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UNIVERSIDADE Ð
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Hannah Sophia Isabell Kuhn

“I stopped being a Normal Person”
An anthropological Approach to the ‘Medical Gaze’ and Diagnostic Category in Bipolar Disorder

VOLUME 1

Dissertação no âmbito do Mestrado em Antropologia Médica e Saúde Global orientada pelo Professor Doutor Luís Fernando Gomes da Silva Quintais e apresentada ao Departamento de Ciências da Vida da Faculdade de Ciências e Tecnologia da Universidade de Coimbra.

Outubro de 2021

Faculdade de Ciências e Tecnologia
da Universidade de Coimbra

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Summary

This thesis aimed to investigate the context and effect of psychiatric nosology on the diagnostic process of Bipolar Disorder. The history of the diagnosis was related to the broader sociocultural framework of its emergence with the third edition of the Diagnostical and Statistical Manual of Mental Disorders, DSM-III, in 1980. Based on the premise that biomedicine is a scientific and a sociocultural practice, the thesis' theoretical framework focused on anthropological and philosophical concepts regarding scientific practices in medicine. Countering assumptions of underlying pathophysiological mechanisms as a disease's etiology with the idea of medical practice systematically shaping the objects it therapizes, the concept of an institutionalized 'medical gaze' was discussed.

To explore tensions between institutionalized health care patterns and subjective experience, ethnographic field work was performed in the Coimbra University Hospital. Following the concepts of subjective *illness* experience as opposed to the observation of a *disease*, semi-structured interviews were conducted with six patients diagnosed with Bipolar Disorder and five psychiatrists treating them, organized into case studies. Qualitative analysis focused on three core aspects: The process of diagnosis, communication and narrative regarding the diagnosis, and the institutional setting's influence.

The diagnosis generally posed a relief allowing for patients to receive help and end their uncertainty towards the cause for their suffering. Communication regarding the disease consistently referred to a natural course of Bipolar Disorder, which seemed beneficial for aspects such as guilt or shame, and contributed to feelings of relief. The DSM and its diagnostic categories were perceived as helpful, yet, limited, constituting a link between individual treatment and institutionalized guidelines, functioning as a regulatory element while enabling standardized communication for social and legal institutions. Altogether, the diagnosis was considered key element for inter-institutional communication as well as the moment in which the *illness* experience materializes to be considered a *disease*.

Keywords: Medical Anthropology, Bipolar Disorder, DSM-III, Medical Gaze, Ethnography.

Resumo

A presente dissertação visava investigar o contexto e o efeito da nosologia psiquiátrica no processo de diagnóstico da Perturbação Bipolar. A história deste esteve relacionada com o quadro sociocultural mais amplo do seu surgimento na terceira edição do Manual de Diagnóstico e Estatística das Doenças Mentais, DSM-III, em 1980.

Partindo do princípio de que a biomedicina é uma prática científica e sociocultural, o quadro teórico da tese centrou-se em conceitos antropológicos e filosóficos relativos às práticas científicas médicas. Contrariando pressupostos de fisiopatologia subjacente como etiologia de doença com a ideia da prática médica moldando sistematicamente os objetos que trata, discutiu-se o conceito do "olhar médico" institucionalizado.

Para explorar tensões entre padrões de cuidados de saúde institucionalizados e experiência subjetiva, foi realizado um trabalho etnográfico de campo no Hospital Universitário de Coimbra. Seguindo conceitos de experiência subjetiva de doença *(illness)* em oposição à observação de doença *(disease),* foram realizadas entrevistas semi-estruturadas com seis pacientes diagnosticados com Perturbação Bipolar e cinco psiquiatras assistentes, organizadas em estudos de caso. A análise qualitativa concentrou-se em três aspetos centrais: processo de diagnóstico; comunicação e narrativa relativamente ao diagnóstico; e influência do contexto institucional.

