidence of hypomania does not come out unless specifically asked. The problem is serious, because the wrong diagnosis usually leads to wrong pharmaceutical treatment. A monotherapy with an antidepressant can provoke hypomania or mania and quicken the illness process. The core question therefore is the right diagnosis. Although the symptoms of depression are similar, the treatment is different." (Bipolaarinen depressio...2003)

A correct diagnosis is of course always important, but as this excerpt points out, a misdiagnosis can be especially serious in this case, because the SSRI medication commonly used in primary health care in treatment of depressive patients could trigger a manic episode and worsen the patient's condition. The above cited article was especially targeted at the clinicians in primary health care, since in the Finnish treatment system at the moment, depression is diagnosed and treated mainly in primary health care. This obviously puts pressure on the clinicians to understand the problematics in a mood disorder diagnosis. The writer continues to provide advice in how to correctly screen the bipolar patients from the depressive ones and recommends the use of the Mood Disorder Questionnaire (MDQ) in screening the

patient and a consultation with a psychiatrist. But the problem is that: "Screening always brings about false positives as well, and the consultations require resources which are scarce at the moment." (Bipolaarinen depressio...2003).

THE PROBLEMS OF THE TWO-LEVEL TREATMENT SYSTEM

It is certainly difficult to screen and diagnose bipolar disorder in the primary health care setting, but not only because of the lack of time or possibilities to consult a psychiatrist. The perhaps most salient factor is the lack of time the clinician has with the patient in the consulting room. The basic consulting hours per patient in primary health care is 15 or 20 minutes. It is obvious that in this limited time, it is almost impossible to conduct a thorough psychiatric diagnosis. Even the basic diagnostic tools, such as the BDI for depression and the MDQ for manic symptoms, take time to be filled in and discussed with the patient. This problem was aptly illustrated by an anecdote one of the researchers I interviewed told me. She was describing a situation where she was training the primary health care clinicians in the Hospital X area:

"...One of them raised her hand and said that now that you have been educating us that we need to recognise bipolar disorder and I have the 15 minute appointment and the patient comes and first I hand her the MDQ and the the BDI and what not. By the time the patient has filled in all the forms our time is already used. What should I do? That is indeed a very good question. I would think that the 15 minutes in the primary health care are used already just to hear what the patient has on their mind, so that the patient would really be greeted and listened. The bipolar disorder patients need to be listened to also in primary health care. But they are in a terrible situation there at the moment." (Scientist2)

Although bipolar disorders should, according to the experts, be *recognised* in primary health care by the general practitioner, the actual diagnosis and treatment takes place in secondary health care outpatient clinics, where there is a treatment team of psychiatrists, specialised nurses, psychologists and social workers (*Käypä hoito -suositus. Kaksisuuntainen mielialahäiriö.*, 2013). This means that the practitioners in primary health care have an increasing pressure to refer their patients to secondary health care, because of the limited time and expertise. Hence, the limited resources in primary health care might in the worst case cause a rush of referrals to secondary health care out patient clinics.

In a small series of interviews with practitioners in health care centres and occupational health care I conducted in 2006-2007 the lack of resources was also a recurrent theme. These interviews were mostly about depression treatment, but one theme in the discussions was also the problems of recognising and treating

comorbid disorders, such as bipolar disorder, in the clinical practice in primary health care. The general practitioners seemed to be quite happy with their abilities to treat depression in the primary health care settings, but they recognised a problem in the lack of possibilities to a consultation with a psychiatrist and, most notably, the problems of getting the more difficult patients referred to the secondary health care clinics.

In an interview, one of the researchers from Hospital X, an active educator and a clinician, also noted the problem of the rush of patients from primary to secondary health care. She joked that perhaps she and the others have been educating too efficiently, and that the clinicians in primary health care refer their patients more often to the secondary care with a suspected bipolar 2 disorder:

“My experience is that almost all the referred patients with depression that we receive here have a suspected bipolar disorder. We laugh here that this might even be intentional, a way for the GP’s to get the patients from the primary health care to the secondary. But I do think it is better this way, that they really have thought about that possibility there.” (Scientist1)

THE PROBLEM OF OVERDIAGNOSIS

In both of the journals I analysed, *Suomen lääkirilehti* and *Duodecim*, the basic message in the articles and research reviews throughout the 2000s was the inadequate recognition of bipolar disorder, in particular bipolar 2 disorder mostly due to the research results from the Hospital X project. In 2010, however, the tide had turned in regards to the problem of not recognising the bipolar 2 patients. In an editorial written by one of the senior researchers in the Hospital X project, the problem of overdiagnosing bipolar disorder arose:

“Bipolar disorder has previously been underdiagnosed. Now there is a the new problem of overdiagnosis. This disorder and its diagnostics has over the past decade raised attention both internationally and nationally. Previous research has shown that bipolar disorder is underdiagnosed. New research, however, also shows overdiagnosis, even more than underdiagnosis.” (Kaksisuuntaisen mielialahäiriön mahdollisuutta...2010).

So in less than ten years it seemed that the message had reached the wider audience of practitioners in both primary and secondary health care, perhaps even too well. I think it is important to note that the worry about recognising the bipolar patients too poorly or too well are rooted in the diagnostic uncertainty, the difficulty of differentiating the pathological from the normal and depression from bipolar disorder. But when the main problem in the early 2000s was the differentiation between depression and bipolar 2 disorder, the problem was

now articulated to be more complex. The writer of the editorial, ponders the problematics of diagnosing bipolar disorder and continues to speculate the possible reasons for the sudden enthusiasm to diagnose patients as bipolar:

“Over the last years scientific discussions have pondered the spectrum nature of bipolar disorder and considered if the current diagnostic criteria is too strict. It is possible that this pondering has, for one, been blurring the accuracy of the diagnosis of this disorder in clinical practice. [...] Possible causes for the proliferating overdiagnosis are many. One of them is the increasing research interest and the observed underdiagnosis, which has brought about a lot of education and training about the recognition of bipolar disorder without balancing information of the possibility and harm of overdiagnosing the disorder. It has also been suggested that the doctors rather diagnose disorders with effective pharmacotherapies. Recently new pharmaceutical options have appeared in the market, the new antipsychotics and the anticonvulsants, which are easier to use and heavily marketed. If a patient’s mood is fluctuating, the doctor might be more prone to diagnose a bipolar disorder with evidence-based pharmaceutical treatments than to diagnose a personality disorder, which in contrast needs more work from both the patient and the doctor.” (Kaksisuuntaisen mielialahäiriön mahdollisuutta...2010)

It seems that the writer, who no doubt has a good grasp on the situation, has also herself witnessed a rapid change where bipolar disorder has become a more ‘popular’ diagnosis amongst the clinicians. She recognises several possible reasons for this.

First, the discussions questioning the current diagnostic classification of bipolar disorder might have caused confusion amongst the clinicians. The awareness-raising and education on bipolar disorder encouraged the clinicians to use the MDQ screen as an instrument to assess the possibility of bipolar disorder, if such question happens to otherwise arise during the clinical encounter. In an interview I had with the writer of the above-quoted editorial, she found it problematic that the MDQ was too often misunderstood by the clinicians in primary health care as a diagnostic tool, when it actually is a quick screening instrument meant to recognise the *possibility* of bipolar disorder. She felt this was causing possible cases of overdiagnoses and at least unnecessary referrals to secondary health care.

The second aspect in the problem of overdiagnosis are the new pharmaceuticals marketed as easy solutions to bipolar disorder. The new evidence-based treatment options constructed bipolar disorder as a more treatable mental disorder and thus, perhaps, the clinicians were more prone to diagnose their patients as having bipolar disorder instead of, for example, a personality disorder, which

requires much more “*work from both the patient and the clinician*”, as the writer of the editorial puts it.

THE PUBLIC HEALTH PROBLEM

There were many similarities in the ways depression and bipolar disorder emerged as public health issues in Finnish mental health care ten or so years apart from each other. The four main triggers to the awakening of depression awareness at the turn of the 1990s, were increased research activity, the adopting of the DSM in psychiatry, awareness raising amongst the mental health professionals and the increasing marketing new psychopharmaceuticals. The depression awakening amongst the mental health professionals yielded a standard of diagnosing and treating depression in primary health care with the help of screening tools and medication (Helén, 2007b, 2007a, 2011b, 2011a).

The overview on the awareness raising about bipolar disorder I have provided in this chapter thus far, shows that in many ways, the depression awakening in Finland formed a ground for similar progression in the handling of bipolar disorder as a public health issue. What I find interesting are the actual consequences this all seems to have had. The idea of recognising bipolar disorder, and particularly recognising the differences in the clinical picture of bipolar 2 disorder and depression, is of course highly relevant in order to the patients to be treated properly and the message also appears to be getting through. However, the two-level organisation of the mental health care generates a problem of where, by whom and with what resources should bipolar disorder be diagnosed and treated?

In what remains of this chapter, I will focus on the treatment of bipolar disorder. Although there are other means to manage bipolar disorder, the drugs are essential in the treatment standard of almost any psychiatric disorder today. In my empirical material, the marketing machinery of the pharmaceutical industry is strongly present in the education of professionals, from medical students to psychiatry residents and qualified clinicians, as well as raising awareness amongst the patients about bipolar disorder. Therefore, in order to set up the milieu where the bipolar disorder treatment standard is formed, I will now take a detour from analysing the actual clinical practice of treating bipolar disorder in Finland and make an exploration into the pharmaceutical regime.

4.4 The pharmaceutical regime

In Chapter 1, I discussed the idea that a *pharmaceutical regime* has been forming since the 19th century around the endeavours of pharmaceutical industry and is in continuing process of commercial, clinical and geographical expansion. The clinical expansion of the pharmaceutical regime refers to proliferating use of drug

treatments in various diseases and illnesses, as well as the expanding scope of what kinds of conditions can and should be treated as diseases and illnesses. The geographical expansion then refers to the globalisation of both diseases and the pharmaceutical solutions to them. It is no longer only the ageing western world where the use of pharmaceuticals is proliferating. The commercial expansion is related to both the clinical and geographical expansions and refers to the fact that pharmaceutical markets are expanding globally (Williams, Katz & Martin, 2011). In this section I will use literature to introduce how the pharmaceutical regime works and provide some examples from my own empirical material.

CLINICAL TRIALS AND THE BOUNDARIES OF RESEARCH ETHICS

New drugs are tested and developed in clinical trials usually conducted by the pharmaceutical industry or its subcontractors, and most of the trials conducted in academic or clinical settings are funded by the industry. Before the approval of a new drug, the developer is required to show its compounds safety and efficacy in Randomised Controlled Trials (RCT). In an RCT, the new drug is tested in patient groups and the treatment outcomes of the active compound are compared against treatment outcomes of either placebo or a comparator compound, which is an existing drug with the same indication. The process of developing a new drug is lengthy and expensive, and the patent of a new drug usually expires in less than 10 years time. This creates the need for the industry to produce blockbuster drugs to the market as quickly as possible to be able to gain as much profit as possible before the patent expires. All this makes it compelling to the industry to cut corners in the process (Angell, 2004; Helen, 2009; Abraham, 2010).

One way to speed up the process is to produce so-called me-too drugs, which means that the 'new' compound is a minor chemical variation from a highly profitable drugs already on the market. This then, leads to a situation where there are lots of similar pharmaceuticals to the same conditions with almost no differences in the therapeutic efficacy (Angell, 2004; Helen, 2009; Abraham, 2010). For instance, the second generation antipsychotics, which are used in the standard treatment of bipolar disorder, such as olantsapine (Zyprexa) by Eli Lilly, quetiapine (Seroquel) by Astra-Zeneca and risperidone (Risperdal) by Janssen, were developed by only slightly changing the molecular structure of one of the earlier compounds called clozapine.¹

Another way to cut the corners, is to brand old compounds anew by applying

¹Zyprexa is infamous of leading to the largest individual corporate fine in US history, \$515 million, when Eli Lilly pleaded guilty of promoting the drug off-label for disorders not approved by the regulatory agency in the US (FDA). The court documents were published by an investigative journalist and have revealed information about the marketing strategies of the industry. Zyprexa was aggressively marketed to be used off-label to treat, for example, Alzheimer's disease. According to the analysis of the court documents, the marketing of this non regulated use of the drugs seemed to be intentional and targeted to increase prescriptions in primary health care (Spielmanns, 2009)

approval for different indications of the same drug. This strategy was used in another treatment option for bipolar disorder, the anticonvulsants. These drugs, such as valproate (Deprakine) or lamotrigine (Lamictal), were previously used only as epilepsy treatments, but were branded anew in the mid 1990s to treat, for instance, bipolar disorder (Healy, 2008, 185-197).

The research and development of new pharmaceuticals can also be outsourced to middle- and low-income countries via so-called Contact Research Organisations (CRO). These companies work as subcontractors for pharmaceutical industry conducting the clinical trials for drug development in, for instance, Eastern Europe and Latin America, where it is cheaper and less regulated. The outsourcing is beneficial for the industry also because in these countries it is easier to find treatment naive research subjects with less history of overlapping use of pharmaceuticals than most of the patients in industrialised West, and this improves the tested drug's efficacy compared to placebo in the trials (Petryna, 2009, 2007; Petryna & Kleinman, 2006).

Another form of subcontractors for the pharmaceutical industry are so-called medical education and communication companies (MECC). For long, high-profile academic researchers have been providing their name to an already written journal article on the results of industry-sponsored clinical trials providing more academic prestige to the publication. Now the whole publication process can be outsourced to a MECC, which provides not only the ghostwritten research reports, but also the management of the whole process of disseminating the knowledge through different channels from publications and journal reviews to academic symposia and educational materials. The MECCs market their services by promising acceptance rates of 80% in medical journals. (Matheson, 2011; Sismondo, 2007, 2009; Sismondo & Doucet, 2010) ²

Are the clinical trials of new, newly branded or me-too drugs then biased or are the clinical trials conducted by the industry and its subcontractors just another way of doing medical research outside the academia? In two systematic reviews of industry-sponsored clinical trials, it was clear that they more often concluded in favourable results of the new drug. The reviewers supposed that the bias is stemming from a number of technical details in the RCT design, as well as from selective analysis and reporting of the trial results (Lexchin, Bero, Djulbegovic & Clark, 2003; Lundh, Sismondo, Lexchin, Busuioc & Bero, 2012).

All in all, these examples show that the clinical trials are not an ideal example of objective and ethical medical research. This has led to an increasing need to regulate the pharmaceutical industry globally.

²See (Logdberg, 2011) for an interesting story of one of the employees in a medical education and communication company.

REGULATION OF THE GLOBAL HEALTH COMPLEX

There are varying national laws and regulations regarding in marketing and pricing of the drugs, but the globalisation of the pharmaceutical markets has led to increasing pressure for transnational regulation of the research, development and patenting of drugs, but these attempts have not been successful.³ From the mid 2000s the medical community has required that the results and data of all clinical trials must be publicly available in clinical trial registers, reporting the negative and inconclusive as well as positive results (ClinicalTrials.org). However, despite the good intentions, clinical trials are still not comprehensively reported to the registers, and, moreover, the registers do not require retrospective reporting of past clinical trials, nor of the abandoned or corrected trials (Doshi, Dickersin, Healy, Vedula & Jefferson, 2013). The regulation, both nationally and transnationally, is in constant flux, because the industry is lobbying very strongly for regulation in its interests. For instance, the pharmaceutical industry has for years been lobbying for changes in legislation that would allow direct-to-consumer (DTC) marketing of prescription drugs in the EU (Mulinari, 2013).

All in all, the problem in regulation is also political: a more strict regulation of the pharmaceutical industry would simply be against the ideals of the freedom of the markets (Abraham, 2010; Helen, 2009; Mulinari, 2013; Williams, Katz & Martin, 2011). The “global health complex”, as Linsey McGoey, Julian Reiss and Ayo Wahlberg (2011) have called it, expands and the injustices and pure exploitation, as well as the serious problems in regards to the discordances between the industry’s interests and the public health concerns in this complex are not likely to be solved with the regulative efforts. The commercial and geographical expansion of the pharmaceutical regime, as well as the failing of the regulation to work in the interests of public health, all speak for the increasing power pharmaceutical industry has upon national economies and individual patients globally.

An important aspect of the pharmaceutical regime is also the aggressive marketing of the new, newly branded or me-too drugs. The marketing strategies of the pharmaceutical industry are redefining and reconfiguring health problems as having a pharmaceutical solution.

MARKETING DRUGS AND MEDICAL CONDITIONS

There is nothing new in pharmaceutical marketing as such, even before the rise of the industry in the 19th Century, the patent medicines were advertised to

³One attempt to form transnational regulation was a joint initiative of the industry and the regulators to harmonise the markets and drug safety regulation between US, EU and Japan in the 1990s (the International Conference on Harmonisation of Technical Requirements for Registration of Pharmaceuticals for Human Use, ICH), but with more emphasis on the market harmonisation than the regulation of the industry (Abraham, 2010).

the consumers and professionals with strategies now common to all advertising (Applbaum, 2006b). For decades, information about new drugs has been mailed as leaflets to doctors' homes and workplaces, disseminated via sales representatives to every small town community health centre and advertised on the pages of medical journals. The industry has also promoted itself to the medical professionals from medical school onwards by financing medical conferences and education, as well as providing small gifts, sample medicines and conference trips abroad (Healy, 2002; Hautamäki et al., 2011). Similar strategies of providing funding also links the patient advocacy associations to the pharmaceutical industry's marketing machinery in hope for lobbying benefits from the associations (Applbaum, 2006b; Hemminki et al., 2010; Toiviainen, 2007).

Direct-to-consumer (DTC) marketing of prescription pharmaceuticals is allowed only in the US and New Zealand and has been criticised widely, especially within the medical community. It is said that DTC is influencing not only the patients as consumers, but also the professionals' prescription behaviour and the health care system as a whole (Donohue, Cevasco & Rosenthal, 2007; Gellad & Lyles, 2007; Hollon, 1999; Ventola, 2011; Mintzes et al., 2002; Robinson et al., 2004). Pharmaceuticals are also advertised via awareness-raising campaigns providing the patient with information about the diseases and the means to treat them, as well as help in managing with the disease in their daily life (Applbaum, 2009d; Glick & Applbaum, 2010; Hautamäki et al., 2011; Hautamäki, 2007; Martin, 2007, 188-196). I will analyse this aspect of the marketing in Chapter 5, where I will go through the online and printed material of bipolar disorder information for the patients.

In the marketing material for the medical profession, there is a similar educational aspect and the drugs are branded to provide the prescribing doctor with efficient means to cure the patient, or even enhance the patients capabilities with the help of the chosen drug. (Healy, 2008; Martin, 2007; Moynihan & Henry, 2006; Kanula, 2008). Together with Ilpo Helén and Saara Kanula (Hautamäki et al., 2011), I viewed the pharmaceuticalisation in Finnish mental health care by analysing drug consumption statistics and marketing for both medical profession and the patients in the context of depression treatment in the 1990s. Our analysis showed how the marketing was one aspect in the pharmaceuticalisation of Finnish mental health care. However, the process was not a simple consequence of increased marketing, but rather coincided with changes inside the psychiatric profession and health administration.

All things considered, the commercial side of the pharmaceutical regime brings along increased pharmaceuticalisation in mental health care, but this is not only due to the marketing strategies of the pharmaceutical industry. The pharmaceutical industry is not creating disorders out of nowhere to market them and the treatments, rather it seems to me that the industry takes advantage of the

clinical knowledge on the field to create the treatments that fit the clinical needs and then *enhance* these needs via the marketing machinery. The actors involved in the commercial aspect of the pharmaceutical regime are numerous, and the marketing strategies are influencing medicine and society in a very complex way, having also some positive consequences of disseminating knowledge to both medical professionals and patients. The professionals are also quite aware of the marketing machinery as the following example of a psychiatric conference shows.

THE FREE LUNCH AND THE PEN: MARKETING DRUGS IN PSYCHIATRIC CONFERENCES

In an article based on ethnographic work in Japan, Kalman Applbaum (Applbaum, 2004) describes a congress of World Psychiatric Association (WPA) held in Yokohama. He describes the setting of a psychiatric conference where world famous academic psychiatrists give lectures and there are 'satellite symposia' on specific topics. Hosts and hostesses distribute flyers on the hall of the convention centre. The exhibit area is filled with different attractions such as complimentary drug samples, brochures, pads and pens, as well as foot and body massages or an interactive demonstration enabling psychiatrists to experience for themselves how psychosis feels. The audience is treated to gourmet meals. All this was possible, because the WPA congress was sponsored by pharmaceutical industry. Reading the article, I realised that I had attended in pretty similar events in Finland, albeit the settings were perhaps less luxurious and grandiose. These educational and social events were very important in disseminating knowledge about bipolar disorder for the audience with psychiatric expertise.

The Finnish Psychiatric Association (FPA) biannual conferences, bore resemblance to the WPA conference Applbaum (Applbaum, 2004) describes. The biannual conferences usually take two days providing different thematic and plenary sessions, added with the so-called 'satellite symposia' sponsored by a given pharmaceutical company. Otherwise the industry was mostly visible in the exhibit area providing printed educational material, journal articles, sample drugs, as well as all sorts of small items, such as the infamous pens with the brand name of the drug.

In all the conferences and educational events I attended, the speakers were international and domestic experts on their subject. David Healy (Healy, 2008, 228) has argued, that in these kinds of situations the medical academics become the brokers in the exchange between marketers of Big Pharma and the nonacademic clinicians. In the events I attended, the focus was on scientific program and substance, apart from the mandatory short sales pitches. Rather than marketing events, these were educational events where researching psychiatrists disseminated their knowledge and expertise to the clinicians in similar manner that they did in the medical journal articles and reviews.

The fact of the matter, however, is that almost all the specialised medical

training in Finnish psychiatry is in one way or another entangled with the pharmaceutical industry. In the conferences of the FPA there are recurring lunch sessions providing panel discussions along the lunch. One of them is a lunch session called "*No lunch without ethics*", providing discussions on contested ethical issue in Finnish mental health care, such as coercive treatment. This session also comments a bit sarcastically the tradition of the sponsored lunches in health care units, where the sales representatives of pharmaceutical industry pitch their products during the free lunch. There are *No-Free-Lunch* -networks based in UK and USA, raising awareness about the industry influence in medicine. In Finland, there is a sister organisation of the network, *Doctors Without Sponsors*, aiming at medical careers without links to the pharmaceutical industry.

The non-free-lunches and the pens with the brand name of a drug are both common symbols of the interconnection between the pharmaceutical industry and the medical profession. My observations from the conferences and training days show how the actors on the field of psychiatry are aware of the meanings invested in the lunch and the pen; they do realise the pharmaceutical industry does indeed provide its funding with the hope of marketing their products. The industry sponsorship is needed and tolerated, but the psychiatrists organising, attending or speaking in these events are not naive brokers of the pharmaceutical marketing. The benefit is not one-way, but mutual. Applbaum's (Applbaum, 2006b) observations show how the conference organisers and the industry play cat and mouse in their attempts to benefit from what the other party has to offer. As one of my interviewees, a senior researcher and a professor noted, there is no way to escape the pharmaceutical industry funding in current research and education environment, one can only attempt to take the best of the collaboration.

All in all, the complexities and ethical problems of the pharmaceuticalisation have not left unnoticed by the medical profession. The Finnish discussion has mostly addressed the problems of biased evidence from the industry sponsored clinical trials and research, or the problems of regulating the pharmaceutical markets and the economic pressure the current situation puts on the health care of the welfare state (Idänpään-Heikkilä, 2006; Idänpään-Heikkilä & Klaukka, 2007; Klaukka et al., 2005; Klaukka, 2006; Klaukka et al., 2007; Palva, 1999; Toiviainen et al., 2004; Toiviainen, 2007; Vuorenkoski, 2004).

Despite all the ethical problems in the research of pharmaceuticals and the fact that there are no psychotropic drugs that would actually cure a disease, the treatment standard of bipolar disorder relies strongly on pharmaceuticals. In the remaining part of this chapter I will return to the clinical practice by analysing the process of compiling a clinical practice guideline for bipolar disorder and by introducing the treatment standard.

4.5 Combining the bits of evidence

Evidence-based medicine (EBM) is the medical technology defining what is acceptable knowledge in assessing the most successful treatments for discretely defined medical conditions such as bipolar disorder. The principles of EBM are guiding the way the knowledge about bipolar disorder is consolidated and stabilised by combining the bits of evidence into a coherent standard of how to diagnose and treat bipolar disorder.

In this section I will first show how the clinical practice guideline was formed in a multidisciplinary working group, and what problems in weighing the best evidence there is in evidence-based psychiatry. I will then analyse the ways EBM in general and the treatment standard of bipolar disorder started to come out in Finnish medical journal articles, and introduce this standard in detail.

THE CLINICAL PRACTICE GUIDELINE AS THE HALLMARK OF EBM

A clinical practice guideline is a document aiming to guide decision-making in clinical practice in terms of diagnosis, management, and treatment of distinct medical conditions. The clinical practice guideline is a device through which the EBM works in practice. The guidelines compile the best evidence-base on diagnostics and treatment options and aims to provide an easy clinical reference for decision-making with individual patients in everyday clinical practice.

The work on the standardised clinical practice guidelines begun in Finland in the early 1990s following the examples of other Western countries. The work started as a project by the *Finnish Medical Society Duodecim*, which in this area collaborates internationally in the *Guidelines International Network*, (*G-I-N*). The project took root quite quickly and the format became the established clinical practice guideline named *Käypä hoito -suositus* (Current Care Guideline)⁴ The guidelines are linked to a widely used online database for medical professionals (*Terveysportti*) and *Duodecim* is responsible for the format, edition and on-line as well as paper publication of the guidelines. The actual work on the systematic review of research, the assessment of the evidence and the recommendations are carried out by a working group of professionals and specialists on the specific medical condition in question, in collaboration with the methodologists and editors from the editorial office coordinating the work (*Käypä hoito -suositus. Kaksisuuntainen mielialahäiriö.*, 2013; Kaila & Nuutinen, 2003; Karma & Mäkelä, 1997; Mäkelä & Ilkka, 1997; Mäkelä & Kaila, 2005; Varonen & Mäkelä, 1996).

The clinical practice guideline for bipolar disorder was first published in 2008 and revised in 2013. I had the opportunity to discuss the process of compiling

⁴The term Current Care Guideline is a translation from the Finnish proper noun for the clinical practice guideline project and the subsequent guidelines. I will use the generic term clinical practice guideline also when I refer to these specific guidelines and the guideline for bipolar disorder.

the guideline with the chair of the working group, a senior researcher in the research project in Hospital X. I will use her interview to describe the process of weighing the evidence for the bipolar disorder guideline in this section. The working group was called together from the experts known to have done research on bipolar disorder in Finland, as well as a psychologist and a nurse to provide their perspective on the diagnosis and treatment of bipolar disorder.

The guideline working groups are guided by a guideline of their own, determining the process from start to finish. The guideline for guideline compiling for instance determines the search criteria, advises the working group on how to weigh the evidence and how to write the guideline (*Käypä hoito -suositus. Kaksisuuntainen mielialahäiriö.*, 2013).⁵

The working group assesses the research and determines which treatments to recommend, and in the final clinical practice guideline different treatment options are coded to show how solid the evidence supporting them is. The Finnish clinical practice guidelines follow a coding from A to D, the best possible evidence being the level A evidence from randomised controlled trials (RCT). The evidence hierarchy is strict, and the evidence from the RCTs is weighed in terms of the quality of the research by the following requirements:

“It is unlikely that new research would change the assessment of the effects direction and quantity. In the research, the best designs for the researched theme has been used. At least two studies of good quality, that conclude in the same direction. The outcome variable significantly measures the clinical benefit or harm for the patient. The false positives and negatives and confidence intervals of 95% are small. The research populations match, or are applicable to, the target population of the guideline” (*Käypä hoito -suositus. Kaksisuuntainen mielialahäiriö.*, 2013)

THE RELIABILITY OF RANDOMISED CONTROLLED TRIALS

The use of evidence hierarchies as the principles of EBM and has been criticised of allowing RCTs too much authority over the other methods of producing knowledge about how and why treatments work or do not work. The RCTs provide answers only to certain kinds of clinical questions and are not the best design to do research on psychosocial interventions, for instance (Cartwright,

⁵The Finnish procedure in collecting the current best evidence for the clinical practice guidelines in a given disease or disorder uses mainly Medline and Cochrane databases, and in psychiatry also PsychINFO database, to search for all relevant research and clinical trials, and for the most current articles the Pubmed database is also checked. International guidelines, if existing, are consulted as well. The search terms and the time frame of the search are decided amongst the working group and the quality of the search applies the SIGN (*Scottish Intercollegiate Guidelines Network*) guidelines. The searches and the search strategies are stored so that the searches can be replicated if needed. (*Käypä hoito -suositus. Kaksisuuntainen mielialahäiriö.*, 2013)

2007; Borgerson, 2009). The problem for the reliability of the evidence from the RCTs is also the fact that the clinical trials on drugs are industry-sponsored.

I already showed how there are serious ethical problems in the industry-sponsored clinical trials on new drugs. There are also problems in the way the industry-sponsored RCTs are technically designed. A common problem in the reliability is that the RCTs are often conducted by comparing the new drug against a placebo, rather than an existing drug for the same indication, because it is easier to demonstrate that the tested drug is superior to the placebo than to show its efficacy against an already established drug (McGoey, 2010). For instance, in a meta-analysis looking through 150 clinical trials on the second generation antipsychotics, used to treat bipolar disorder, the RCTs were usually conducted in this manner. The outcome was that the second generation antipsychotics *“are no more efficacious, do not improve specific symptoms, have no clearly different side-effects profiles, than the first generation antipsychotics, and are less cost effective”* (Tyrrer & Kendall, 2009).

Another problem is the research population in the RCTs. The ethical standards for clinical trials require that the drug developers curtail the use of placebo and avoid recruiting patients from the severe end of the disorder. For instance, in anti-depressant trials this means that the available clinical trial data is skewed towards patients with milder depressive symptoms and this of course leads to a situation, where the target population and the research population do not match. In consequence, there might be a disconnect between the drug’s performance in the trial setting and in the clinical setting it is actually used (McGoey, 2010).

The placebo effect itself can also be a problem in the RCTs. According to Andrew Lakoff’s (2007) ethnography and documentary research, the drug developers have come up with various practices to eliminate those patients that are too responsive to the placebo effect. The standardised diagnostic tools do not identify a coherent enough group of patients to conduct a successful trial in favour of the researched drug, and to overcome this problem the isolated the so-called “placebo-responders” and the “drug responders”. Enrolling the latter in the trial obviously leads to a more favourable outcome. The drug developers are in the search for “the right patients for the drug”, not the other way around as one would suppose.

So the difficulty the drug developers have in including the right patients to the trial boils down to the diagnostic uncertainty: the choice of the diagnostic tools and the way the severity of the disorders is weighed affects the the outcome of the trial. The RCTs on psychopharmaceuticals face the exactly same problems in patient selection as does any other research on mental disorders: what kind of bipolar disorder or depression is the clinical trial about? Are the clinical trial populations representative of the clinical population using the tested drug?

WEIGHING THE EVIDENCE FOR THE CLINICAL PRACTICE GUIDELINE ON BIPOLAR DISORDER

The chair of the working group told me that the most important discussions and disputes of the bipolar disorder guideline working group had, concerned the evidence-base of the research and the ways to weigh the evidence. But as the chair of the working group confirmed, although the process is strictly guided by the principles of searching the evidence and using the evidence hierarchy, these requirements are under discussion amongst the working group members and the process is not as straightforward as it might seem (Knaapen, 2013). She pointed out that there was a need to thoroughly discuss all the claims of evidence on certain treatment options and the group was aware of the fact that the evidence from the RCTs leaves room for interpretation. The chair of the clinical practice guideline working group described the main difficulty the working group had in weighing the evidence:

“We specifically tried to dig up the negative results, because we all do have the information that a given research group has studied this and that, and the results have remained negative. These results have obviously not been published anywhere, so we can’t get a hold of them. But when no one knows if there is anything else, any other negative results, it’s completely arbitrary what any of us in the group happen to know when there are no publications. This is the problem we actually dwelled upon a lot: that how should we arrange our words in the recommendation, and what can actually be said. There is a lot of pondering behind the recommendation and very heated discussions. Even up until a situation where one of the members of the working group stood up and asked if she had to continue this process ((laughing))” (Scientist2)

As I already noted, the medical community requires that the results and data of all clinical trials must be publicly available, but are still not comprehensively reported, and the registers require neither retrospective reporting of past clinical trials, nor of the abandoned or corrected trials (Doshi et al., 2013). Even though the RCTs have flaws in reliability, all these problems could be weighed by the experts compiling the clinical practice guidelines if only the data would be available. In an interview with Linsey McGoey, these problems are summarised by Tim Kendall (a lead partner in developing the guidelines for NICE in the UK) from the experience he had in attempting to find the best evidence in treating adolescent depression to a clinical practice guideline: “if you don’t have the full set of data there’s a risk that you would make the wrong decision, and you would make the wrong recommendation to people” (Kendall & McGoey, 2007).⁶

⁶The working group members report their liabilities in terms of funding from the pharmaceutical industry. The Finnish bipolar disorder group had mostly received compensations on

Loes Knaapen (2013) has, based on ethnography and documentary research, examined how the evidence actually is compiled in practice, particularly in the case of some evidence being absent. She argues that actually what counts as evidence, depends more on the agreement between the members of each working group who mobilise a range of 'other' knowledge, such as knowledge stemming from the clinic. All in all, the clinical practice guidelines are not, after all, a hallmark of the EBM. The guidelines use the EBM as a medical technology and an attempt to combine the bits of evidence into something that can be used in clinical practice by trumping the evidence hierarchy and using the other available sources of knowledge.

This could also be seen in how the bipolar disorder working group relied on the research results from the clinical epidemiology project in Hospital X, particularly in the recommendations regarding the diagnosis of bipolar disorder. The recommended diagnostic procedure was to first screen the possibility of bipolar disorder using the Mood Disorder Questionnaire (MDQ) and then use the DSM categorisation for the diagnosis in order to differentiate bipolar 1 and 2 disorders thoroughly. All the diagnostic tools used in the research project, listed in section 3.6 in Chapter 3, were recommended to be used in some phase of the diagnosis or the follow-up. In the treatment of bipolar disorder, the clinical practice guidelines recommends to use all the pharmaceuticals with level A evidence gained from RCTs, but also strongly recommends psychosocial treatments, a classic example of treatment options where the evidence is based more on clinical knowledge and other research designs (*Käypä hoito -suositus. Kaksisuuntainen mielialahäiriö.*, 2013).

I will now analyse the treatment of bipolar disorder by taking a few steps back into the history of bipolar disorder treatment. I am analysing how bipolar disorder treatment was portrayed in the Finnish medical journal articles to show how the evidence-based thinking has slowly and subtly invaded the ways the professionals write about both the pharmaceutical and the psychosocial interventions. The most current writings in the journals also introduce the particulars of the treatment recommendations of the current clinical practice guideline.

4.6 The treatment standard of bipolar disorder

LITHIUM (LI) AS AN EVIDENCE-BASED DRUG OF CHOICE

The very first article specifically on manic depression in the Finnish medical journals I could find was from 1940. This was a case report about "*The treatment of the depressive states in manic-depression with cardiazol*", from the Pitkäniemi

lecturing, conference trips abroad, and some of the members had received "expert fees". Only one had participated a clinical trial sponsored by the industry (*Käypä hoito -suositus. Kaksisuuntainen mielialahäiriö.*, 2013).

hospital in Central Finland, where Dr. Ilmari Kalpa had experimented with a new convulsive treatment causing epileptic-like seizures in the patients. The treatment was carried out by injecting a drug called Cardiazol to the patient's bloodstream in order to induce a shock reaction in the patient and thus reduce the symptoms (I. Kalpa, 1940). ⁷The pharmacological treatment of mental illness was, until the mid 20th century, mostly limited to sedatives, such as opioids, chloral, bromides and barbituates, drugs that were also commonly used outside the asylum as over-the-counter headache and nervousness remedies of the day. These drugs were, from the mid-century onwards, rather quickly replaced with new revolutionary pharmacological treatments, the *antipsychotics*, such as chlorpromazine (Thorazine, Largactil) and the first antidepressant imipramine (Tofranil) (Healy, 2002, 32-46). A new pharmacological treatment particularly efficient in the treatment of manic depression was lithium salts.

David Healy (2008, 89-134) has written about the history of the discovery and rediscovery of the element lithium (Li), modified as lithium salts as a pharmaceutical treatment for manic depression. Lithium was used already in the late 19th century to treat various diseases, such as gout, because of its ability to dissolve urate stones. In the 1880s brothers Carl and Fritz Lange in Denmark used lithium as a prophylactic treatment for the so-called endogenous depression. This prophylactic effect of lithium was then rediscovered and researched in the late 1940s and early 50s by a few enthusiastic psychiatrists. Amongst them was Mogens Schou, who conducted one of the first RCTs in psychiatry to demonstrate that lithium actually worked in the treatment of manic depression. All in all, lithium was an oddball in the psychopharmacology of the time, because it was not clearly an antidepressant, nor was it an antipsychotic, but something that seemed to stabilise the mood swings of the patients and was therefore seen as a prophylactic drug for manic depression (Healy, 2002, 47-50).

From the late 1960s, Finnish psychiatrists also started to report these new findings on the pages of the two medical journals I have analysed in this chapter. The readers were advised on how this new pharmaceutical agent was discovered, how it works and how to use it properly. The shift from using individual cases as evidence of the effectiveness of lithium to a more evidence-based thinking can be seen in the example of two articles.

In an article from 1968 a group of leading psychiatrists report in detail the discovery of lithium, and recommend its use in manic depression, basing their argument on their experience on a sample of 38 cases of manic depressive patients' treatment outcomes. They state: "*According to the experience we have gained*

⁷This method was one of the so-called convulsive treatments, along with insulin shock therapy (ICT) and electroconvulsive therapy (ECT), which is still in use as a treatment for serious depression. Convulsive treatments, or shock treatments if you wish, as well as lobotomy, were one of the first attempts to find somatic treatments to mental illnesses: mainly schizophrenia and manic-depression in the first decades of the 20th century (McCrae, 2006; Healy, 2002, 71-73).

from the patients in this data, we have settled on an impression that lithium seems to be a very promising pharmaceutical in mania and the cyclic depressions." (Litiumin käyttö... 1968). Where in the first article, the writers' recommendation to use lithium is based on the clinicians experience and cases of their own patients, the second one is based on the evidence from "*controlled follow-up studies*", recommending the use of lithium as a prophylactic drug to prevent the mood episodes in manic depression. Eight years later, in an article from 1976, lithium is already seen as the drug of choice to treat manic depression, a specific compound for a specific illness: "*Nowadays lithium is considered more specific and effective than the neuroleptics in the treatment of mania.*" The writers also explain the methods of the research and the relevance of the results:

"The conclusions are based on large and thoroughly controlled studies, where the subtotal of the patients has been several hundreds and the follow-up time many months, even years. Without exception, it has been possible to show in all the controlled follow-up studies that the continuous use of lithium reduces, in statistically relevant measure, both mania and depressive episodes in the manic depressive patients." (Litium ja trisykliset...1976).