O diagnóstico constituiu geralmente um alívio, permitindo aos pacientes receberem ajuda e terminando a incerteza em relação à causa do seu sofrimento. Comunicação relativa à doença referia-se consistentemente ao curso natural da Perturbação Bipolar, que parecia benéfico para aspetos como culpa ou vergonha, e contribuía para sentimentos de alívio. As categorias de diagnóstico do DSM foram úteis, mas limitados, constituindo uma ligação entre tratamento individual e diretrizes institucionalizadas, funcionando como elemento regulador ao mesmo tempo que permitiu uma comunicação padronizada para instituições sociais e legais. Em conjunto, o diagnóstico foi considerado elemento-chave para comunicação interinstitucional, bem como o momento em que experiência da doença (*illness*) se materializa para ser considerada *disease*.

Palavras-chave: Antropologia Médica, Perturbação Bipolar, DSM-III, Olhar Médico, Etnografia

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I dedicate this thesis to my family, for without them this would not have been possible: To my mother, who has always uncompromisingly supported me; to my father, who put new ideas and questions into my head for as long as he was able to do so; to my sister whose love, laughs and patience have accompanied this process; to my uncle, whose advice I am always grateful for and whose annotations greatly facilitated writing; and to Tonguç, whose fine linguistic, logical and reflective skills keep amazing me and who contributed to this thesis to be what it is through countless conversations. Thank you.

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Introduction

> „The need for a classification of mental disorders has been clear throughout the history of medicine, but there has been little agreement on which disorders should be included and the optimal method for their organization" (American Psychiatric Association 2005, xvi).

This statement from the introductory chapter of the fourth edition – published in 2005 – of the Diagnostic and Statistical Manual of Mental Diseases (DSM), a diagnostic catalogue according to which psychiatry operates, highlights the central debate that is the starting point of this thesis: There has always been a need for classifying symptoms into disorders, however, there has not been a coherent central idea throughout the history of mental disorders indicating which criteria to follow for the categorization of mental disorders. The changes in how the categorization of mental disorders was organized were and still are to be understood in a broader social, political and scientific context.

This thesis aimed to investigate the context and effect of nosology in psychiatry based on the present-day example of the psychiatric diagnosis of „Bipolar Disorder". The history of this particular diagnosis is taken into consideration as well as how and when it emerged as a classification within the broader sociocultural framework of the classification of mental disorders in general. To explore the tension between institutionalized patterns of treatment, neurobiological approaches, a yearning for objectivity, fear of stigmatization, and hope for alleviation of suffering, it was opted for an ethnography in the form of case studies as a research method. In the process, semi-structured interviews with patients diagnosed with Bipolar Disorder and their treating psychiatrists in the context of a psychiatric hospital were conducted, followed by a qualitative analysis of the findings and the setting of the interviews.

In practice, there are various problems with the ways in which categorization and validation of symptoms define suffering: Some patients do not fit into either category due to artificial boundaries or gaps between diagnoses. Other patients do not achieve the level of severity of a condition to qualify for diagnosis. Still others fulfill criteria for multiple conditions due to a considerable symptom overlap, thus, complicating an accurate diagnosis (Phillips and Kupfer 2013; Vieta and Phillips 2007, 888). In this thesis, an attempt will be made to describe and analyze the history and development of diagnosis categorization of mental disorders. The history of nosology serves as a context to highlight relations between the progress of biomedical research with emphasis on the biological (e.g. neurobiology, pharmacology, cognitive sciences, etc.) developments, on the one hand, and the social, political, cultural and economic development, on the other hand, that were observed over approximately the same course of time.

The theoretical background to the research conducted is structured around concepts and reflections of biomedicine. Biomedicine structures and categorizes human disease in a certain manner, which can be considered something inherent to scientific as well as to sociocultural practice. The philosopher of science Thomas Kuhn states in his famous book *The Structure of Scientific Revolutions* in 1962:

> "Close historical investigation of a given specialty at a given time discloses a set of recurrent […] illustrations of various theories in their conceptual, observational, and instrumental applications. These are the community´s paradigms, revealed in its textbooks, lectures, and laboratory exercises" (Kuhn 1996, 43).