ANTICONVULSANTS AND ANTIPSYCHOTICS AS MOOD STABILISERS

The prophylactic use of lithium paved the way for the idea of a distinct, but heterogeneous, group of psychopharmaceuticals, *mood stabilisers*, used in the treatment of bipolar disorder. David Healy (2008, 178-184) points out that the term mood stabiliser was actually rarely used until the mid 1990s. This term was coined in the context of the branding anew both the anticonvulsants and the second-generation antipsychotics for the treatment of bipolar disorder, which I already discussed in this chapter.

The anticonvulsants are drugs used to treat epilepsy. In the 1990s, first carbamazepin (Neurotol, Tegretol, Temporal.) and then valproate (sold by various brand names, in Finland Deprakine, Absenor), were licensed for the treatment of bipolar disorder. The hypothesis of why these drugs seemed to work for bipolar disorder as well as epilepsy stemmed from earlier research by Robert Post in the 1980s, who assumed that the pathogenesis of bipolar disorder would be similar to the kindling effect in the brain causing seizures and sensitising for recurrent seizures in epileptic patients. This kindling effect had been successfully treated with the anticonvulsants. The key aspect in the kindling hypothesis was that the anticonvulsants worked as a *prophylactic* medication for the recurrent depressive and manic episodes and could prevent more severe and rapid cycling of the mood episodes. This observation generated a significant amount of RCTs on many other anticonvulsants, such as gabapentin (Neurotin), topriamate (Topimax), tiagabine

(Gabril), but only lamotrigine (Lamictal) has been seen to show promise in treating bipolar disorder (Healy, 2008, 161-184).

Since the early 2000s, also the second-generation antipsychotics, olantsapine (Zyprexa), ketiapine (Seroquel) and risperidone (Risperdal), have merited the term mood stabiliser. In the early 2000s these new treatment possibilities were reported to the Finnish professional audience: *“The new antipsychotics are a more recommended choice than the neuroleptics. The antipsychotics seem to have wider effects, fewer side-effects and possibly greater treatment compliance in treating bipolar disorder.”* (Manian lääkehoito...2003). As I noted earlier in this Chapter, these second-generation antipsychotics were all very similar, both in molecular structure and treatment outcome, to the older group of antipsychotics and indeed had their own adverse-effects, such as weight-gain, hyperglycemia and diabetes, which in long term maintenance treatment can of course be even life threatening (Tyrer & Kendall, 2009).

The idea of a prophylactic medication, or maintenance treatment, for manic depression, stemming already from the early lithium studies, paved the way for the idea of anticonvulsants as prophylactic mood stabilisers in the late 1990s, which generated a hype for the new group of drugs directing the pharmaceutical industry to license and market the second generation antipsychotics as mood stabilisers in the 2000s. Perhaps this process threw some promising new drug discoveries out with the bathwater, when certain molecules were researched and others forgotten (Healy, 2008, 161-197).

The mood stabilisers is an important actor in the consolidation of bipolar disorder into Finnish mental health care. The idea of maintenance treatment of bipolar disorder with the mood stabilisers clip onto manic depression, later known as bipolar disorder, and the connection endures regardless of the transforming classifications and changing treatment practices throughout the decades. The meaning of the term mood stabiliser varies and it is basically used as a generic term to refer to the overall stabilisation of the patients acute mood episodes and the maintenance treatment preventing the recurrent cycling of the episodes. I discussed the muddled meaning of the term with the chair of the clinical practice guideline working group and she described the discussion in the group as follows:

“Well, the question of what actually is a mood stabiliser is an international scientific discussion. Back in the day, when I was a resident, we had the mood stabilisers and that was it. The term referred to the drugs used to treat bipolar disorder. But there really is a lot of discussion about the definition of a mood stabiliser, and some recommendations don't use the word at all. But we decided that in Finland it is an established term, which we can use, but we also decided to specifically define what it means in this text. But there

sure was a lot of discussion in the working group about this as well. ((laughing))” (Scientist2)

Lithium is still in 2013 the first choice in maintenance treatment of bipolar disorder in the Finnish clinical practice guideline and in the current updated version the term mood stabiliser is dedicated to the lithium and anticonvulsants, whereas antipsychotics are tentatively regarded as mood stabilisers: “*Also the antipsychotics may have mood stabilising effects*” (*Käypä hoito -suositus. Kaksisuuntainen mielialahäiriö.*, 2013). The main point is that the treatment of a thoroughly diagnosed bipolar disorder is always life-long maintenance treatment, and only in some cases of bipolar 2 disorder the maintenance treatment can be gradually dismantled (*Käypä hoito -suositus. Kaksisuuntainen mielialahäiriö.*, 2013).

MIXING THE COCKTAILS

There are ten compounds, lithium and a number of different anticonvulsants and antipsychotics, listed in the clinical practice guideline with the best level A evidence in the EBM evidence hierarchy for treating acute mania. Six of these compounds also have evidence of being effective in treatment for the mixed episodes with rapidly fluctuating manic and depressive episodes. The main problem in the current assortment of pharmaceuticals that can be used in bipolar disorder is the lack of evidence-based treatment options for the common and painful depressive episodes. Four of the compounds can be used in treating the depressive episodes in bipolar disorder, but only with evidence from level B and C. Some patients benefit from some of the listed compounds added with an antidepressant, but in other patients this might induce a turn to a hypo/manic episode (*Käypä hoito -suositus. Kaksisuuntainen mielialahäiriö.*, 2013).

The medication of bipolar disorder inevitably means mixing cocktails of different compounds and usually many experiments are needed until the right combination for the patient is found. Moreover, because the disorder is episodic and different episodes need different pharmaceuticals, and almost all of the pharmaceuticals have relatively severe adverse effects, finding the right medication is an art for the clinician and most usually quite frustrating for the patient. One of the psychiatrists I interviewed explained the difficulties of bipolar disorder treatment:

“I think it is only good that we have different kinds of pharmaceuticals, because these drugs do not only have their wanted effects but also the adverse effects. It often happens that a certain individual cannot use a certain drug, and we need to try another one. Sometimes the individual happens to be very sensitive to the adverse effects of different drugs or there are no effects at all. It is good that we have options.” (Scientist2)

The drugs always have their curing effects and the adverse effects. The etymology of the modern term 'pharmaceutical' illustrates this doubled effect: in ancient Greek, 'pharmakon' was a complex term meaning sacrament, remedy, poison, talisman, cosmetic, perfume or intoxicant (Martin, 2006; Rinella, 2010). Emily Martin (2007, 150-154) has analysed pharmaceutical advertising and argues that the drugs are portrayed as products invested with attributes that make it possible to think of the drugs as having nurturing relationships with the patients using them. The drugs are actors that are at the same time thing-like and person-like: nurturing compounds in relationship with the patient, but also sold and combined on demand in many ways, like ingredients of a cake or a cocktail. In addition, the brand names, like the first largely marketed SSRI, the 'happiness pill' Prozac (fluoxetine), can signify something more than just the compounds and become symbols of enablement in a culture fostering enhancement (Fraser, 2001; Vrecko, 2013).

The cocktails of pharmaceuticals are a very frequent topic amongst the patients on the discussion forums in the Internet. The patients compare their own cocktails and ask peer guidance on how to live with the adverse effects, as well as attribute meanings to the drugs by, for instance, using nicknames for their pharmaceuticals. I will go to the details of the patients' perspectives on pharmaceutical treatment in Chapter 5. As I have shown in this section, drugs are important actors and mediators in the process where evidence-based psychiatry and the treatment standard of bipolar disorder were consolidated into Finnish mental health care. But the pharmaceuticals are not the only treatment option in bipolar disorder and I will now continue to the psychosocial aspects of treating bipolar disorder.

THERAPEUTIC APPROACHES TO BIPOLAR DISORDER TREATMENT

Pharmaceuticals are not the only means to work on a bipolar patients' mind or brain. The psychotherapies of various kinds are techniques by which the patient, in collaboration with the therapist, attempts to influence the moods swings, feelings and emotions, thought processes and behaviour. In the writings of the medical journals the therapeutic aspect of treating bipolar disorder in a way summarises the process where evidence-based psychiatry becomes implemented in Finnish mental health care and clinical practice. I will take examples from two articles with slightly different perspectives on the so-called psychosocial treatment, which is a catch-it-all term for the different therapeutic approaches in bipolar disorder treatment.

In general, the psychoanalytical approaches do not distinguish bipolar disorder from depression. For instance, in *Mourning and Melancholia*, Freud (2001), writes: "*The impression, which several psycho-analytic investigators have already put into words, is that the content of mania is no different from that of melancholia, and that both disorders are wrestling with the same 'complex', but that probably in melancholia*

the ego has succumbed to the complex whereas in mania it has mastered it or pushed it aside." So the depressive experience of the patient is turned the other way around, forming the state of mania, and so the circular nature of the disorder goes on unless the "complex" in the patient's life is thoroughly investigated in psychoanalysis. This is the way bipolar disorder was covered in the earlier writings in the Finnish medical journals (Neuroottiset depressiot...1985).

Later on, the psychoanalytic explanation is replaced by the idea that there is a whole range of different kinds of therapeutic or psychosocial treatments, which are not explanations to the disorder as such, but parts of the treatment standard. In the first example from 1999, the article lists individual, family and group therapies, as well as psychoeducation for the patient and the family (Kaksisuuntainen mielialahäiriö ja...1999). These are different kinds of therapeutic approaches that aim to help the patient in accepting the idea of being bipolar and to support the patient in coping with the life-long illness.

Of the traditional therapeutic techniques, the cognitive and interpersonal approaches are said to be efficient in the depressive states, but when it comes to the manias, the writer in this article notes that there are advantages in the "psychoanalytic experience" of mania being the depressive reaction turned the other way around. This idea can help the clinician to meet the patient in the manic state, and understanding this reversibility can turn the manic manipulative and negative behaviour into acceptance and dependence of the therapeutic relationship. The writer acknowledges that the classic psychoanalytic technique, with its meetings four times a week and the passivity of the therapist, is ill-fitting with the *"erratic nature of the illness episodes and the biological dimension of the disorder"* (Kaksisuuntainen mielialahäiriö ja...1999), but the psychodynamic and investigative approaches to the patients life events, social relations throughout the life course, and the traumatic experiences can benefit the bipolar patient.

In the other example from 2010, the psychodynamic or psychoanalytic theory is conspicuous by its absence and there is a shift towards the cognitive and behavioural approaches in treating bipolar disorder. This might of course be because of the writers' preferences, but all in all the cognitive and behavioural approaches have gained increased popularity especially in treating mood disorders. In bipolar disorder, the starting point for cognitive approaches is not the distorted thought processes, as in depression, but a so-called stress-vulnerability model: *"in the illness, there is on the one hand the biological vulnerability that requires pharmaceutical treatment. On the other hand there are the stress factors in life and their effects on the course of the illness and as the triggers of illness episodes."* (Kaksisuuntainen mielialahäiriön psykososiaalinen..2010). This shows how the long tradition of genetic research on bipolar disorder, introduced in Chapter 3, influences the way bipolar disorder is understood: it is something inevitably biological.

The chair of the clinical practice guideline working group told me that the

psychosocial aspect of treating bipolar disorder was discussed within the working group:

“Our mutual viewpoint was that bipolar disorder is an illness where the patient always needs pharmaceutical treatment, but the drugs alone are not appropriate treatment. There always needs to be some kind of supporting psychosocial treatment. But what that psychosocial treatment then is varies individually. It is obviously not wise to recommend family-based therapies for someone single or a patient, who does not accept the diagnosis of bipolar disorder, does not benefit from the group psychoeducation. Like, it really needs to be tailored according to the patient’s individual needs.” (Scientist2)

The catch-it-all term, psychosocial treatment, does not only, or even mainly, mean traditional psychotherapeutic methods, but *“interventions on different levels, aiming at improving compliance to the pharmaceutical treatment and also the patients adjustment to the illness in general and the abilities to control its course and symptoms.”* (Kaksisuuntaisen mielialahäiriön psykososiaalinen..2010). In addition, psychosocial treatment consists of a good therapeutic relationship between the clinician and the patient, support in the patient’s compliance to the treatment and education on how to recognise the triggers for manic and depressive episodes, as well as education on self-management skills in daily life. The psychosocial treatment can be provided in the form of family therapies, group therapies or as psychoeducation. Psychoeducation in groups consisting of peers is the most common form of psychosocial treatment for bipolar disorder. I will return to this practice in Chapter 5, but the idea of psychoeducation crystallises the roles of the team of professionals and the patient. Consider this excerpt from an article where the ideal is that the patient is provided with a team of trainers or coaches:

“Good psychoeducation is mutual learning about the illness, experiencing it and coping with it. The relationship of the doctor and the patient changes. The doctor becomes more like a coach and less paternalistic without losing the expertise. When the compliance to the pharmaceutical treatment is addressed, the use of medication should not be made a question of authority. A better starting point is to ponder together the difficulties the patient might have when she tries to carry out the pharmaceutical treatment plan agreed upon together.” (Kaksisuuntaisen mielialahäiriön psykososiaalinen..2010)

HOW THE TREATMENT STANDARD WORKS IN PRACTICE?

The treatment standard outlined in the clinical practice guideline does not necessarily come true in every part of the country or in every out-patient clinic. It is a recommendation and a guideline, not a binding norm for the treatment of bipolar

disorder. Research reports of the current equality of access to the treatment is poor because of the already mentioned inconsistency in the two-level treatment system, as well as lack of resources in both of primary and secondary health care (Mieli 2009. *Mielenterveys- ja päihdesuunnitelma*, 2009). In addition, the guidelines seem to have little influence on the treatment practices of the general practitioners in primary health care, partly because the daily clinical work is premised so differently than the EBM guidelines. The reality of the clinical practice does not meet the ideals of the evidence-based medicine (Nummenmaa, 2007).

One my interviewees, a senior researcher, who also worked as an administrative doctor, elaborated on the situation in regard to the psychosocial interventions in bipolar disorder treatment:

“Every patient has a right to personal psychoeducation about the disorder. And at the moment we have a fair amount of researched psychotherapeutic approaches. But these, such as the family-based psychoeducation, are laborious to arrange, and in many clinics the resources are just not sufficient. The group-form interventions are more cost-effective, but for some reason the clinics do not integrate these in their programs. I think it is strange, because it is not hard to arrange the six months of sessions for the patient groups. Usually the patients themselves like to hear their peers’ experiences.” (Scientist2)

The pharmaceuticalisation of Finnish mental health care has increased over the past two decades, and the increase does not only stem from the mass use of antidepressants, but the use of antipsychotics has increased as well (Hautamäki et al., 2011; Klaukka et al., 2005). Pharmaceuticals are perhaps seen as quicker and more cost-effective than the psychosocial approaches, but the problems are in many ways in the mental health care system, and not that much in the minds of the clinicians. In primary health care, the resources a general practitioner has are very much limited to pharmaceuticals and perhaps meetings with a specialised nurse in some primary health care centres. The situation is not that much better in the out-patient clinics: pharmaceuticals are the main treatment and, additionally, the patient has regular counselling meetings with a specialised nurse and in some cases the clinics do provide the psychoeducation groups.

The EBM is the medical technology organising the principles for objective medical knowledge, and it fosters the use of drugs, because the RCTs are the golden standard for evaluating what is evidence-based treatment. The use of clinical practice guidelines in the lived reality of treating patients does suffer from this bias (Borgerson, 2009; Cartwright, 2007; Saarni, 2010).

4.7 Conclusion: Bipolar disorder as a treatable mental disorder

In this chapter I showed how bipolar disorder was consolidated into Finnish mental health care as a mental disorder, which should be recognised and treated better using the a standardised clinical practice guideline.

The chapter consisted of two parts. I started by analysing the ways knowledge on bipolar disorder was disseminated for different audiences and how the awareness of the disorder was raised amongst the medical profession. The need to strengthen the knowledge stemmed from a public health concern that bipolar disorder was inadequately recognised and hence incorrectly treated. This worry originated partly from the research results of the clinical epidemiology project in Hospital X I analysed in Chapter 3. The scientists in the project were writing and lecturing to a wider audience of professionals to consolidate bipolar disorder and its treatment standard in Finnish mental health care. I introduced the discussion about the pharmaceutical regime and the way drugs are developed and marketed, to set up the analysis of the treatment standard of bipolar disorder mainly based on psychopharmaceuticals.

In the other part of this chapter I analysed the process of compiling the evidence-based knowledge about the diagnosis and treatment of bipolar disorder to form a clinical practice guideline. The principles of EBM were used to combine the bits of evidence to a coherent treatment standard for bipolar disorder. However, I showed how the working group of professionals preparing the guideline had to bend the these principles in order to produce a guideline suitable for the messy reality of clinical practice (Armstrong, 2007; Borgerson, 2009; Saarni, 2010). I introduced the treatment standard of bipolar disorder by analysing how evidence-based medicine subtly took root in the way psychiatrist wrote about bipolar disorder in the medical journals.

On the whole, the process of consolidating bipolar disorder into Finnish mental health care was about coordinating the unstable object into something that can be diagnosed and treated in clinical practice. I am not arguing that bipolar disorder would have been non-existent in Finnish mental health care before this burst of knowledge dissemination and education, only that the knowledge that was already there needed to be strengthened, perhaps revised and certainly compiled to standardised the diagnosis and treatment of bipolar disorder.

In this chapter I have discussed the limits of evidence-based psychiatry, and the problems of acquiring evidence about what treatments work or do not work from the randomised controlled trials (RCT). The first problem stems from the fact that the drug developers face the same problem as did the scientists I introduced in Chapter 3: how to actually tame the diagnostic uncertainty in psychiatry and determine what kind of patient population to enrol in the trials (Healy, 2009;

Lakoff, 2007; McGoey, 2010; Wahlberg & McGoey, 2007). The second problem in the RCTs is that they put an emphasis on pharmaceutical treatments because the different therapeutic approaches used in psychiatry are not easily research in the design and this is something the professionals needed to work through in the process of compiling the clinical practice guideline for bipolar disorder. Then there is obviously the problem of how to consider the objectivity of the evidence from the industry-sponsored clinical trials. But perhaps the most fundamental problem in evidence-based psychiatry is the individuality of the patients, which in the end can not be generalised into all encompassing evidence-based knowledge (Armstrong, 2007). Evidence-based medicine as a medical technology attempts to tame the uncertainty in clinical practice, but the clinician is always left with the decision of how to interpret the individual patient's needs for cocktails of pharmaceuticals or psychosocial interventions.

Despite these uncertainties, the treatment standard of bipolar disorder is useful in the day-to-day practices of the clinicians because the evidence-based clinical practice guideline sets the *recommendations* of how to diagnose and treat bipolar disorder. The recommendation is a precondition for the clinicians' decision making applied to the individual patients' situation. The process of consolidating bipolar disorder is a process of putting the knowledge about bipolar disorder into effect. The message put into effect is that bipolar disorder is something that needs to be diagnosed more thoroughly, and that it is something that can, despite the uncertainties, be treated. In the next chapter I will go further in analysing how the diagnosis and treatment happens in clinical practice, but I am now changing the perspective of my analysis to the patients' experiences.