By highlighting the importance of textbooks and laboratory exercises, he refers to practices that constitute a social structure "around" as well as "within" the acquisition of knowledge: a scientific community, certain paradigms that the community has agreed on and taken to be their principles. The ground rules persist until new knowledge comes to light and a paradigm is abolished or evolves. These structures, already implied in the book's title, are manmade, and so are (their) revolutions. The structures are not simply "there" to be discovered but instead serve to organize questions, observations, experiments, results, etc. into scientific laws or eventually into knowledge. As such, the sociocultural context is implicit in every science. Therefore, this thesis explicitly investigates biomedicine as a scientific practice that can never be exercised in a vacuum outside a sociocultural context.

In the first chapter of this thesis, a closer look shall be taken at what exactly defines biomedicine as well as at the premise that biomedicine is a sociocultural system just as much as it is a science dedicated to investigating and healing disease. Biomedicine does not simply observe and scientifically study the human body as a natural phenomenon. Instead, it should also be considered, as described by the authors Robert Hahn and Arthur Kleinman as an “artifact of human society, founded in a cultural framework of values […], taught by the communications of social interaction and then enacted in a social division of labor in institutional settings” (Hahn and Kleinman 1983, 306). In other words: Biomedicine is not merely an accumulation of biological properties that can be perceived as health or disease in the human body, but a cultural practice embedded in social and historical context – which holds for every other science as well. In his book *Writing at the Margin: A Discourse between Anthropology and Medicine*, Kleinman summarizes: „There is, then, no essential medicine. No medicine that is independent of historical context” (Kleinman 1997, 23).

In a continuous debate on assumptions regarding epistemology, many philosophers or scientists would state that reality does not particularly care for our attempts at dissecting it. That it is indifferent towards humans trying to understand it. However, as reality is dissected by humans embedded in sociocultural systems, with moral values, expectations, limitations of how to “scientifically dissect” reality as well as numerous other reasons to be biased, it is important to look at the way reality is dissected, and thereby shaped or even created. The concept of an indifferent reality that exists to be discovered, or not, contradicts French philosopher Foucault’s ideas. His concept is that of a construction of reality through signs, through language and through orders socially and politically established. Concerning the field of medicine, he accentuates the medical discourse and states that “[it] is not one of signs but a practice that systematically shapes the objects of which it speaks.” (Foucault, quoted in B. Good 1993, 68). Foucault’s words go beyond Kleinman’s description above, he emphasizes that healing activity is not merely a practice to be applied in case of disease but also takes part in shaping the objects it therapizes. According to him, the body can be considered an object of social practices and biomedicine as an instrument to perform a necessary interaction. In his book *The Birth of the Clinic*, Foucault describes the medical discourse as a means of organizing and interpreting the experience of disease, thus projecting idealized and anticipated realities onto the patient’s body – hereby becoming an object – that result in certain ways in which doctors interact with patients. These interactions are in turn shaped by a medical gaze, a “glance [that] has simply to exercise its right of origin over truth” (Foucault 2003, 4). The medical gaze is to be understood as a concept less individual but rather institutional(ized), something that Foucault considers a characteristic inherent to biomedicine as practiced in the last two centuries approximately.

Linking Kuhn's concept of the creation and constitution of knowledge of a scientific community with Foucault's observation of the medical gaze that gains access to as much as it creates the object(s) that it observes, acquires knowledge and speaks about, leads to another fundamental concept this thesis sets out to investigate, a phenomenon described by the philosopher Ian Hacking. He calls it the "looping effects of human kinds", a feedback effect that occurs when a classification (e.g. a diagnosis of a psychiatric disease) affects the behavior of those classified (e.g. a patient that acts in accordance with his diagnosis and the expectations of it) (Hacking 1999). This is crucial to the subject in question because it is important to recognize that there is an interaction – both ways – between the diagnosed patient and the observing, diagnosing, and treating physician. Biomedicine not only "press[es] the practitioner to construct disease, [a] disordered biological process, as the object of study and treatment" (Kleinman 1997, 31) it also influences and shapes the very subject along the way. The medical gaze penetrates the body and separates the disease from the complex overall appearance of the patient. In most cases, this affects the course of the disease as well as the patient who lives with the condition. According to Kleinman, there is very little, if any place for the patient's suffering in this narrowly focused therapeutic vision and a patient's "family's complaints are regarded as subjective self-reports, biased accounts of a too-personal somewhere" (Kleinman 1997, 32), while in practice it remains the physician's task to replace these supposedly biased observations with "objective data: the only valid sign of pathological processes" (Kleinman 1997, 32). This affects the patient before and after his diagnosis, as much as it affects the expectations and judgement a physician has when observing, diagnosing, and treating patients. For example, specific information may be sought to fit a certain diagnosis, while other complaints of a patient will remain unheard. Once a diagnose is made, it becomes the patient's label, he will often times stop being an entire person and *become* a diagnosis. According to Foucault "the patient must realize that each of his answers has meaning within a field of an already constituted knowledge in the doctor's mind" (Foucault 2006, 185). Physicians are taught to dissect the patient's complaints in a certain way that is according to the standards at a given time and context.

For this reason, the way the medical education is organized is an important factor contributing to the diagnostic process and treatment of a patient.

The Anthropologist Byron J. Good describes the process of studying medicine as a "process of coming to inhabit a new world" (B. Good 1993, 72). He describes attending medical school as a formative process through which medicine creates the world it operates in. Medical education legitimates medical practices in the way it teaches them. In the process of becoming a professional, the physician will reproduce what he or she has been taught: To regard the patient's experience as being of inferior priority, volatile or even misleading (as the designation "biased" suggests), to deny the moral or social reality of suffering and even to take part in constructing the object of healing practice appropriately to the medical gaze taught and considered "valid" (B. J. Good 1993, 70-73).

This leads to the second chapter, which offers an exploration of the history of diagnostic categorization of mental disorders as well as its changes in the 20th century to briefly depicting what "is" Bipolar Disorder according to the DSM. Bipolar Disorder was introduced with the DSM-III in 1980, the disease catalogue's third edition that is considered a historical landmark in psychiatric nosology, as it exemplifies a shift in treatment ideals in the 20th century from a causal, psychoanalytical to a more descriptive, observing approach (Shorter 2015). After being introduced as a DSM-diagnosis, Bipolar Disorder was to become one of the most popular diagnoses in psychiatry (Vieta and Phillips 2007) as well as being pushed by the pharmaceutical industry as it proved to be helpful to sell the rising "mood stabilizers" (Shorter 2015). In order for an individual to "get into" a diagnosis – as a common expression stated (Shorter 2015, 65) – and become a patient, the DSM-III established criteria for symptoms a patient was required to have. As these criteria follow a certain pattern and are subject to several factors that change over the course of time or depend on an individual's situation, it seemed adequate for this thesis to opt for a qualitative research method in order to investigate more closely personal experiences and expectations – from patients as well as from the psychiatrists – in relation to this diagnosis.