Chapter 5

Becoming bipolar

5.1 Introduction

In the chain of mediations from science to clinical practice, the target is the patient. The patient is the reason the scientists introduced in Chapter 3 were enthusiastic about their research and the patient is the reason for the public health concern I discussed in Chapter 4. The patient is also the ultimate target of treatment standards and the one that actually uses the pharmaceuticals and receives the psychoeducation.

In this chapter, I analyse bipolar disorder from the perspective of the patients' experiences. Diagnostic uncertainty is experienced in their day-to-day lives of the patients, and it is not an issue to be solved by standardised diagnostic classifications or clinical practice guidelines. The question is: who determines how to interpret the symptoms of bipolar disorder? Who determines what the patients should or should not feel and how they should or should not live their life with the bipolar disorder diagnosis?

The experience of bipolar disorder does not limit to the fixed illness identities or subject positions, nor is the experience situated in the realms of either psyche or soma (Buchman, Borgelt, Whiteley & Illes, 2013; Gross, 2011; Karp, 1994, 2009; Martin, 2010; Moutaud, 2003). The experience of living with bipolar disorder overcomes the dichotomies of, for instance, mind and brain or pharmaceuticals and psychotherapies. The disorder itself and the treatment processes affect the patients minds, brains and bodies. Day-to-day practices of living with bipolar disorder, shows how bipolar disorder is a process of adjusting to the ever-changing situations of the mood swings, emotions, cocktails of pharmaceuticals, diet, sleep, thought and biological processes.

In this chapter I will analyse these processes by paying attention to how scientific knowledge, Big Pharma marketing and the standardised treatment practices discussed in the previous two chapters mediate into the lived experiences of the patients.

THE MATERIAL USED IN ANALYSING PATIENTS' EXPERIENCES

I have analysed the patients' lived experiences by using various sources. For long, I have had a research interest in the *educational material* on mood disorder provided for patients, and I have previously analysed this kind of material on depression (Hautamäki, 2007; Hautamäki et al., 2011). The educational material ranges from medical books and encyclopedias to the immense information flow online, and to the more specific patient information material handed to diagnosed patients in mental health care. Before, when people were concerned about health issues, they contacted the family doctor or perhaps consulted a medical book or encyclopedia from their bookshelves or in the library. Today, the obvious source of information is the Internet. I have been following the field of mood disorders online for several years and the situation has dramatically changed in the last 15 years or so. The medical books and encyclopedias have moved online. The more specific patient information material that is targeted at diagnosed patients also finds its way online. I have analysed this kind of educational material provided online and in printed form.

For the purpose of this research, I have been following several discussion forums dedicated to bipolar disorder, so that I have visited the forum roughly once every two months and exported the interesting discussion threads to a text processor. In addition, I have followed personal blogs kept by patients with bipolar disorder. This material has been a source to learn about patients' experiences, therefore I have not analysed the interaction of the discussions or the nature of the forums as communities for the patients (Giles & Newbold, 2011; Vayreda & Antaki, 2009). I have complemented the material on patients' experiences by interviewing a few patients diagnosed with bipolar disorder. Finally, I have used the interviews with the psychiatrists and other professionals in this chapter in order to view the clinical situations of reaching a diagnosis.

To map the printed educational material, I have searched the archives of the National Library of Finland. The oldest patient information leaflet I found was from 1991 by the Finnish pharmaceutical company Orion, but most of the material is published from 2000 onwards. Most of the material is targeted at the diagnosed bipolar patients as psychoeducational information aiming to improve the patients' compliance to the treatment. The concept of treatment non-compliance is used to refer to the patients' unwillingness to accept their diagnosis and treatment. The pharmaceutical industry has used this as a marketing device (Applbaum & Oldani, 2010; Brodwin, 2010; Gardner, 2003), but I will rather read the educational material from the patient's perspective: what does the education tell the patient about bipolar disorder and coping with it in day-to-day life? The patients do of course acquire information from many other sources as well, but for the scope of this research I have omitted from my analysis for instance the traditional media coverage of bipolar disorder or autobiographies.

THE STRUCTURE OF THIS CHAPTER

I will start this chapter by analysing the Web as the first instance of searching for knowledge about bipolar disorder. I am hypothesising a concerned patient-to-be, reflecting her moods and surfing the mental health bazaar online. The web provides the hypothetical patient-to-be with a bipolar disorder vocabulary, the mutual language to speak about the mood swings. I will then take a moment to analyse the patients' own ways of describing how the symptoms of bipolar disorder actually feel like. In the next section I bring up the important process of reaching the bipolar disorder diagnosis in clinical practice with the help of the diagnostic tools.

In the remainder of the chapter I will elaborate the situation of receiving a bipolar disorder diagnosis from the patients' perspective with the help of two case examples, and analyse bipolar disorder treatment standard from the patients' perspective. In the last section I analyse the different aspects of the bipolar disorder experience:

the bodily and the mental.

5.2 Making up a patient

In Chapter 3, I discussed how the diagnostic classification of bipolar disorder is *making up people* as objects of medical knowledge and interference. This idea comes from Ian Hacking's thinking and refers to the way scientific classifications, like bipolar disorder, affect individuals. The existence of the classification, bipolar disorder, provides a space of possibility to interpret certain kinds of mood swings as bipolar disorder (Hacking, 1995, 1999, 2002a, 2007). Education about bipolar disorder, online and in printed form, is one route for the classification to provide the possibilities for an individual to reflect her own situation to the classification.

The use of Internet in seeking and acquiring health information has been widely studied from many angles. In social sciences the increasing amount of health information online has been seen, on the one hand, as an empowering force mitigating the power relations between medical professionals and laypeople and democratising the medical expertise (Hardey, 1999, 2002; Henwood, Wyatt, Hart & Smith, 2003; Eriksson & Salzmann-Erikson, 2013). On the other hand, concerns have been expressed about the quality of the on-line health information or peer support and sharing advice between non-professionals (Clark, 2002; Eastin & Guinsler, 2006; Eysenbach & Köhler, 2002; Lewis, 2006; White & Horvitz, 2009). Lay people seem, however, to be quite literate and critical while seeking health information online, and seem to find the sites that provide relevant information. The so-called expert patients or consumer patients are utilising the Web to make themselves better informed before presenting their problems to health professionals and feel capable of judging the medical relevancy of the information,

whereas some gladly hand the authority of medical decision making to the professionals and feel that ignorance is bliss (Henwood et al., 2003; Lewis, 2006; Nettleton, Burrows & O'Malley, 2005; Seale, 2005).

One of the results of the clinical epidemiology research, I introduced in Chapter 4, was that it can take years before an individual patient is correctly diagnosed in the health care system and one afactor in this delay is that patients tend to seek help mainly when they are in the midst of a devastating depressive episode, not when they are on the top of the world during hypo/manic episodes. Some patients seek help more or less forced; family members, friends or loved ones being the instigators in these cases, but others come willingly with perhaps an already prepared diagnosis to tprovide the clinician. The fluctuating nature of the disorder further complicates the situation, because a patient can feel 'normal' for years between the manic or hypomanic and depressive episodes and the overall rotation of the episodes varies from one patient to the other.

However, from the patients' perspective, the process of reaching the diagnosis and becoming a bipolar patient does not originate when entering the consulting room; a lot has usually happened in the patient's life before the first contact to the health care system. The individual might have experienced a period of being a *patient-to-be*, that is someone who has been concerned about her mental health issues and mood swings. In this section I will show what that patient-to-be encounters while seeking information about bipolar disorder online and in printed form.

BIPOLAR DISORDER INFORMATION AND EDUCATION

The imaginary patient-to-be would probably start by seeking for information about bipolar disorder on the Internet in Finnish, and a popular search engine such as Google provides 118 000 hits. Among the first hits: the Wikipedia article, patient information sites provided by a patient association and a pharmaceutical company, the patient's version of the clinical practice guideline, and many threads about the topic on popular discussion forums. A majority of the lay information seekers use search engines to find information about a given health problem and, due to the algorithms accentuating the most popular and in-linked sites, this usually leads the seeker to the most popular and mainstream sites, such as the governmental, pharmaceutical industry and patient association sites (Introna & Nissenbaum, 2006; Eysenbach & Köhler, 2002; Seale, 2005).

In Chapter 4, I analysed the dissemination of scientific knowledge from the scientists to wider audiences of medical professionals. In the medical journal articles and research reviews, as well as the presentations at the resident trainings days, knowledge about bipolar disorder was translated into a form that was assumed to be more beneficial for a clinician. In the patient information material, scientific knowledge is translated to benefit the patient by summarising and

simplifying the message.

However, the basic information is not all these sites and leaflets provide, because they are also meant to be psychoeducational material for patients diagnosed with bipolar disorder. In addition to the general medical information, the sites and leaflet provide cases as examples of a typical bipolar patient, self-care guidance and tools for managing ones own moods and medications.

Many of the patient information leaflets are introduced with is a small overview on the prevalence of bipolar disorder and a statement that bipolar disorder is a common problem in the population:

“You might think that you do not know anyone else that would have the same illness, but bipolar disorder is not uncommon. At least 1.5% of us have bipolar disorder. This means that there are as many people with type I and II diabetes as there are with bipolar disorder. Bipolar disorder has not been discussed publicly as much as diabetes, and this is due to the fact that the disorder cannot always be recognised. A significant part of the patients have a wrong diagnosis, like depression for instance. It has been estimated that only every fourth patient makes an appointment with a doctor and receives proper treatment” (Kaksisuuntainen mielialahäiriö. Vastauksia...2003)

The argument that bipolar disorder is quite common amongst “us”, even as common as diabetes, seems to be an attempt to normalise bipolar disorder into any common public health problem; to reduce the stigma attached to mental illness. The basic message about bipolar disorder as a misdiagnosed, and hence inadequately treated but common public health problem is exactly the same that could be read from the medical journals for the professionals I introduced in Chapter 4.

On most of the websites and in the leaflets, the scientific knowledge about the pathogenesis and aetiology of bipolar disorder is explained to be unknown, but the disorder is said to be “*unusually biological*” (Bipoinfo.fi, 2013). The unknown biological mechanism can also be portrayed using metaphors:

“The manic episode seems to be some kind of ‘electric whirlwind’ [...] The metabolism of serotonin, noradrenaline and dopamine can in the manic episode ‘boil over’ and in the depressive episode stagnate.” (Elämää vuoristoradalla...2005).

The usual way of explaining what causes bipolar disorder is quite straightforward and faithful to what actually is known by science: bipolar disorder is strongly linked to heritability, it has something to do with neurotransmitters, there are structural changes in the patients’ brain and many factors together affect the onset of bipolar disorder.

The core symptoms of bipolar disorder are listed according to the DSM classification and the fluctuating nature of the disorder are explained so that the up and down nature of the disorder becomes clear. Symptoms are but also described in more detail to open up the meaning of, for instance, increased activity:

“A person’s increased activity might have to do with work, hobbies, business or in daily routines in overall. The person might start several different tasks at once, but fails to get anything carried out. Increased activity might also mean irritability and inability to stay still.” (Bipoinfo.fi, 2013).

The treatment of bipolar disorder plays a substantial role in the educational material. Psychosocial treatments, like different therapies, are usually mentioned, but the emphasis is on the self-management of the symptoms and pharmaceutical treatments. The above primary is the importance of taking the medication regularly and not seizing the medication unaided, because one of the objectives of the education is to increase the patients compliance to the treatment:

“For the treatment to be successful, the medication must be taken as instructed. A substantial part of the patients do not use the medication according to the prescription.” (Mieli.fi, 2014).

The basic information is backed up by case histories about typical bipolar patients’ life stories. Usually the narrative is about how it took time to for the patient to first seek help, and how the diagnosis was received by trial and error. Then the story continues by describing how the patient became adjusted to the idea of having a lifelong illness, and how the treatment improved the patient’s condition.

The educational material is often written by a psychiatrist, so the case histories are seen through the clinicians gaze, but some sites do provide autobiographical stories written by the patients as well. In the discussion forums and blogs, one can find a multitude of different real-life illness histories and stories about how to survive in the mental health care system. I interpret these personal case histories as narratives of an illness identity. Illness identity has been seen as something individuals tend to adopt when a serious and/or chronic illness disrupts their life forcing them to reflect their identity and life history to come to terms with this disruption (Bury, 1982; Jones, 2005; Karp, 1994; Radley, 1999; Skultans, 2000). In the context of being posted online for anybody to read, these illness identity stories call for reflection from the reader: does this sound like me?

The purpose of the education is, however, not only to provide information about bipolar disorder for anybody concerned, because the patient education is also a marketing platform for the pharmaceutical industry.

MARKETING BIPOLAR DISORDER

These same characteristics, general medical information, self-care guidance and patient cases, can be found in almost all patient information material online and in printed form, but the information provided by pharmaceutical industry seem to be directed more to the already diagnosed patients as psychoeducational material. In the industry-sponsored material the importance of compliance to the pharmaceutical treatment and the self-care guidance is stressed, whereas the information provided by patient associations and public health care seem to stress the importance of seeking help.

Kalman Applbaum (2009d) has analysed the ways treatment non-compliance, a long-standing problem for healthcare professionals, has become a form of marketing platform for the Big Pharma. The strategy is to impact patients' experience of illness, as well as the participation of those involved in the treatment: nurses, psychiatrists, case managers, family and friends (Applbaum, 2009d; Glick & Applbaum, 2010). The industry-sponsored leaflets and workbooks on bipolar disorder are used in the psychoeducation groups for bipolar patients. I will analyse these groups in more detail later on in this chapter.

This kind of awareness-raising is part of the marketing strategies of the industry a way to promote the sickness without promoting the drugs, because direct-to-consumer (DTC) advertising is not allowed. The information material on the companies websites changes in accordance to to new and closing therapeutic areas. For instance, Eli Lilly initiated a depression awareness site when the anti-depressant Cymbalta (duloxetine) came into market, and similarly H. Lundbeck launched their website (Bipoinfo.fi) about bipolar disorder when they started to market a new drug Sycrest (asenapine), an atypical antipsychotic, in Finland.

Although it is clear that the information online is provided by the pharmaceutical industry in marketing purposes, the information itself can be just as relevant as the information provided on the educational sites by the patient associations or public health care. These actors are also interrelated in the process of producing patient information, so that a patient association can publish material in collaboration with a pharmaceutical company and the professionals responsible of the content can be the same psychiatrists (Hautamäki et al., 2011; Hautamäki, 2007).

DIAGNOSTIC TOOLS AND SELF-DIAGNOSIS

In addition to the information on the educational bipolar disorder websites, the mental health bazaar on the Web provides 'quizzes' and other quasi-diagnostical tools for the concerned patient-to-be. The 'tests' or 'quizzes' are usually the same screens and questionnaires used in clinical practice to diagnose a patient, such as the Mood Disorder Questionnaire (MDQ) discussed in depth in Chapter 3. In the Internet the same screen can be found titled "MDQ-test" added with

the instructions to interpret the results, and a caution that the *“result is only approximate and the diagnosis of bipolar disorder can not be made based on the result”* (Tohtori.fi 2013). For the hypothetical patient-to-be, browsing the Web due to mental health concerns, the questions in the “MDQ-test” provide one way to reflect the symptoms of bipolar disorder.

The MDQ screen, in its original use in research and clinical practice, is indeed a tool developed to put into words of the abstract symptoms of bipolar disorder. In Chapter 3 and 4 I analysed the problematics of how the screens and questionnaires travel from research use to the clinical practice and become the objective measurement of bipolar disorder. As online ‘tests’ anybody can assess the possibility of bipolar disorder and the diagnostic tools are disconnected from their original use. In this new context the MDQ is no longer used and interpreted by a professional in the consulting room, instead it becomes a tool to conduct an instant self-diagnosis.

The hypothetical patient-to-be might also end up seeking answers from the discussion forums dedicated to bipolar disorder. One manifestation of the disquietude about determining the fine line between normal ups and downs and bipolar disorder, is a repeated topic on the discussion forums for bipolar patients where someone posts the question: is this bipolar?

“I am emotionally somehow so lost that I have started to suspect that this is something else than just often-changing ‘good day, bad day’-cycles and low self esteem. I heard a while ago that bipolar disorder has been diagnosed in my family and by googling I found out, that the susceptibility is heritable. Is it susceptibility to bipolar disorder that I have had an unsafe relationship with my mother? And how about my habit to fool myself and the others by damping down my feelings? Please, be so nice and tell me how does this sound like. I need help.” (Discussion forum)

The discussion forums I followed were full of threads starting like this. This excerpt is from a longer thread and the question of the patient-to-be were followed by responses from others, already diagnosed bipolar patients, providing their insights on the situation.

The peers could act as diagnosticians on the spot by stating that those symptoms are or are not bipolar disorder, but a more common response was to provide a the personal story of recognising the symptoms and reaching the right diagnosis. A common advice from the peers was also to contact mental health care to have a proper diagnosis and to receive treatment. Hence, some kind of act of diagnosis takes place on the discussion forums (Giles & Newbold, 2011; Vayreda & Antaki, 2009). These threads can also pop up from the information flow of the Internet in the future when someone else is seeking information about bipolar disorder.

All in all, the information flow about bipolar disorder on the Web provides the hypothetical patient-to-be with a mirror for reflecting personal feelings, moods and behaviour and perhaps recognising the symptoms of bipolar disorder. On the one hand, all this might reduce the stigma attached to bipolar disorder and raise awareness of the symptoms of bipolar disorder so that ever more people in need of treatment would indeed seek for help. On the other hand, the information flow on the Web also opens up the possibility for the concerned patient-to-be to perform a hasty self-diagnosis by interpreting quite normal ups and downs as signs of a mental disorder.

For the hypothetical patient-to-be, the information online provides new ways of putting mental distress into words and opens up the possibility of bipolar disorder. Scientific categorisations of human beings, such as bipolar disorder, interact with the individuals, such as the patient-to-be surfing the web and in the process the categorisations are making up the patient (Hacking, 2002a, 1995). I am not arguing here that anyone would become bipolar simply by surfing online, just that the information can provide the means to interpret mental distress as bipolar disorder. The education about bipolar disorder is one part in the ensemble of factors affecting how bipolar disorder can be understood and acted on by the individual.

The education about bipolar disorder also provides the patient diagnosed with bipolar disorder the medical vocabulary to speak about the disorder, where the symptoms are described as they are represented in the DSM classification. In the next section, I will show how the patients themselves are putting the feelings into words.

5.3 How does hypo/mania or depression feel like?

THE DSM LANGUAGE

In her ethnography on mania and depression in American culture, anthropologist Emily Martin (2007) followed bipolar disorder and depression support groups as a participant-observer on a regular basis for several years. Martin (2007, 140-142) noted that the participants in the support groups used the shared and familiar DSM diagnostic categories, *the DSM language*, to describe their feelings to the peers and it was not customary for someone to actually describe inner experiences and psychic states such as the sensory experiences in a manic episode (olfactory, tactile, visual, or auditory sensations).

The DSM language provides words, a specific bipolar disorder vocabulary, that the patients can adopt and by which they can describe their moods, feelings and behaviour. I would argue that the education online can also help with the difficulties of translating personal inner experiences into the DSM language, as

the following excerpt from a discussion thread exemplifies. This is from a thread started by someone who has just realised that she might indeed have bipolar disorder and seeks for confirmation from the peers in the discussion forum. Another discussant, answered her as follows:

“As you said, you have had those symptoms throughout life, but you can’t understand them until you have information, so that you can see the symptoms as part of something that can be treated. When you have the right diagnosis, or as right as possible, it can significantly help you to understand yourself” (Discussion forum)

The writer, who seems to have had the bipolar disorder diagnosis for a long time, points out the importance of having knowledge about bipolar disorder in order to be able to see one’s own symptoms as part of a particular disorder. A close enough diagnostic category can help to acquire an understanding of oneself in a new way, but the information is not the same thing as understanding:

“To know about the illness and to understand the illness are two different things, I think. It is easy to find information about the illness, but it is a completely different thing to actually understand what one goes through in, for example, depression. It is in a way unreasonable to ask the other to understand something you do not fully understand yourself. Personally I, for instance, could explain hardly anything about the illness, like what’s wrong with me, because it was new also to myself and I didn’t have names for things. Things were inside me as emotions. Many things are still without words.” (Discussion forum)

This excerpt is from a thread, where one of the discussants elaborated the difficulties caused by the situation where one can gather information and acquire knowledge, but is still not quite able to understand bipolar disorder or find the words to describe it. Although all the information is available, it does not provide insight into the *experience* of bipolar disorder.

The DSM provides the list of symptoms, hypo/manic and depressive, but the symptoms remain quite abstract. This is why I was interested in how the patients with a bipolar disorder diagnosis themselves defined the symptoms and characterised the feelings and behaviours associated with the symptoms. I analysed the discussion forum material and sought for patients’ articulations of the symptoms of bipolar disorder.

HYP0/MANIC BEHAVIOUR

In Chapter 3 I introduced the DSM categorisations and symptoms of bipolar disorder. The symptoms of hypo/mania consist of changes in mood, either elation

or irritation and changes in behaviour, such as decreased need for sleep, goal-directed activity (social, at work or school, sexual) or involvement in pleasurable activities (buying sprees, sexual indiscretions or foolish business investments). On the discussion forums, the patients do talk about their symptoms in the DSM language, but also reflect the symptoms more extensively, especially the mood changes: the elation, energy and joie de vivre they experience or the irritation they feel because the rest of the world is too slow and static for their energy. Consider for instance this patients description of the hypomania:

“I sweat, I’m enthusiastic and excited, I speak fast, I’m energetic and feel deep happiness and joy of life, I do all my deeds, like washing the dishes or walking, in a fast pace, I sleep less, I want a lot of sex, I don’t have an appetite and sometimes I forget to eat, because I’m so excited.” (Discussion forum)

The patient sketches the symptoms listed in the DSM in his own words and adds some descriptions of bodily reactions like sweating or the ways the increased energy affects his daily chores. Along with the feelings of elation, some of the patients feel themselves overtly irritable and describe how the irritation to other people, voices and touches affect their lives and how they get provoked by the slightest things and take it all out on their loved ones or anybody nearby.

Along with these mood symptoms, there are the so-called behavioural symptoms of hypo/mania. The patients I observed in the discussion forums described hypersexuality, buying sprees, excessive alcohol consumption, travelling or road rage as of cravings that could no longer be controlled. These behavioural changes are highly normative and it is not easy to determine what is excess in these behaviours and what actually differentiates normal behaviour from the hypo/manic.

In the context of bipolar disorder these urges come to be interpreted as symptoms of the disorder sometimes so that the patient personally consider the behaviour quite normal and it is the families and loved ones of the patient’s or the treatment team in mental health care who think otherwise. There is a medical term, *illness behaviour*, which refers to the patient being unconscious about the behaviour that can be seen by the clinician or the family members. The question of course is, who has the power to interpret the patients behaviour as pathological or irrational, and what is the normative context within which to reflect the symptoms of bipolar disorder? (c.f. Martin, 2007, 5-11)

The other cluster of behavioural symptoms, increased energy and goal-directed activity towards work and other projects, are, in turn, interpreted more often as characteristics of a rational and efficient individual. Hypo/mania is often associated with a cultural imagery of energetic creativity, entrepreneurship and bold risk taking. The flexible, innovative, efficient and rational citizen of the capitalist world quite ironically has the same characteristics as the irrational hypo/manic one (Martin, 2007, 234-268).

The discussants on the forums, however, describe the way their increased energy is oriented to round-the-clock working, but then the engine shuts down and the individual deteriorates into depression:

“When I’m thinking of it in retrospect, it happens that in hypomania, you don’t have a realistic view of yourself and your abilities. You think it’s possible to take up demanding work projects just like that on top of one another. Come to think of it, that kind of state of mind is actually perfect for the employers today, but but... too little sleep and constant overload do remind you of your mortality at some point. But you still try to go on with the show until you just can’t take it no more. If your self-esteem has been very oriented towards activity and pursuit, you get quite a kick in the head when the depression hits and it becomes impossible to lift a hand anymore.” (Discussion forum)

Bipolar disorder is associated with artistic creativity. The Web is filled with listings of great politicians, business men and artists that are known to have suffered, or benefited, from bipolar disorder. These listings keep alive the imagery of bipolar disorder as simultaneously something admirable, wanted and virtuous, but yet irrational and frightful. In the discussion forums I observed, how the creativity of the hypo/manic state manifested itself also in homely things and day-to-day domestic chores like cleaning, baking, cooking and decorating.

One of the symptoms of bipolar disorder feelings of grandiosity, which many of the patients describe in a self-ironic tone. They do realise that the grandiose thoughts about ones abilities to follow through the innovative business plans or home decoration projects, are not fully realistic, but they are still enjoyable. This is exactly the part of experiencing bipolar disorder that patients themselves do not consider as something they would like to be treated as a mental disorder. These symptoms are something they feel is part of their identity and personality, something they do not want to turn down with pharmaceuticals. I will return to this aspect in the patients’ experiences later on in this chapter.

The manic energy could be sensed in long posts consisting of stream of thought without full stops, or as these kinds of exclamation-marked rhapsodies for the wonderfulness of life of a supermom:

“I feel like running wild, I’m enthusiastic, I have energy for the whole village!!! I have a hard time to concentrate, I feel like dancing and I want to fool around. I laugh easily and OOOOH!!! I just feel so great!!! I never want this feeling to stop!!! I would not want to take the pills, the stupid pills that make one a dull and a grey shadow!! I ENJOY LIFE!!! [...]

But yeah... what was I supposed to say... Oh yes! The psychiatrist... i don’t know if I dare to go to the appointment... they can force me

to go to a round room because I have the courage to be happy and enthusiastic about life and all the things in it! It is damn strange, who has defined the limits of normal happiness... It feels like one can not be happy at all, when immediately they give you pills and numb you..." (Discussion forum)

This post on a bipolar disorder discussion forum could be interpreted as an outburst from a patient who has stopped her medication and is in an irrational state of a hypomania or even mania, but I think there is something more in this excerpt and others like it.

These kinds of outbursts reminds me of Emily Martin's (2007) observations of the ways the patients could *perform* manic behaviour by overdoing the symptom characteristics in the safety of the peer support group. In the above excerpt the putatively irrational patient's way of performing her mania is commenting many phenomena in the assemblage of psychiatry: the numbing pills, the psychiatrists, the round room and the elation of being high on life. These are all things that the other bipolar patients recognise due to their own experiences as something not that irrational, but more normal in life. For them this kind of outburst is not a sign of irrationality, but perhaps a slightly alarming sign that the dosage of the "numbing pills" indeed should be raised, because eventually the energy and elation would turn into devastating depression.

DEPRESSION AND MIXED EPISODES

In the lives of patient's with bipolar disorder the highs of hypo/mania will eventually turn into depression. While reading the bipolar patients' descriptions about their depressions in the discussion forums, blogs and interviews, I wondered, if their depressions were perhaps even more debilitating than usually in depression, just because the depressive episodes followed the extreme energy and elation of hypo/mania.

I introduced the DSM categorisation of a depressive episode in Chapter 3. The basic symptoms, in addition to depressed mood, are loss of interest and pleasure in life and activities. In a depressive episode there are less behavioural symptoms than in hypo/mania, but more distorted thought patterns, such as feelings of worthlessness and suicidal thoughts.

There was an interesting thread on one of the discussion forums, where the patients described the feeling in depression with one word. This collection of words portrays their mood in the midst of a depressive episode:

"stagnation, shaft, prison, hell, black, emptiness, end, stigmatised, futility, fuck, insignificance, seize, flopped pancake, tired, death, lost, hole, nightmare, loneliness, drowning, braking, cracking, swamp,

darkness, tunnel, endless, pain, vortex, unbearable, blind alley, sadness, capsule, suffocation, fear, total isolation, concrete casket, possibility.” (Discussion forum)

It seems like the patients had used their energy and stamina to the extreme in the hypo/manic state and the depression that eventually follows is a complete shut-down of the system. The symptoms of psychomotor retardation, extreme fatigue, sleeping too much and diminished interest were often described.

Along with these dull and empty depressive episodes and the hypo/manic highs, the DSM has a distinct categorisation of a mixed episode (or mixed features). This characterises a different state, where the hypo/manic and depressive symptoms are experienced simultaneously. The DSM-IV definition of a mixed episode: *“the criteria are met for both a Manic Episode (see p. 362) and for a Major Depressive Episode (see p. 356) (except for duration) nearly every day during at least 1-week period”* (APA (American Psychiatric Association), 1994, 365).

During a mixed episode, the patient experiences rapidly alternating periods of sadness, irritability and of euphoria accompanied by symptoms of a manic episode. The symptom presentation frequently includes agitation, insomnia, appetite dysregulation, psychotic features and suicidal thinking. A patient can experience a mixed state as a very disturbing state of rapidly fluctuating strong emotions:

“I wonder why live, what is the meaning of life and why does it have to hurt? The next minute I can be sewing, home decorating and singing along to the radio. I burst into tears for no reason, like when I see an old granny in the street or something. I can’t be still, although I would like to take a nap. Also, I’m at the same time really irritated, the whole world is full of shit and I plan new education and apply to schools and and...

Doesn’t this sound unfocused? This was a few hours period of this day in my life and this is how it is now ALL the time. I was discharged from the hospital on Friday, I heard voices a couple of weeks ago, but not anymore. I think I’m going crazy, why can’t this end???” (Discussion forum)

The patients describe how the mixed episode makes one feel anxious and unfocused, because the roller coaster goes too fast and the subtle feeling of control over the moods is lost. According to the research done on mood disorder suicidality, the suicidal acts do often occur during the depressive episodes or the mixed states (Holma et al., 2008; Isometsä, 2014).

Suicidal thoughts were openly discussed on the forums and the peers try to help each other to go through and fight those thoughts. I find these discussions hard to read, but when it comes to the experiences of the patients, suicidal thoughts and attempts are unfortunately part of their lives.

Here is how one middle-aged man, who is still among the active writers in the discussion forum, described his thoughts about life and its meaning two years ago:

“I don’t have much lust for life at the moment. (...) The reasons for continuing this life seem so thin. I should probably find some meaning in my life (how brilliant!), and find the ability to feel anything else than anxiety. When you have once lost contact with yourself and with your own true emotions, it seems to be impossible to get them back. So I’ve been thinking that I am actually watching a really bad film, starring me myself and I. This has nothing to do with real life, real life being something where you genuinely feel a whole range of emotions. No, this is only damage control.” (Discussion forum)

The writer feels the he is living in a fiction, a film, and that he has no connection to his real emotions and genuine being. I think this excerpt illustrates how overpowering bipolar disorder can be for the one experiencing the descent from the hypo/manic elation, grandiosity and overwhelming sensory experiences to the total meaninglessness and life absorbing numbness of depression.

All in all, when I was reading and listening to the patients’ own characterisations of how it really feels to experience the symptoms of bipolar disorder, it was clear that the actual experiences were not narrated in the DSM language. Also, the way the patients articulated hypo/manic, depressive and mixed state symptoms show that the mental states are not that sharply divided into separate mental states or episodes in the day-to-day experiences of the patients.

However, the DSM language is in use when the symptoms of bipolar disorder are discussed in medical settings. When the diagnosis is placed in the clinical practice the personal experiences are translated into the DSM language.

5.4 The dynamics of reaching a bipolar disorder diagnosis

DIAGNOSIS IS ABOUT DISCUSSION

As I have already pointed out many times in this research, a psychiatric diagnosis is reached in discussion between a clinician and a patient. The DSM language mediates this discussion and provides words not only for the patient, but also for the clinician to speak about the mood swings in the consulting room. One of my interviewees, a psychiatrist doing both research and clinical work, described the problematics of reaching a bipolar disorder diagnosis from her perspective:

“Well the starting point is that I am the one making the diagnosis. I need to have all the information and the patient’s description about

the symptoms and so on, bearing in mind that if the patient does not want the bipolar disorder diagnosis, I will not be told about the mania a few years ago. You need to have informants to check these out. It is like the relevant information is hidden, or then there are other disorders that are as in served on a plate to me. I might have a gut feeling that what the patient says really sounds just like taken from the clinical practice guideline. That is not lived reality. ADHD seems to be a fashionable diagnosis at the moment" (Scientist1)

So according to the psychiatrist, the patients can indeed adopt the DSM language and enter the consulting room with an idea of a diagnosis of their liking. In our interview, the psychiatrist continued to ponder the consumer patient who comes has acquired all the information and knows the DSM language. She found that patients have more information and they know how to use it as a positive development, because the more knowledgeable patients "*diminish the power relation between the psychiatrist and the patient*" (Scientist1). I think this psychiatrist articulates many very important aspects in the process of reaching a psychiatric diagnosis.

First of all, the psychiatrist points out that she is the authority doing the diagnosis, and as a medical professional she also bears the responsibility of the diagnosis and the treatment that follows. However, it is the patient who is responsible for describing her symptoms to the clinician. The patient can choose what to mention in the discussion. If the psychiatrist's assessment is not in alignment with the patients interpretation, the "*informants*", family and friends, can help the clinician to dig deeper into the life of the patient.

Secondly, the psychiatrist I interviewed emphasises that some psychiatric diagnoses are more agreeable than others. The "*fashionable ADHD*" seems to be a mental disorder particularly resonating with the difficulties in patients' lives, and perhaps this disorder is somehow less stigmatising to the patient. The clinicians, in turn, might favour diagnoses that can be managed with medication and require less therapeutic work, such as bipolar disorder over borderline personality disorder. Consider this interviewee's thought about the sensitivity and interactivity of a psychiatric diagnosis process:

"Many of the patients we have diagnosed and treated here [in the Hospital X during the research] are in a situation where the previous clinician has had no idea what bipolar disorder is. The patients have then been treated as having depression or borderline personality disorder. So of course the patients are confused. But in many cases it might have been the patient, who has not agreed to the bipolar disorder diagnosis in the first place, and the clinician has then followed the patient." (Scientist1)

Yet again, from the patient's perspective there are several reasons not to want a bipolar disorder diagnosis. On the forums, diagnoses are discussed, as well as the possible implications of a certain code in the medical records:

"I was at the doctor's in primary health care and he went through my files while writing an epicrisis from my sports injury. Then he said: "You are the youngest Lithium patient I ever met. Good old Lithium..." he laughed. I pretty much hate doctor's appointments. I mean the normal doctors, not psychiatrists. Because every so often you notice that the doctors do not take you seriously when you have this diagnosis." (Discussion forum)

A bipolar disorder diagnosis might be seen differently than a more common depression diagnosis in various situations from treating somatic problems in primary health care to receiving benefits for long term therapy, or to qualifying as a customer for an insurance company (Cooper, 2004).

Hence, the problems in misdiagnosing bipolar disorder are not only problems of educating the clinicians so that they are able to reach a more accurate diagnosis. The patients are also actors here. Patients are educated as well and can acquire the DSM categorisation of some mental disorder they feel most resonate with their own life experiences. The psychiatrist and the patient are the main actors, but they come to the situation of reaching a bipolar disorder diagnosis with their personal knowledge about what bipolar disorder is and what the implications of this diagnosis are. They also have their personal ways of communicating and understanding the moods, feelings and behaviour they are discussing.

The diagnostic tools are designed to tame the diagnostic uncertainty in these kinds of situation in the clinical practice. The diagnostic tools are important actors in the consulting room and serve as mediators between the clinician and the patient.

THE DIAGNOSTIC TOOLS AS MEDIATORS

I have analysed the diagnostic tools — rating scales, screens and questionnaires — created to measure mental disorders earlier. In chapter 3, I introduced the tools in detail in the context of the clinical research project in Hospital X, where the tools were used not only to diagnose patients, but also to from a research population. In chapter 4, I situated these tools to the context of clinical practice guideline.

The promise invested in these tools is that the standardised way of addressing the symptoms of bipolar disorder renders the subjectivity of both the clinician and the patient into an objective diagnosis. The diagnostic tools can be seen as parts of a historical continuum of different questionnaires, interviews and surveys and tests created to measure, for instance, intelligence, personality or

cognition. These are all disciplinary techniques aiming to tame and standardise the differences in human beings (Rose, 1998, 105).

The clinical practice guideline (*Käypä hoito -suositus. Kaksisuuntainen mielialahäiriö.*, 2013) recommends clinicians to always ask a depressed patient, if there have been any periods of increased activity and screen possible hypo/manias using the Mood Disorder Questionnaire (MDQ). In the event that the screen is positive, the clinician should perform a thorough anamnesis with the help of the family and loved ones if needed. To trace back the past episodes in the patients life and the effect medication might have in the timing of the episodes, the clinician can use the *Life-Chart Method* (LCM), which provides an graphic display of the patients personal illness history and pharmaceutical treatment.

The assortment of questionnaires and rating scales designed for measuring mania, hypomania and depression, such as the *Young Mania Rating Scale* (YMRS) or the *Beck Depression Inventory* (BDI), are recommended to be used in the follow-up treatment of the patient, not in the actual diagnosis. In addition to these measuring tools, the *Mood Diary*, a daily routine for the patient to assess mood swings and related factors, is recommended to be used in the follow-up meetings with the patient. I will return to the use of the mood diary later on in this chapter.

The DSM language is inscribed in all these diagnostic and measuring tools. The rating scales, screens, questionnaires and charts are materialisations of what bipolar disorder as a psychiatric diagnosis is. In the consulting room where the patient and the clinician discuss the diagnosis from their subjective perspectives, these tools are important actors. The pieces of paper that are filled in, read and discussed are mediating between the clinician and the patient.

However, the diagnostic and measuring tools cut both ways. On the one hand, they aid the process reaching a mutual understanding of the patients condition and aid the patient in understanding the experienced symptoms. On the other hand, these tools can act as abstract check-lists for the clinician to ensure that the process of reaching a diagnosis has been conducted according to the clinical practice guideline, and alienate the clinician from the patient's real situation, as well as the patient from her own symptoms and their meaning (Healy, 2009; Lakoff, 2007; McGoey, 2010).