The third chapter describes why and how a qualitative research method was used. The necessary steps are depicted, taking into account the field work happening inside the hospital, an institution not accessible to the public, as it has a responsibility towards their patients, a vulnerable group of people who are to be protected by confidentiality. The ethnographic field work was carried out inside a psychiatric hospital, a biomedical institution of the 21st century, interviewing individuals diagnosed with Bipolar Disorder and the psychiatrists who treat or used to treat them. Bipolar Disease was chosen as an especially interesting diagnosis in this setting, because it is classified as a "mood disorder", a category that depends on a socio-cultural context and the subjective expression of an individual's suffering. Additionally, it is a disorder usually treated with medication, resulting from a neurobiological approach to mental disorders. Subsequently, this would justify research to further shift to neurobiological approaches in terms of measuring validity and efficacy of treatment as well as seeking biological causes for the disorder. It is a disorder located at the intersection of the subjective experience of suffering, neurobiological explanatory models – locating psychiatric disease in the brain – and a vast spectrum of symptoms. All this can fit into categories and match a classification that is a diagnosis – if observed by a psychiatrist – yet, sometimes overlapping with symptoms that make different diagnoses. Situating this project in a fast-growing body of ethnographical research in Medical Anthropology, very few studies have been conducted investigating Bipolar Disorder in particular. The comparable ethnographic studies that do exist, have found that the rendering of an accurate diagnosis is of crucial significance for the people suffering from Bipolar Disorder and have emphasized the complexity of the diagnosis (Sajatovic et al. 2008; Stiles et al. 2019). However, none of them included interviews with the psychiatrists' perspective as well as was the case in this study.

This thesis does not propose to evaluate diagnostic criteria and treatment for Bipolar Disorder from a scientifically medical point of view, nor does it intend to deny or even question the physical or material reality of biomedicine. It rather aims to look at the historic and sociocultural aspects of biomedicine in order to investigate the effect epistemology and power relations have on the perception of health, disease and biomedical treatment. Questions to be explored in the ethnographic field work include, among others: How is the clinical, hence, the institutionalized situation created? How does one gain access to be in that situation? Which factors determine it and how does one gauge its impact on the people in that situation? How is it shaped by met or unmet expectations?

By depicting the ways in which patients diagnosed with Bipolar Disorder experience their illness, the ways in which psychiatrists (learn to) observe it and assign it with the name of a disease as well as how diagnostic criteria may possibly have an impact on the very course of Bipolar Disorder, this thesis aims to contribute to the field of study.

Biomedicine, the ‘Medical Gaze’ and ‘Looping Effects’ – Theoretical Considerations

What is Medical Anthropology? And what constitutes Biomedicine?

According to Helen Lambert´s encyclopedia entry in the *Routledge Encyclopedia of Social and Cultural Anthropology*, Medical Anthropology is „generally understood to refer to the study of social and cultural dimensions of health, ill health and medicine.” (Lambert 2010, 456). In the encyclopedia’s section, the history of medical anthropology is delineated as having originated in studying “primitive medicine” as a social institution in foreign cultures (“ethnomedicine”) until “Western Medicine” became an object of study itself. While Medical Anthropology as a subdiscipline became known in the 1960s, the interrelation of psychiatry and anthropology dates back to at least 1932, when Edward Sapir, an American anthropologist published his article titled “Cultural anthropology and psychiatry”, and describing them both as „disciplines concerned with human behavior” (Sapir 1932). While the anthropologist investigates individuals in order to gain conclusions about a structure of a given society, psychiatry’s aim is to diagnose and treat an individual’s behavior deviant from a “normal attitude” towards the physical and social environment. In his analysis – and this is interesting considering the historic context of 1932 – psychiatry is a specialty of medicine merely due to tradition, yet, in reality, it is compelled to address sociological problems if they were to make an individual suffer. According to Sapir, thus, it is important that cultural anthropology and psychiatry “join hands" because while culture is an impersonal whole, the study of cultural patterns cannot be disconnected from “those organizations of ideas and feelings which constitute the individual”. Additionally, unconscious mechanisms of the neurotic/psychotic are “by no means closed systems imprisoned within the biological walls of isolated individuals” (Sapir 1932), as he referred to the other “biological” subdisciplines of medicine.

A part of Medical Anthropology would later develop to be a discipline of anthropology concerned with precisely the split between the “biologically” medical and the “traditionally” medical (to repeat Sapir’s assessment) but really more sociocultural aspect of human behavior, possible deviations and suffering. By then, and this is valid until today, “Western Medicine” was an entity no longer limited to the “western” world. Therefore, the term Biomedicine seems more adequate to use for what is to be studied in this thesis’ framework. But what defines “Biomedicine”?

In their 1983 article “Biomedical Practice and Anthropological Theory”, the previously mentioned authors Robert Hahn and Arthur Kleinman list five core features to identify sociocultural aspects of biomedicine:

> “[…] a distinctive domain and system of ideas, that is ‘medicine’; a division of labor (i.e. medical specialties); corresponding roles, rules of practice and interaction, and institutionalized settings; a means of ‘socialization’ by which this domain and its procedures are taught and reproduced; and an enterprise of knowledge construction (i.e. Biomedical research).” (Hahn and Kleinman 1983, 311)

They further elaborate these distinctive features and here it is strikingly noticeable how they repeatedly emphasize concreteness and operationalism – in creating precise categories and lines between healthy, sick and the different kinds of sick – as a “definitional theme” of Biomedicine.

In his book “Writing at the Margin” (referring to being at the margin of Medicine and of Anthropology), the medical anthropologist and psychiatrist Arthur Kleinman opens with a chapter called “What is specific to biomedicine?”. Before specifying, he explains that medicine or “organized health practices” are “fundamental to what is deeply human in experience” (Kleinman 1997, 21). He further goes on to describe that it is a human practice to develop categories in which health is normalized and illness defined, categories that structure a narrative of suffering into culturally “meaningful syndromes” that call for healing roles and careers. He states that different socio-cultural contexts have, accordingly, specific distinctive forms of medicine or therapeutic practices, to conclude that there is no medicine independent of historical context. (Kleinman 1997, 23)

That being said, it seems appropriate to narrow down and define the term “Biomedicine” to the form of medicine to be discussed in this thesis: Its distinctive features are a commitment to epistemology and a theoretical backbone, a *scientific paradigm*; its systematic creation and passing on of knowledge through high-technology care institutions that hold a respectable status in medicine; and its "extreme insistence on materialism as the grounds of knowledge and […] its discomfort with dialectical forms of thought" (Kleinman 1997, 29). That entails causality chains that explain a given pathology, and standardized mechanisms that can account for treatment efficacy. Kleinman further delineates that biomedicine as a science and as a practice is based on a ground where "*nature* is physical" (Kleinman 1997, 30) in a sense in which it is there to be discovered, to be "seen" – under a microscope if necessary – giving special significance to the role of observing and "seeing" that is highly important and almost ritually practiced in medical research and teaching. Supposedly, Biomedicine is knowable independently of perspective or representation. Kleinman frames biology per biomedical definition as the "architectural structure", the "real substance" underlying suffering of illness narratives, as if psychological or social factors were epiphenomena disguising the truth below (Kleinman 1997, 30–31).

When trying to define Biomedicine, it seems that Anthropology has high potential in a reflection of this discipline. Going back to the encyclopedia entry on Medical Anthropology, Lambert further describes the efforts that were made, mainly in psychiatry and anthropology, to characterize non-biomedical views of ill-health and to relativize the seemingly dominant biomedical paradigm of treatments. She quotes American psychiatrist Leon Eisenberg, who first shaped the "analytic dichotomy" of a disease/illness distinction (Lambert, 1996, p. 360) in medical anthropology and beyond:

> " 'Disease' is taken to be the biomedical, measurable identification of bodily disorder central to the process of biomedical diagnosis and is contrasted with patients' experiential awareness and understanding of their 'illness'." (Eisenberg 1977)