THE POWER OF PLACING A DIAGNOSIS

Who or what then has the final word on the diagnosis? Although there are those patients, who have already acquired the DSM language, there are others who are not familiar with the symptoms of bipolar disorder, and the vocabulary of bipolar disorder needs to be introduced to them. This is how one of my interviewees, a senior psychiatrist and a clinician, described how the patient can be introduced to the diagnosis:

“Some individuals might have difficulties in agreeing with the

fact that they could have bipolar disorder. But usually when you go through the symptoms, like the kinds of symptoms the patients have had, and then I dig up the ICD manual and tell the patient that you see we use this kind of diagnostic classification. And then we go through the symptoms defined there together and I try to explain to the patient that when you have had these kinds of symptoms for this period of time, this book says that it is one check in the diagnosis, and when you have had these symptoms, it says here in the book that this is also a symptom of bipolar disorder. And then it says here, that if you have had this many of these symptoms for this length of time, we do then speak about bipolar disorder in psychiatry. I also tell the patient that we can use whatever word you think describes this situation of yours best, but according to the diagnostic manual, this is how it goes. After this, the patients usually do accept the diagnosis” (Scientist2)

This excerpt shows one example of how the DSM language is actually used in the clinical practice when the diagnosis is being discussed between the patient and the clinician. The situation of placing the diagnosis is an act of power. Emily Martin (2007, 99-133) points out that the diagnosis is always a performative speech act where the medical authority has the power to place a diagnosis and the individual becomes someone “under the description of manic depression”, as Martin puts it. However, the process of reaching a bipolar disorder diagnosis is not always limited to the situation in the consulting room, where both the clinician and the patient are using language as a device to accomplish something.

I argue that the diagnostic situation is not a simple act of discursive power, but a much more complex situation of interaction where the actors - patients, clinicians, diagnostic tools - are not disinfected from a multitude of socially and culturally inflicted practices. The unstable object, bipolar disorder, is being enacted in the sense that it puts into effect a complex set of scientific knowledge, objectivity, standardisation, education, expertise and subjectivity, emotions, interpretations, experiences and uncertainty (Mol, 2002).

The diagnosis can be placed and written into the patient’s medical record, but what happened before and what happens after this situation is perhaps even more important. Bipolar disorder as a diagnosis is also enacted in the activities of the patient who seeks for information before and after the diagnosis, the hesitation the patient might feel towards the diagnosis and the attempts to come into terms with the diagnosis. In the next section, I will go to the experiences of the diagnosed patients, who are unsure of how to interpret their life, moods, emotions and behaviour with bipolar disorder.

5.5 What is the normal me?

YES, THIS IS BIPOLAR DISORDER, BUT I CAN DEAL WITH IT

“Some of us are soothed by the idea of an accurate diagnosis. But others do not mind the diagnosis at all, and usually not the medication either. I myself feel that in some ways I want to be indeterminate to others and to myself as well.” (Discussion forum)

This is how one bipolar patient on a discussion forum described the meaning of a diagnosis for the patient. Receiving a mental disorder diagnosis is probably never easy, but some feel relieved to have a name for all their symptoms and possibly long-lasting problems in life, whilst others feel stigmatised and do not want to interpret their life in DSM language as a mental disorder (Russell & Moss, 2013; Tucker, 2009). In this section I will provide two case examples of different paths to a bipolar disorder diagnosis and different ways of reacting to the diagnosis.

One of the bloggers I have been following, I have named her Emma, tells her story of becoming a bipolar patient starting from her first sick leave due to long lasting sleep disturbances. This quotation from her blog is somewhat lengthy, but it summarises many aspects of the process of reaching a bipolar disorder diagnosis that I have gone through in this chapter thus far. Emma seems to be an ideal type of the knowledgeable patient, who seeks for information and is aware of her illness and recovery. The following is an excerpt from a longer post, where she elaborates on her story:

“During my sick leave, I wrote down my feelings, and did a test online, which said that I should contact a doctor. I printed out that test and booked another appointment with the doctor [...] I was very nervous of what was to happen. I was so relieved when I at last was truly listened and the doctor did not trivialise my situation. On the contrary, the doctor took me very seriously. I was diagnosed with serious depression without psychotic features. I continued the follow-up meetings with the same doctor in two weeks intervals. [...]

The doctor started to suspect that I would have bipolar disorder, instead of just depression. The doctor made me fill more tests and one of them was the bipolar screen [MDQ]. The test was positive and the doctor referred me to the secondary care out-patient clinic. [...] The first visit with the nurse was in march, and we mapped my life history with ups and downs, we talked about the possibility of bipolar disorder and what the goal of the treatment was [...]

I had been active myself and searched for information about the illness and already from the beginning of the treatment, I started to take notice of my own behaviour and mood swings. I was genuinely

interested in my treatment and ready to really work for the recovery and to find out what had caused the low mood and the over energetic feelings. The longer the meetings at the clinic went on, the more I knew about this disorder and the more I became sure that this was the right diagnosis. (Emma, Blog)”

Emma knows the DSM language: she knows what her diagnosis is in medical terms, she understands what the symptoms mean and she knows the treatment procedure as well. Emma has used the diagnostic tools online and later on in the clinic, where she receives the right diagnosis. She is also a model student in adapting the principles of psychoeducation and is interested in following the changes in her moods and behaviour on the path to recovery.

But when I observed the discussion forums and read about all the different stories of the patients there, it was clear that stories like Emma’s are rare. The process of becoming a diagnosed bipolar patient is often not a linear path, where the disquietude of the patient leads to a contact with the health care, which leads to diagnosis and treatment.

IS THIS, REALLY, BIPOLAR DISORDER?

One of the patients I interviewed told me about his refusal to accept the bipolar disorder diagnosis. The interviewee, I have named him Elijah, had been suffering from episodes of deep depression for a long time and had been treated with SSRIs. Otherwise he had felt himself quite good and capable, able to work and find meaning in life in general. Elijah told me it was his mother who first noticed the symptoms of bipolar disorder and urged him to see a doctor again and he was diagnosed to have bipolar 2 disorder.

He told me that at that point he ignored the diagnosis, because he felt the psychiatrist had not listened to him, and that the symptoms he had were not really examined. The diagnosis was never explained to him and he felt that the only thing he got from the clinic was a prescription:

“I wanted this to be researched more deeply, and I admit that part of it was simply being afraid of the stigma, but also a need to consider my feelings and thoughts I had, and not from the medical perspective, I mean as signs of some illness, but as just simply feelings and thoughts. But after the doctor has put the symptoms into a certain box, everything you say is either confirming the judgement or keeping it the same, but never changing it. I am quite critical towards such labelling in Western medicine and psychiatry” (Elijah, interview)

Elijah argued that he felt he would need therapy more than the medication, but there are no resources to provide therapy in the out-patient mental health clinics, which was clearly stated to Elijah. The psychiatrist also told him that he would

not be able to get the compensation for psychotherapy, if he did not comply to his diagnosis and treatment. What he felt was disappointment and anger.

By the time of our interview, Elijah had decided to take the matters into his own hands by taking part in a support group provided by a patient association. He had also decided to finally take his medication regularly. He was slowly starting to accept his diagnosis:

“It is like I do recognise and admit the relation of depression and hypomania in bipolar 2 disorder, but what then is normal in the sense of energy and such for anyone? For me the reason I started to take the medication is that for so many years this whirlpool has gone on, and once or twice a year I end up in pretty deep waters. At this point I don’t mind what the doctors think of me and my condition, I just want to start to unravel what is behind all this myself.” (Elijah, interview)

Elijah’s story about refusing to accept the diagnosis for the first time and the problems in the mental health care system that follow from this non-compliance are a common story also in the discussion forums.

His story also highlights the fact I discussed in Chapter 4 that especially bipolar 2 disorder is often misdiagnosed and wrongly medicated as depression. One of the psychiatrists I interviewed pointed out that the diagnosis is never easy and with the current poor resources, the out-patient clinics do not have time to actually immerse into the patients situation and the differential diagnosis.

The process of reaching a bipolar disorder diagnosis in the mental health care system is also complicated because of the two-level system of primary and secondary health care. Depression is diagnosed and treated in primary health care and bipolar disorder in the out-patient clinics.

On the discussion forums, the two-level treatment system invokes anger, and the patients feel like they do not receive the treatment they should because of the structures of the mental health care system. One of the psychiatrists, who also worked as a clinician in an out-patient clinic, considered the system from a patient’s perspective:

“For the patient it would be so much easier if the psychiatrist could visit the primary health care unit to make the diagnosis, so the patient would not always have to be referred to the out-patient clinic. The stigma for the patient of being so mad that you are referred to the out-patient clinic, would be avoided” (Scientist2)

The cases of Elijah and Emma show how different the reactions to a bipolar disorder diagnosis can be, but also highlight the role of mental health care in directing the patients reaction. Although both of these patients surely have different personalities that direct their relationship to the health care system, it still seems that Emma happened to be lucky and Elijah less lucky when it

comes to the medical professionals treating them. Emma had a steady treatment relationship with one psychiatrist and one nurse, whereas Elijah received his diagnosis from two different psychiatrists and had three nurses treating him.

Both of them needed to reflect their own life histories and experiences in order to orient their lives with the diagnosis. The question of what is the normal self in the different phases of the patient's life, is the theme I will take up next.

THE NORMAL ME?

In his classic article, David Karp (1994) writes about depression as an identity turning point, a disruption in one's biography that calls for a new way of making sense of the ambiguous life situation. The depressive patients Karp interviewed performed an illness career, starting with the inchoate feelings of distress to a feeling that something really is wrong, to a crisis and then adapting an illness identity. Sometimes the patients defined depression as something possible to overcome (Hardey, 2002; Jones, 2005; I. Kangas, 2001; Radley, 1999; Skultans, 2000). However, the idea of a linear process or an illness identity career, does not quite fit with the patients' experiences with bipolar disorder, I read on the discussion forums and heard from my interviewees.

I argue that the patients with bipolar disorder do become patients when they receive the diagnosis in mental health care and accept the diagnosis as part of their life, but this is only one transformation or becoming in a series of many others in the patients' lives. For instance, Emma and Elijah have both suffered from the symptoms of bipolar disorder in one form or another already before the diagnosis was placed. Elijah also fought against the diagnosis for a long time, as do many other patients writing about their stories on the discussion forums. Hence, the diagnosis is only one episode in the bipolar patients' process with the disorder that lasts throughout their life course.

The process of questioning what is normal and what is pathological mood, emotion and behaviour does not end in the official diagnosis. For instance, Elijah had difficulties in accepting his diagnosis, and part of the anxiety stemmed from the problem of differentiating his normal thoughts and feelings and the DSM language used in the mental health care that defined him irrational. The patients are *at the same* time rational, controlled and constant subjects of their lives, and irrational, uncontrolled and lost in their lives (Martin, 2007). There is no decisive moment where normal becomes pathological.

The question what is an what was the normal me is asked again and again in a continuous process of reflecting one's mental states. Consider this patient's reflection:

"I don't know what is going on. It feels like I'm swinging and swaying and crying, but now in a quite good mood again. A change for the good perhaps? But then again, if I think of my previous

symptoms, these are not so bad yet, but it still feels like everything is not ok. Today I have been lively. I have had a couple of horrific days with anxiety and impulses, so I wonder if this might be a mixed episode or just stress because of the change in my mood? Today I started to wonder do I really know what my normal mood is? Maybe this healthy joy of life and good mood today is the normal me? Should I just stop defining myself all the time? I do have a treatment contact after all." (Discussion forum)

The possibilities of becoming and being a patient with bipolar disorder are formed in an interaction between the individual and the whole assemblage of psychiatry. The individual with a personal life situation, genes, hormones, temperament, attitude, as well as material and cultural resources interacts with the DSM language, the diagnostic tools, neuroscientific knowledge, clinical practice guidelines, medical professions practices, pharmaceuticals, marketing and the mental health care system. In what remains of this chapter, I will analyse the treatment of bipolar disorder from the patient's perspective and the ways the generalisations of evidence-based medicine do not always fit the particular patients.

5.6 Evidence-based treatment standards meet the individuality of the patients

In chapter 4, I showed how the medical profession was educated on diagnosing and treating bipolar disorder more accurately and how the treatment standard became validated in the clinical practice guideline, the technology based on the principles of evidence-based medicine (EBM). EBM is an organising principle for research and treatment practices, determining what is valid knowledge about different treatment options, and guiding the clinicians to treat patients based on this knowledge.

The basic problem in the treatment standards and clinical practice organised by the principles of the EBM is that the statistical generalisations of the best possible treatment do not necessarily fit a given individual patient. The clinicians and treatment teams need to adjust the treatment for each patient and the patients themselves need to adjust to the treatment and balance their lives accordingly.

In this section, I will show how the medication cocktails are adjusted and how the psychosocial treatment is carried out in psychoeducation groups. I will also concentrate on how the patients themselves experience, adjust and enhance their treatment and balance their life with bipolar disorder.

THE MAINTENANCE TREATMENT

The clinical practice guideline states that bipolar disorder is a long-term mental disorder, a lifelong illness that is perhaps never fully cured, but can be cared for and managed with the treatment. The treatment focuses on preventing the recurrence of depressive or hypo/manic episodes. This means that usually a patient is a subject to lifelong maintenance treatment, although the medication for some bipolar 2 patients can be taken down (*Käypä hoito -suositus. Kaksisuuntainen mielialahäiriö.*, 2013).

As I noted in Chapter 4, lithium was the first mood stabilising pharmaceutical particularly thought to *prevent* subsequent episodes of depression or mania. The anticonvulsants developed to prevent epileptic seizures were later branded for similar use in bipolar disorder. The third group of pharmaceuticals in use are second generation antipsychotics, which are initially developed to alleviate psychotic patients' delusions. This group of drugs was also branded by the industry to serve as a prophylactic treatment to bipolar disorder.

The treatment is based on pharmaceuticals and the clinical practice guideline states that: "*psychosocial interventions can improve the outcome*" (*Käypä hoito -suositus. Kaksisuuntainen mielialahäiriö.*, 2013). However, as I pointed out in Chapter 4, psychosocial interventions, mainly psychoeducation groups, which are targeted to improve the patients compliance to the treatment, as well as to help the patient to adjust to the illness and manage its course and symptoms. This means education on how to recognise the triggers for manic and depressive episodes and to teach the patient self-management skills with the help of tools like the mood diaries.

The psychosocial treatments, psychoeducation and, in some cases, psychotherapies are means to manage the lifelong illness in a wider sense in the patients life, whereas pharmaceuticals are means to manage the hypo/manic or depressive episodes.

MIXING COCKTAILS AND BALANCING THE EFFECTS

"In some patients, it hits the mark right away, and then in some patients it feels like it is very hard to find the drug that would work and not cause too much adverse effects. Always when a treatment does not work, you go back to square one, and wonder why this does not work. Is the diagnosis wrong or might there be some factor that you have not taken into account or is the patient actually taking the medication at all." (Scientist2)

In this excerpt, a clinician and psychiatrist describes the problems in bipolar disorder medication. In Chapter 4, I discussed the fact that the medication of bipolar disorder inevitably means mixing cocktails and usually many experiments

are needed until the right combination for the patient is found. All the more so, because the supposed effects of a drug or a cocktail take a while to kick in and a so-called washing off period is needed need before changing the medication. The dosage of the drugs needs to be slowly increased to the therapeutical level and decreased in the same manner. Hence, finding the right cocktail to the right patient is a very difficult task for the clinician. It is also noteworthy that the medication can affect the diagnosis: in cases where the medication does not seem to work, the clinician might indeed need to rethink the patient's diagnosis altogether.

“It took years to find the right medication for me. Now it is ok and I can live a relatively normal life. So here's my cocktail: in the morning Lamictal and Antabus, mornings and afternoons Risolid, in the evening Zyprexa, Lamictal, Sertralin, Ketipinor and Tenox.”
(Discussion forum)

In the above expert a patient describes the daily cocktail of pharmaceuticals consisting of antidepressants, anticonvulsants, second generation antipsychotics, two types of benzodiazepines and disulfiram to control alcohol addiction. The medication sets the pace for the patient's day and the timing of the different cocktails is well thought out to control the moods and see through the nights sleep. This excerpt portrays a quite usual way for the patients to discuss pharmaceuticals in the discussion forums, where the cocktails, and particularly the adverse effects of different compounds or cocktails, are very frequent topics.

The most common adverse effects of bipolar disorder medication are: nausea, vomiting, ingestion problems, significant weight gain, tremors, dizziness, double vision, motoric skill problems, tiredness and skin reactions. In the long run, and sometimes without the patient noticing, the mood stabilisers and antipsychotics can cause pancreas and liver problems, cardiovascular and hematologic problems, as well as metabolic syndrome (*Käypä hoito -suositus. Kaksisuuntainen mielialahäiriö.*, 2013). These more severe and long term adverse effects of in particular the second generation antipsychotics have raised questions of whether the harms are more serious than the benefits of the pharmaceuticals (Tyrer & Kendall, 2009).

The patients are more concerned about the immediate adverse affects than the possibility of health problems in the long run. There are some bodily sensations, the discussants describe widely: dizziness, feelings of falling or not fully controlling the senses, extreme fatigue and trembling hands or even muscle twitching. Weight gain is a adverse effect often complained in the discussion threads, particularly in relation to *Zyprexa* (olantsapine), and patients have their own ways of dealing with this. One discussant described the benefits of omega 3 fatty acids in controlling her urges for sweets, which she interpreted as an adverse effect from her medication. Another patient had an extreme diet and exercise routine to prevent the “*classic 10 kilos weight gain with Zyprexa*”.

Along with the bodily symptoms, the adverse effects can concern cognitive functions and processing, as a patient describes:

“Particularly in connection to coding, which is my hobby, I noticed that my thinking was not what it used to be, that lost its best sharpness. I had blackouts and memory lapses, mental arithmetic was slower and it was harder to learn new things. None of these adverse effects proved to significantly restrain my life. But on the emotional level I noticed that the drugs caused numbness.” (Discussion forum)

The emotional side effects are among the most debilitating for the patients. The drugs are meant indeed to take the edge off the patients emotions, to damp the feelings of both elation and sadness. In the discussion forums, the patients described that they feel emotionally “neutral”, “flat” or “numb” because of the medication. One discussant described his life that it had been 35 years of blessed hypomania now followed by the numbing medication, and he thought he was now “retired from emotions”. Being on the medication for a long time also changes the way the patients see themselves and their life situation more widely:

“I have noticed that when it is long enough since I had the previous pill, the reality bites... When the drug fades away, I really understand my situation. But when I take my daily Abilify-Septram morning cocktail, I remain contented, although life really goes straight to hell... I’m like, hey is this really the right solution? Happy with medication? This way there certainly won’t be any changes in life and everything is going to stay the same as it ever was.” (Discussion forum)

The above excerpt raises questions: what is actually achieved by the medication, and is enabled and what is narrowed down in the patient’s life?

The way bipolar disorder medication is presented in the clinical practice guidelines and advertised or informed to the patients represents a pill as a fix to a distinct disorder. That is what drugs are supposed to do, cure distinct diseases in the human being. The same logic of fixing a problem with the help of something *outside the patient*, works in terms of the psychosocial interventions as well. There the hope lies in the therapist to cure the patient and solve the problems of life. The pharmaceuticals used to treat bipolar disorder do not have specific effects, they are not targeting specific brain processes or regions where the specific and easily fixed problem would be (c.f. Martin, 2007, 171-172).

In this kind of thinking, the actual actor in the process of managing bipolar disorder is not the patient, but the magic bullet of targeted medication cocktails or the therapist as a saviour. One of the objectives of the psychoeducation groups is to foster the patients’s agency in managing bipolar disorder and I will next introduce the routines of these groups.

LEARNING BALANCE IN PSYCHOEDUCATION

The most used psychosocial intervention for bipolar disorder is psychoeducation, which in the broadest sense means any intervention that educates and informs the patient, and sometimes also the family, about the disorder concentrating on improving the treatment outcome. Psychoeducation can thus be as simple as the diagnosing and treating psychiatrist explaining the patient what bipolar disorder is, how it is treated and how to manage the symptoms and treatment in the future. The education material online and in printed form I introduced earlier in this chapter can also be considered as psychoeducation. However, most commonly, psychoeducation is provided for the patient with courses in group-form, which also provide peer support.

Many out-patient clinics in the metropolitan area in Finland provide psychoeducation courses in the treatment procedure of bipolar disorder. The courses are usually led by specialised nurses and take three to six months, the group convening once a week for 1.5 to 2 hours. I had an interview with two specialised nurses planning and moderating psychoeducation courses in an out-patient clinic in the Hospital X area. We talked about the ways these groups convene, the topics they covered, the tools they used and the patients' experiences about the group.

The groups usually had a theme for the day. The themes covered topic like the symptoms of bipolar disorder, medication, alcohol and other substances, triggering factors, coping in daily life with the disorder, the means for early detection of the symptoms, stress-management techniques, as well as the social security and insurance for the bipolar patients. The subsequent 45 minutes of the session were then dedicated to peer support and sharing. The same informational and educational leaflets I introduced earlier in this Chapter are used in this context as workbooks for the group. The symptom and medication management tools, the mood diary and the life chart, are included in the workbook and used as an integral part of the psychoeducation groups work.

One of the nurses I interviewed acknowledged the bipolar patients to be especially suitable for group work, compared to depressive or psychotic patients in other groups, because they are so different linguistically. The bipolar patients:

“seem to have a rich vocabulary and an ability to use language to describe things, they have names and concepts for things, this is something the patients in the depression group do not have, and the patients in the psychosis group are not as capable of using symbol language, as the bipolars are” (Nurse1)

The nurses also talked about how the patients have already sought knowledge online and are very much aware of the symptoms of bipolar disorder and are able to use the DSM language to describe their symptoms and early signs, but they still need to talk about the individual variation of the symptoms and “*what the*

symptoms mean to them, because they are different things to different patients” (Nurse2).

However educated, knowledgeable and linguistically able the patients are, the hypo/manic symptoms need concretisation, particularly the normatively indeterminate behavioural symptoms. The concretisation of bipolar disorder symptoms can mean talking about exactly how many portions of alcohol is too much? Does one think driving 120km/h is moderate speed? If one has changed jobs nine times, has it really always been the boss that is the problem? The nurses also described how the patients concretise the depressive symptoms into various kinds of inabilities: can't got to shower, can't eat or eats only goodies, can't read the newspaper but one page, can't watch a movie till the end, the laundry is piling up, haven't changed the bed linen for five weeks, same clothes on as last week, can't open the mail, can't pay the bills. These concretisations of the symptoms are ways for the patients to better recognise the early signs of both hypo/manic and depressive symptoms, and in this work the family of the patient is also enrolled to detect these signs.

When I asked the nurses what they thought was the most beneficial for the patients in psychoeducation, they emphasised the significance of balance. Balance was something the patients needed in many aspects of their daily life with bipolar disorder, such as taking the medication promptly, taking care of a regular circadian rhythm and detecting the early symptoms. I would argue, that the whole practice of psychoeducation is designed to ensure the patients compliance to the treatment; both in terms of taking the medication and leading balancing lifestyle. One of the tools to achieve these is the mood diary -routine.

THE DAILY MOOD DIARY

The first assignment the patients have in the psychoeducation group is to start a daily routine of keeping a mood diary. A mood diary or a mood calendar is a tool designed for the patient to keep track of the symptoms of bipolar disorder on daily basis by assessing the mood swings and factors that might have affected the mood of the day, such as changes in medication, sleep length, alcohol and caffeine intake, menstrual cycle and stressful life events. The mood diaries are used as a measurement tool for the patients treatment outcome and thus work as a mediator between the patient and the treatment team.

In the mood diary, the patient is asked to fill in current mood from stable to mania or depression, the medication taken and the hours slept. In some versions also alcohol intake, as well as exercise and diet are reported. For women, also menstrual cycle is filled in. This example is from a leaflet by Eli Lilly, which I have filled in with fictional information. The diaries provided in Finnish are the same:

MONTH: APRIL **YEAR:** 2014 **WEIGHT:** 60
Fill in the circle that describes your mood each day.

DAYS	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
Severe	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
Moderate	<input type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
Mild	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
STABLE	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
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Moderate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Severe	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<small>Did you experience any of the following symptoms? If yes, fill in the circle.</small>																															
Anxiety	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Irritability	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
Mood swings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
Record hours slept	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Alcohol consumed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Menstrual cycle	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
DOCTOR'S NOTES:	<small>Did you take your medication(s) today? If yes, fill in the circle.</small>																														
_____	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
_____	<small>Were you physically active today? If yes, fill in the circle.</small>																														
_____	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
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How did you feel today?

(i.e., Were there any significant life events that could have had an effect on your mood?)

This daily recording continues with another page, where the patient is asked to fill in life events that might have affected the mood. In the end of the month, the mood diary shows a graph of the ups and downs of the patient’s mood.

In some versions of the mood diary the patient’s are asked to establish a contract with themselves, and with family members, a support person or friends. The contract obliges the patient and the other parties to observe the moods of the patient and to note whenever there are alarming signs of hypo/manic symptoms. The family members and friends are included in the process of mood control by allocating the task of observing the symptoms to them. Family and friends are advised to create “strategies” and “plans” with the patient to increase the compliance to treatment, control the changing moods and cope with them (Kaksisuuntaisen mielialahäiriön tuntemus, 2005).

The mood diary is also a tool for the treating professionals to monitor the patient’s situation. The diaries are used in the psychoeducation groups and shared with the peers and the nurses, as well as brought to the psychiatrists appointment to monitor the effects of medication. I suggest that the mood diary connects to the continuum of the diagnostic tools used in the consulting room with the clinician in the situation of reaching the diagnosis. The mood diary can be seen as yet another tool for observing and measuring the patients moods, emotions and behaviour.

The mood diary is, however, most important to the patients themselves. In the discussion forums I observed, the patients talked about their ways of using this tool and modifying it. The patients created their own Excel sheets and calendars to monitor their daily moods. They also invented their own codes, letters or

numbers, to note the moods of the day. They also personalised the meanings of different moods and other observed items to resonate with their own situation. One discussant described how she in the end of the month did research on her own data by searching for correlations between different moods and medications, exercise, diet, menstrual cycle, sleep patterns or life events.

All in all, the mood diary routine renders the mood symptoms measurable and visualises the mood swings for the patient. The mood diary is used together with the Life Chart Method I introduced in Chapter 3, which measured the patient's mood episodes from a longer time period retrospectively. The Life Chart together with the mood diary visualises the mood swings of the individual patient throughout her life, from small scale daily mood swings to larger scale changes within months or years. These mood measuring tools structure the time and space of the patients's experiences with bipolar disorder (Martin, 2007, 177-195).

EVIDENCE-BASED MEDICINE AND THE TREATMENT SYSTEM

Ideally in the mental health care system in Finland, a bipolar disorder patient is being treated in the secondary level out-patient clinics by a treatment team consisting of the psychiatrist and a specialised nurse, added with a psychologist and a social worker when needed. In addition, the patient can also be in a psychotherapy process outside the municipal mental health care, subsidised by the Social Insurance Institute of Finland (KELA), but the therapist is not a member of the actual treatment team. In ideal cases the right cocktail of pharmaceuticals is easily found and the patient benefits from the six months psychoeducation and can then be referred back to the primary health care for maintenance treatment.

The mental health care system and the inadequacy of the treatment are a frequent topic in the discussion forums in the Internet. Earlier in this Chapter, I discussed the case of Elijah, who was on and off treatment in both primary and secondary health care and who did not seem to be able to find a stable and therapeutic doctor-patient relationship. The most negative experiences stem from the high turnover in the professionals treating the patient. One of the discussants reminded of the consequences of unstable treatment relationships: *"Nobody has an overall picture of my situation. This inevitably leads to a situation, where I believe only myself and end up trusting my abilities to survive without medication"* (Discussion forum). What the patients sharing their experiences in the discussion forums needed, was stability in their treatment, one treating psychiatrist that would not change.

The other wish the patients had, was that the treating psychiatrist or GP would be someone who would not only write the prescription for the pharmaceutical cocktail, but also *"sees the human being as something more than swinging atoms, like as spirit, soul and body"* (Discussion forum). The patients also recognise that

psychiatrists have different perspectives on mental health care in general: *“there are psychiatrists with the conviction that as long as one has the right stuff in the brain all is well”*.

The patients do also acknowledge their own role in the interaction with the treating professionals, and many discussants describe a tendency to sugar-coat the situation for the psychiatrist and the real life troubles never come to the attention of the treatment team: *“I have a good and competent psychiatrist. The only problem is that I instinctively put on a happy face in the consulting room. I am a brisk patient taking care of herself, even if I would have been planning a suicide on my way to the appointment”* (Discussion forum).

The patients also acknowledge that the treatment options in the mental health care today are better than before, and many discussants also compliment the good treatment they have received. Here is how one patient described the bipolar disorder treatment in Finland today:

“I have received requisite and adequate treatment. Though I have gone through the whirlpool of several hospitalisations and experiments with several pharmaceuticals. I have received good care in out-patient clinics and good psychotherapy. They listen to my opinion in the clinics even in medication issues. BUT, this kind of good care does not seem to be the case for us all! What is it that divides us mental disorder patients to those that receive adequate treatment and those that don't? Why is a somatic illness an obstacle to good mental health care? Why do we here in the western world think that those two, the soma and the psyche, are detached and can be treated separately?” (Discussion forum)

There are indeed regional differences in receiving adequate mental health care in Finland, the somatic and psychiatric problems are handled separately in the health care system, and as I have pointed out many time in this research the two-level system is problematic particularly in the treatment of mood disorders. These problems are known and suggestions to organise mental health care differently has been produced in various projects (ja hyvinvoinnin laitos, 2010; *Mieli 2009. Mielenterveys- ja päihdesuunnitelma*, 2009). However, there is a large scale healthcare, social welfare and regional government reform package in Finland that has been pending for several years. Before the political consensus of how to conduct this reform is reached and the laws enacted, the Finnish mental health care system remains as it is.

The clinical practice guideline sets the standards of what is considered as adequate treatment of bipolar disorder. The guideline compiles the evidence-based knowledge on different treatment options, but the problem is that the EBM principles emphasise interventions that can be studied in randomised-controlled trials. The effects of pharmaceuticals are plausible to study using the RCT design,

but such traditional and clinically valid interventions like psychotherapies are harder to fit into this design. Pharmaceutical interventions are also considered more cost-effective, but only in the short-term evaluation (Psykologiliitto, 2006).

However, the fundamental problem in evidence-based psychiatry is that the statistical generalisations of the best possible treatment do not necessarily meet the needs of the particular patients with their individual biology and response to the cocktails of pharmaceuticals. The clinicians do have to use their experience and judge the adequate treatment case by case, and they need to adjust the EBM treatment standards just like the scientists I introduced in Chapter 3 needed to adjust the DSM standards in order to investigate the particularity of the patients in clinical reality.

The attempts to tame the uncertainty in the world by the medical technologies of EBM and DSM sometimes fail because the the particular patients reality is messier and more complex than the standardisations. The patients are unique in the ways their minds and bodies, in connection, react to the treatments and attempts to categorises the symptoms they experience, and in their experiences the psyche and the soma are closely connected.

5.7 Experienced brain, mind and body connection

Many analyses in social sciences on patient perspectives, personal experiences and subjectivity in mental health and illness have addressed the dichotomy between psyche and soma. The accounts of patients with different mental disorders have been seen to speak about either the the biological or the psychological in the illness experience, or the starting point has been to analyse the how the brain-related scientific thinking affects the personal experiences with mental disorders (Gross, 2011; I. Kangas, 2001; Karp, 1994, 2009; Martin, 2010; Moutaud, 2003; Pickersgill, Cunningham-Burley & Martin, 2011; Rüsç, Todd, Bodenhausen & Corrigan, 2010; Vidal, 2009). In this section, I will approach the relations of mind, brain and body in the experiences of the patients with bipolar disorder by trying to overcome this dichotomy.

I have mapped the empirical material to specifically search for the patients' accounts where they either repeat the dichotomies or speak about their experience with bipolar disorder in ways that connects the brain, the mind, and the body in their experiences. I have been attentive not to presuppose the prevailing dichotomies, or bifurcations, in psychiatry. I have taken inspiration from the Scottish anthropologist Tim Ingold (Ingold, 2013). He suggests that being a human is neither pre-given through biology, nor learned through culture, and that human beings are essentially *biosocial* shaped by the interactive processes between various things like genes, cells, brain, nutrition, family, education, environment, politics and culture (see also Debaise, 2013; Stenner, 2008). I will

start by describing how the patients experience the bodily symptoms of bipolar disorder.

THE BODILY SYMPTOMS

Along with the mood and behavioural symptoms of bipolar disorder I introduced earlier in this chapter, there are also bodily symptoms listed in the DSM: increased or decreased appetite, sleep disturbances, increased energy levels and psychomotor agitation. These moods, feelings, behaviours and bodily reactions or sensations together form the experience of hypo/manic or depressive episodes and I found it interesting how the patients themselves describe how the mind, brain and body are in connection in the way they experience certain symptoms and in the disorder as a whole.

The symptoms of anxiety, irritability and psychomotor agitation and most commonly experienced in panic attacks were commonly described by the patients. These were episodes where some bodily sensation like numb limbs take over the thoughts like in panic attacks, but the agitative anxiousness can also be related to the hypo/manic episode. This is how one discussant described his hypomania in a thread where the discussion circled around the question of how to distinguish mania and hypomania from each other:

“I am very frenzied and ardent all the time, I hyperventilate, my heart is pounding hard, I can’t stay still, I can’t concentrate on anything. Like during the time I have been writing this short text, I had the need to jump up and walk in circles or something. There is a hum in my head and I can’t think clearly. I try to accomplish five tasks at the same time and can’t complete anything, then I already start new ones.”
(Discussion forum)

The characterisation of this particular patient’s experience in hypomania shows how the increased energy can also be a very corporeal state, where the thoughts and the bodily sensations are both at the same time overloaded and run wild. Sometimes the excess of all these sensations has a positive and energetic tone to it. The hypo/manic excess is not only in the patients behaviour, such as sociality, shopping, work projects or domestic chores, the excess can also be a bodily experience.

The so-called behavioural symptoms also include addictive and pleasure-seeking behaviour. In the discussion forums the questions of drinking and eating, but just as well diets and exercise can become excessive:

“One could think that a healthy diet and exercise is good for you, but for me even those things went out of control! Last autumn I was in the hospital with a triple diagnosis: mania, addiction to sleeping

pills and eating disorder. Eating is so mood-specific, now when my mood is swinging, the eating goes crazy as well!" (Discussion forum)

The patients describe an overall tendency to become addicted to many things from alcohol, sleeping pills, food and exercise to reading books, making music, coding or watching television. The addictions and the so-called behavioural symptoms of bipolar disorder seem to blend into a more comprehensive experience of excess and loss of control. The distinct symptoms of bipolar disorder and the possible comorbid anxiety disorders, eating disorders or substance abuse can not be distinguished in the patient's experience. This kind of complexity in the experience of the symptoms is what the diagnostic uncertainty is about: it is hard for the patient and for the clinician to try to cut the experience into pieces and tell apart the distinct disease entities.

AFFECTING THE PLASTIC BRAIN-MIND AND THE BODY

Because the fact that bipolar disorder runs in families was emphasised in the education material on bipolar disorder and in the psychoeducation groups, I thought that the patients would have talked about genetics. But there was hardly any 'gene talk' on the discussion forums and the theme did not come up in the interviews either. The patients did not seem to attribute their bipolar disorder to genetic factors, nor did they attribute their condition to any specific mechanism in the brain (Callard et al., 2012; Meiser, Mitchell, McGirr, Van Herten & Schofield, 2005; Rüsçh et al., 2010). The patients I observed used a variety of 'causes' as pieces of their own personal account of what bipolar disorder is (Pickersgill et al., 2011).

The patients I observed used a variety of scientific explanations as pieces of their own personal understanding of what bipolar disorder is (Pickersgill et al., 2011). In this excerpt from an interview the patient elaborates his understanding of how neurotransmitters work in mental disorders:

"(Patient): I do believe, like, in the neurotransmitters. And I do believe that with lots of training, practice and meditation the neurotransmitters can be readjusted. But I also believe that there are, like, models for reaction, which have formed, like, through the heredity and experiences and everything. You can't change your brain like that, but I think it is a good idea to acknowledge that the brain as a nervous system is trainable. I do believe the brain is an organ that can be moulded. This is something on which I base the idea that I can get rid of the harmful thought patterns and reactions. That I can learn to deal with those things.

(LH): Do you think your mind is in your brain?

(Patient): I think the brain is a physical bundle of nerve cells, it is not, like, a spirit or a soul. "

The interviewee believes that neurotransmitters, as well as patterns of reaction that are formed in the interplay between the genes and the environment play a part in his bipolar disorder. He also believes that all this can be acted upon, because the brain is “an organ that can be moulded”. He is optimistic that he can indeed readjust the the mind/brain connection with the help of meditation. His thinking is premised on the idea of brain plasticity, which means that the human brain is constantly creating new synaptic pathways affecting the moods, thoughts and behaviour (Rees, 2010; Rubin, 2009).

One of the ways to mould the brain, mind and body are of course pharmaceuticals and the medication can mediate the interplay between the brain, the mind and the body. Consider the experiences of the following patient who analyses the way an antidepressants affects him:

“They usually say that starting a SSRI, or an increase in the dosage, should not feel like anything. And that the delayed mood enhancing effect is due to the brain growth factor ‘activating’, and depression in general is related to the growth factors. However, I have physically felt like something would begin to ‘flow’ in my body immediately when I start to take the SSRIs or increase the dosage. I mean that the worst psychomotor retardation eases and my digestion works better etc.” (Discussion forum)

The patients used many means outside the evidence-based treatment standard to alleviate depression and balance the excess of hypo/mania. The brain is also targeted through the mind and the body. Some of the patients have made substantial lifestyle changes to be able to live a balanced life with bipolar disorder. There is a need to “*take responsibility of oneself*”, as one patient put it, and this might include: regular circadian rhythm, enough sleep, exercise, rest, regular healthy diet and medication. In addition, the patients have benefited from for instance a paleo diet, regular yoga practice and different modes of meditation and visualisation techniques. Consider this patient’s daily routines:

“I don’t eat anything sweet, downsized the carbohydrates to the minimum. I only use alcohol by the strict rules I have made for myself. Every morning I do my ‘ritual’, which consists of shower, glass of water, yoga, 5-10 minutes of zen meditation and breakfast. At work I am able to concentrate for the whole eight hours. After work I go for a brisk walk for an hour or jogging in the woods, after this a half an hour of zen meditation. Then my own research, reading, etc., if there is no social program for that night.” (Discussion forum)

Some of the patients feel that by leading this kind of controlled life they can reduce the cocktails of pharmaceuticals to the minimum or drop off some parts of the cocktail, like sleeping pills. All in all, these lifestyle choices are alleviating

the patients' symptoms and I think that speaks for the idea that bipolar disorder is not only a problem of the mind or of the brain, but affects the individual as a bodily being as well.

In this chapter I have shown how the patients balance with the mood swings with various different means, like the cocktails of pharmaceuticals, psychoeducation, psychotherapies, mood diaries, diet, meditation, yoga, exercise or jogging in the woods. These are all technologies of the self acting on the patients mind, brain and body (Foucault, 1984, 2000; Rose, 1998; Rose & Abi-Rached, 2013). I think it is important to notice that from the perspective of a particular patient's day-to-day life, there is no need to distinguish evidence-based treatments from the multitude of practices used to affect the connection between mind, brain and body.

5.8 Conclusions: Biosocial becomings

I started this chapter by analysing the mental health bazaar in the Internet that provides bipolar disorder information, awareness raising and education, as well as tests to conduct an instant self-diagnosis and case examples. The educational material in the information flow of the Internet can be *making up a patient* because it opens up the possibility of interpreting one's moods, thoughts and behaviour as bipolar disorder (Hacking, 2002a, 1995). The education fosters the DSM language by which to speak about certain cluster of moods, emotions and behaviour as bipolar disorder in the context of mental health care. However, I showed how the patients themselves do not use the DSM language to put their experience of the symptoms of bipolar disorder into words. The way the patients articulated the symptoms show that in the in the day-to-day experiences of the patients, the mental states are not sharply divided into separate mental states or episodes.

The DSM language is, however, useful in the situation where the patient and the psychiatrist discuss the diagnosis in the consulting room by the help of the diagnostic tools. I argued that this situation is not a simple act of discursive power, where the psychiatrist places the diagnosis, but a practice where the patient and the clinician interact with their sometimes different understandings of what bipolar disorder is. The diagnostic situation puts into effect scientific knowledge, objectivity, standardisation, education, expertise, as well as subjectivity, emotions, interpretations, experiences and uncertainty (Martin, 2007; Mol, 2002).

I also showed that many processes take place before and after the diagnosis is placed and that the diagnosis. The patient seeks for information before and after the diagnosis is reached, and the diagnosis is either accepted or resisted in the process where the patient tries to adjust to the life with the diagnosis. I argued that in the case of bipolar disorder this process is not straightforward path of acquiring an illness identity, but a continuing process of trying to figure out what

is and was the normal, or the pathological, self amid the changing mood episodes (c.f. Karp, 1994; I. Kangas, 2001; ?, ?).

In the next part of the chapter I continued by viewing the evidence-based treatment standards from the perspective of the patients' experiences. The objective of the usually lifelong maintenance treatment is to find a balance in the patients life with a cocktail of pharmaceuticals by tinkering and modifying the medication. The clinician needs to adjust the generalisations of the evidence-based treatment standards to fit the mind, brain and body of the particular patient. In addition, I showed how the psychoeducation groups teach the patients to acquire a daily routine of self-observing via the mood diary, where the mood swings are concretised and visualised for the patient and for the treatment team. I showed, how the mental health care system at the moment does not meet the patients' wishes for a stability in their treatment.

I concluded the chapter by analysing how the patients experienced the interplay between their minds, brains and bodies in the context of bipolar disorder, and how they acted upon the mind/brain/body connection using various technologies of the self from pharmaceuticals and psychotherapies to things like meditation, yoga, diet and exercise (Foucault, 1984, 2000; Rose, 1998; Rose & Abi-Rached, 2013). I argued that the patients do not necessary use the dichotomies of mind and brain or soma and psyche in the way they understand what bipolar disorder is (Buchman et al., 2013; Gross, 2011; Karp, 1994, 2009; Martin, 2010; Moutaud, 2003).

I argue, that the patient diagnosed with bipolar disorder is in a lifelong process of becoming. The fluctuating mood episodes come and go as the patients go through different phases of living their life with this disorder. There might be an initial phase of worrying and searching for information, a phase of seeking help from the mental health care, as well as phases of trying to come to terms with the idea of a stigmatising diagnosis like bipolar disorder and accepting a lifelong treatment procedure. This lifelong process is affected equally by the biology of the patient and the environment of scientific and socio-cultural understandings of what bipolar disorder is. The minds, brains and bodies of the patients' become a slightly different each time they try different cocktails of psychopharmaceuticals, connect to others in therapeutic situations in mental health care, meditate, write their daily mood diaries, periodically take up drinking or change their dietary and exercise regimes.

I am taking the idea of human beings as *biosocial becomings* from Tim Ingold (Ingold, 2013) to summarise the patient's day-to-day experience with bipolar disorder because the concept acknowledges that human beings are changing throughout their lives at the same time biologically, socially and culturally. The patients' lives are shaped and moulded by bipolar disorder, but also by the interventions attempting to cure, alleviate, control or balance that disorder. The

patients live their life with their individual genes, hormones and neurotransmitters. But at the same time they are situated in a social environment with friends, families, loved ones, peers in psychoeducation groups, educative material online, treatment teams, psychiatrists, therapists, mood diaries and diagnostic tools. They are also situated in a cultural environment with new scientific knowledge about bipolar disorder, Big Pharma marketing and awareness raising, ready-made illness identities, as well as in a societal environment with a certain kind of health care system and insurance policies.

Chapter 6

What is psychiatry?

This research has analysed psychiatry through the lens provided by bipolar disorder. I analysed the interplay between science, clinical practice and patients' experiences using the empirical material of various texts, observations, and interviews with scientists, clinicians and patients. In order to subject the diverse empirical material to analysis, I constructed three ethnographic sites: science, clinical practice and patient' lives, which I have described and analysed in the previous three chapters.

My starting point was the inherent diagnostic uncertainty in psychiatry: that psychiatric science and clinical practice cannot quite take over the processes of life. Following the example of Annemarie Mol's (2002) empirical philosophy, I concentrated on the mundane practices where bipolar disorder was enacted, *put into effect*. The practices are snapshots of the interplay and bipolar disorder is slightly different in each snapshot, but still coordinated into an object that can be researched by the scientists, treated by the clinicians and experienced by the patients.

In this concluding chapter, I will sum-up my findings and elaborate how science, the clinical practice and the patient are in interplay, as well as consider the ways global psychiatry is in interplay with the local. I am answering the question what is psychiatry as an assemblage of actors and practices seen through my case example. I will start with the questions of global psychiatry and end this research to the subject of psychiatry: the patient.

GLOBAL PSYCHIATRY IN LOCAL SETTINGS

There is a constant interplay between the global structures of psychiatry and the mundane practices of researching, treating and living with bipolar disorder in the situated settings in Finland (Collier & Ong, 2005; Collier & Lakoff, 2005). The research and development of new drugs is a globalised business for the pharmaceutical industry and its subcontractors. The marketing apparatus of the Big Pharma reaches efficiently both the professionals and the patients. The

pharmaceutical regime have an impact on mental health care more and more globally (Applbaum, 2006a; Helen, 2009; Lakoff, 2005a; Petryna & Kleinman, 2006; Petryna, 2009; Williams, Martin & Gabe, 2011). This research has been one case example of how the global structures affect local settings and it has been clear that there the pharmaceutical industry have an impact on Finnish mental health care, but that impact is not straightforward. The sponsorship of the Big Pharma is an inevitable part of Finnish psychiatry, but the impact is recognised and also utilised by the professionals, as I showed in Chapter 4. This does not mean that the situation would be desirable, it is just tolerated in Finnish health care (see also Hemminki et al., 2010; Toiviainen et al., 2004; Hautamäki et al., 2011).

Although I did not particularly study the pharmaceutical regime in this research, the pills were always there as the number one treatment choice for bipolar disorder. I argue that in this context the pills are mediators in the interplay between science, the clinical practice and the patient. The pills are tested far from Finland in randomised-controlled trials and then implemented into the treatment standard of bipolar disorder applying the principles of evidence-based medicine. The pills are prescribed by the clinician using the clinical practice guideline and careful consideration of the patient's situation. In the end the pills of various sizes and colours are purchased and used by the patient, whose everyday life is dictated by the cocktails of different pharmaceuticals. In the patients' minds, brains and bodies both the wanted and the adverse effects of the pills are actualised. The pills *put into effect* certain kind of mental health care and this is actualised in the patients' day-to-day experiences.

In addition to the pharmaceuticals, also psychiatric diagnoses are more and more global. Andrew Lakoff's (2005b) ethnography on bipolar disorder shows how a French biotechnology company implemented the western model of diagnosing and treating bipolar disorder into a psychoanalytic psychiatric culture and epistemic milieu in Argentina. In Finland, psychiatric thinking has followed the Anglo-american developments (Helén, 2007b). The ideals of evidence-based medicine, advances in pharmaceutical treatments and the diagnostic thinking based on the DSM became part of Finnish mental health care during the last decades of the 20th century.

In this research, I have shown how bipolar disorder was consolidated into this epistemic milieu in the mid 2000s. The ground was already build in the processes by which depression became the key target of Finnish research and mental health care in the 1990s (Helén, 2007b, 2011b, 2011a). Bipolar disorder tagged along depression: the research was intensive, treatment guidelines were created, the clinicians were educated to recognise the disorder, and the awareness-raising amongst the lay people proliferated. Bipolar disorder has become part of Finnish mental health care and culture.

I approached psychiatry as a globally expanding and changing assemblage of human and non-human actors, as well as diverse material, symbolic and social elements (Collier & Ong, 2005; Pickersgill, 2012d). In the analysis of the interplay between science, clinical practice and patients' lives I have conducted, it becomes clear that some of the elements are globally affecting, whereas others are more local and mundane, and there are technologies mediating in between the global and the local. I argue that the most important mediators between the global and the local are evidence-based medicine and the DSM, which both act as medical technologies attempting to stabilise the changing assemblage.

I will now sum-up the analysis I have conducted on how the coordination work happens in the mundane practices within science, the clinical practice and the patients' day-to-day experiences, and elaborate how evidence-based medicine and the DSM contribute to the process.

OBJECTIVE SCIENCE OF THE MESSY REALITY

In the first part of Chapter 3, I started by introducing the day-to-day of conducting psychiatric research in Finland and what interested and motivated the scientists. I showed how the scientists balanced between the disappointments they had with the limits of neuroscience and the hopes of translating research results into the clinical reality of treating patients. I continued by showing how the scientists worked through the discrepancies between the diagnostic uncertainty and the demands of objective and valid research. Neuroscience using molecular genetics and brain imaging has not, at least yet, provided conclusive explanation for the question of what bipolar disorder is in the human organism. The research infrastructure and the publication policies favouring only positive results hinder the accumulation of the knowledge.

However, I argue that the problem is also the diagnostic categorisation, which prevents the scientists to actually engage in what bipolar disorder is outside the DSM categorisations in the messy reality (c.f. Hacking, 2013; Insel, 2013). This is why the "DSM-IV bipolar disorder" was a key actor in Chapter 3. In order to produce applicable knowledge about bipolar disorder in the clinical reality, the scientists needed to adjust the diagnostic categorisation. Because of the different research designs and different inclusion criteria as to what kinds of bipolar patients to enrol in the research, the two projects I followed were conducting research on slightly different kinds of bipolar disorder (about same kinds of problems in clinical trials see Healy, 2009; Lakoff, 2007; McGoey, 2010; Petryna, 2009).

All in all in the mundane practices of psychiatric science different ideals are put into effect and the ideals sometimes clash with reality. The ideals of scientific objectivity and translatability clash with the reality of what bipolar disorder is in human organism and in the experiences of the patients. The scientific

ideals and the demanding research infrastructure sometimes also clash with the scientists own subjectivity: their enthusiasm in conducting research, orientations, educational backgrounds, personal choices and feelings (c.f. Despret, 2013; ?, ?; Pickersgill, 2012a).

EVIDENCE-BASED MEDICINE AND CLINICAL REALITY

I continued with the analysis in Chapter 4 by showing how the unstable object, bipolar disorder, was coordinated to be a treatable mental disorder, and consolidated into the Finnish mental health care. I showed how the scientists disseminated knowledge for different audiences with various expertise in psychiatry in conferences, resident training days and on the pages of medical journals. I argue that this process of education and awareness-raising amongst the medical profession consolidated bipolar disorder into Finnish mental health care.

I introduced the process of compiling the bits of evidence of what bipolar disorder is, and how it can be diagnosed and treated, into a clinical practice guideline. I showed how the working group collecting the knowledge was guided by the principles of evidence-based medicine, and how they needed to bend these principles in order to produce a guideline suitable for the messy reality of clinical practice. They needed to discuss what actually counts as evidence: can the clinical trials on new drugs be trusted to provide the best treatment options or how to consider psychosocial treatment options for bipolar disorder (Borgerson, 2009; Cartwright, 2007; Lakoff, 2007; McGoey et al., 2011; Wahlberg & McGoey, 2007). I also showed how evidence-based medicine subtly took root in the way psychiatrists wrote about bipolar disorder in the medical journals and introduced the treatment of bipolar disorder with both pharmaceutical and psychosocial interventions.

On the whole, the process of consolidating bipolar disorder into Finnish mental health care was about coordinating the unstable object into something that can be diagnosed and treated in clinical practice. I argue that evidence-based medicine is a medical technology that is needed in order to stabilise the uncertainty in clinical practice, but in practice there is more coordination work to be done: the professionals compiling the clinical practice guideline needed to do this and in the reality of treating bipolar disorder in the hospitals and out-patient clinics, the clinician is always left with the decision on how to interpret the individual patient's needs for different cocktails of pharmaceuticals or psychosocial interventions (Armstrong, 2007; Borgerson, 2009; Saarni, 2010).

LIVING WITH BIPOLAR DISORDER

The patient is the object of both the sciences studying bipolar disorder and the clinical practice diagnosing and treating the disorder; the scientific knowledge

and the evidence-based treatment is put into effect in the patients' day-to-day life with bipolar disorder.

I started Chapter 5 by analysing the awareness-raising and education about bipolar disorder available for both the patients diagnosed and, particularly on-line, for anybody concerned. When the DSM descriptions of bipolar disorder travel from science and clinical practice to the information flow in the Internet, it becomes more possible for anyone to interpret one's moods, thoughts and behaviour as bipolar disorder. The so-called DSM language spread online provides a mutual language to speak about the symptoms also in the consulting rooms of hospitals and out-patient clinics (Martin, 2007, 134-147). I argue that the DSM categorisation is looping between science, clinical practice and the patients' experiences and *making up* the possibilities of being a certain kind of patient, a patient with bipolar disorder (Hacking, 1995, 2002a, 2007).

I continued by analysing the ways the DSM language and the diagnostic tools are used in the situation where the bipolar disorder diagnosis is placed, and how the different ways of expressing and interpreting the symptoms of bipolar disorder are put into effect in this situation. I argue that in the patients' experiences the diagnosis written in the medical record does not mean an identity turning point from health to illness or from normal to pathological (Karp, 1994). On the contrary, the reflection on moods, thoughts, emotions and behaviour is a day-to-day process of contemplating the mood swings and perhaps measuring the symptoms using a mood diary.

I concluded the chapter by showing how the patients acted upon themselves outside the treatment standard. In addition to the cocktails of pharmaceuticals and psychoeducation, the patients' used meditation, yoga, diet and exercise as means to balance their moods (Foucault, 2000; Rose, 1998; Rose & Abi-Rached, 2013). I argue that the patients' experiences with bipolar disorder treatment exemplify how connected the mind, the brain and the body are in the human organism. The individual patients are affected by different interventions in various ways and this makes the management of bipolar disorder so complicated for both the treatment system and the patients themselves.

The day-to-day practice of living with bipolar disorder is a process of adjusting to the ever changing moods, emotions, behaviour, sleep, thought and biological processes, as well as the interventions attempting to balance the situation; it is a continuous process of *becoming* slightly different every time the situation changes. (Ingold, 2013).

THE COORDINATION WORK

In this research, my aim was to analyse how, despite the diagnostic uncertainty, bipolar disorder is coordinated into something that can be researched, diagnosed and treated.

Indeed, the DSM is coordinating the assemblage of psychiatry, since it is the DSM categorisation of bipolar disorder that in the end determine what is considered as normal or pathological, as health or illness in psychiatry. The DSM is a medical technology categorising human beings in order to stabilise the diagnostic uncertainty and it provides the most important snapshot of the complex reality within psychiatry. However, in the mundane practices within science, clinical practice and patients' lives, the coordination work differs.

In science, the DSM categorisation groups individuals as bipolar disorder patients and the individuals thus grouped become parts of research data: epidemiological populations or genetic data probands. The DSM is designed for commensurate individual illness experience into a standardised classification, so that the knowledge produced can be globally convertible, an universally valid categorisation of the particular patients (Lakoff, 2005a).

The DSM is not only a discursive form, a mutual language to speak about bipolar disorder for very different actors from pharmaceutical industry to patients, it is also a material artefact. The DSM is a manual the clinician can leaf through in the consulting room and it is materialised in the diagnostic tools. In clinical practice the DSM and the diagnostic tools are coordinating the situation where the medical authority places the diagnosis. I argue that this is not a simple act of discursive power, many things are put into effect; the situation in the consulting room is not clean from the ideals of scientific knowledge and objectivity, education received by the clinician and the patient, expertise and subjectivity, emotions and interpretations or experiences and uncertainty (Martin, 2007, 99-133). This is because the diagnostic tools travel from science to the clinical practice, and to the patient through the information flow in the Internet (Hacking, 2007).

I argue that the DSM is creating a looping effect in psychiatry. The DSM was designed to standardise psychiatric diagnosis in order to better the reliability of the diagnoses made in clinical practice. However, the DSM system does not capture the individual variation of symptoms patients experience in clinical reality just because it is a standardising technology. The symptoms still need to be interpreted by both the clinician and the patient. As a consequence, the problem of diagnostic uncertainty remains and psychiatry needs to balance between the standardised categorisation and the variety of the individual patients. This requires the coordination work I have described in this research.

In the treatment of bipolar disorder, evidence-based medicine provides a similar snapshot, it coordinates the uncertainty of determining what is effective and safe treatment. I argue that the fundamental problem in evidence-based psychiatry is that the statistical generalisations of the best possible treatment do not necessarily meet the needs of the particular patient. The medical technologies, EBM and DSM, cannot fully tame the uncertainty in the world because the particular patients' reality is messier and more complex than the standardisations.

INCONSISTENCY BETWEEN THE PARTICULAR PATIENTS AND UNIVERSAL KNOWLEDGE

The objective of this research was also to analyse what is put into effect in science, clinical practice and patients' experiences. The answer is different *ideals*: of scientific objectivity, standardised diagnosis, evidence-based medicine and balanced life. These ideals are looping in the interplay between the science, clinical practice and patients' experiences affecting each other and the ways bipolar disorder is interpreted and acted on within the practices (Hacking, 2007).

These ideals put into effect in the mundane practices in science, in the clinical practice and in patients' day-to-day life are attempts to tackle the inconsistency between the objective and universal knowledge and the variety of the particular patients' with their unique genotype and phenotype, as well as life course and experiences with bipolar disorder.

I argue that this is the most integral bifurcation taking place in psychiatry. The processes of life are more complex than the snapshots in the practices attempting to standardise those processes with, for instance, the diagnostic categorisation in the DSM or the principles of evidence-based medicine.

Both psychiatry and its objects, the patients, are neither pre-given through biology, nor learned through culture (c.f. Debaise, 2013; Ingold, 2013; Stenner, 2008). Mental health and illness is inherently both biological and cultural because it is experienced by individual minds and bodies in a social and cultural context. Psychiatry is coordination work, where the scientists and the clinicians attempt to capture the individual in the process, and psychiatry must work through the individual mind and body. This requires tinkering and balancing, but it often happens that the particular patient receives just the right diagnosis and the right treatment; and psychiatry manages to treat both the illness, the experienced, and the disease, the biological, in the individual (c.f. Mol, 2008).

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