The distinction between disease and illness exemplifies what seems to constitute biomedical practice, a valorization of the observable, the objectifiable. It stands in line with Kleinman´s description of *nature* as materialist foundation to understand disease, and Kleinman took great part in shaping the concept of illness and disease in the 1980s to exemplify what Biomedicine deals with and what it often misses (see e.g. Kleinman 1988). Interestingly, when writing about *nature*, Kleinman – who is also a practicing psychiatrist – immediately goes into differentiating between "hard" and "soft" specialties in medicine, harder ones being more "biological", respected, have higher wages and fewer female physicians. Psychiatry at least formerly being one of the “softer” disciplines has made the effort to transform into a “harder” specialty over time, with objectifiable symptoms and treatment options (Kleinman 1997, 30). Without wanting to judge this shift at this point, it seems important to note that Kleinman writes about this to clarify that “biological” knowledge about a given pathology has a very high status in biomedicine and that aspiring this kind of status or professional credibility within and outside the field means aspiring and valuing “biological” knowledge – through biological research.

This results in a kind of dichotomization (mind vs. body, functional vs. “real” diseases, etc.) in which, according to Kleinman, the physician is pressed into “construct[ing] *disease*, disordered biological processes, as the object of study and treatment” without regarding the patient´s experience as “valid” (Kleinman 1997, 31). Physicians are to replace patient’s “biased observations with *objective* data […] based on verifiable measurements” which he then refers to as a “dehumanized disease process” in a constructed object of biomedical care (Kleinman 1997, 32) whose suffering is not taken into account as a quality of disease. Hahn and Kleinman even refer to Biomedicine as “the product of a dialectic between culture and nature” (Hahn and Kleinman 1983, 306), as if it were evolved from to entities contradicting each other while inseparable in the domain of disease – humans experiencing bodily dysfunctions.

Another important aspect to consider when trying to specify what is Biomedicine, is its functioning through bureaucratization and institutionalization of medicine. The bureaucratic rationality and the resulting generalizability, predictability, efficiency or quality control are considered the “virtues of biomedicine” by sociologist Max Weber (Freudenberg 1993). Predictability ensures transparency and generalizability, standardized practice, protects the individual from arbitrariness, which has become helpful in the industrial society, for instance, to identify medical malpractice. However, as biomedicine and its care institutions are a “leading institution of industrialized society´s management of social reality”, having the capacity to stigmatize an individual as sick just as much as protect it from suffering (Kleinman 1997, 38), biomedicine is closely interrelated with social welfare systems of the postmodern state. To gain access to support, one must pass a physician who holds a sort of gatekeeper function and thus is located in a crucial position of power. Biomedicine’s terminology and taxonomy additionally have great “legal and regulatory significance”(Kleinman 1997, 40) as it holds the power of definition about what is to be considered healthy or normal and how to treat the absence of healthiness, or, for example, when to allow someone to retire due to a disease. Thus, it is not only progressive and transparent but also an instrument of social control, deeply interwoven with a social system’s political economy. Kleinman further states that biomedical care can end up being an institutionalized and “misguided search for magic bullets for complex social problems; and it can obfuscate the political and economic problems that influence these behaviors” (Kleinman 1997, 38). As no other form of medicine has assumed such an important position when it comes to exercising social control, large-scale bureaucratization and institutionalization constitute another distinctive feature of Biomedicine as a scientific and therapeutic practice.

Medical knowledge and Medical teaching: How Medicine constructs its objects

The disease/illness distinction also figures prominently in anthropologist Byron J. Good’s work on medical teaching. In his book *Medicine, Rationality and Experience*, he describes how Biomedicine constructs an object of therapeutic work, the patient, as a *medical problem*, without legitimating suffering. This is reflected in medical teaching: Good’s ethnography of medical students at Harvard Medical School – a highly prestigious American university –portrays the process of studying medicine as a “process of coming to inhabit a new world” (B. Good 1993, 72). He quotes a student talking about medical education as follows: “[…] I feel like I’m changing my brain every day, molding it in a specific way – a very specific way”(B. Good 1993, 65). The statement describes how the student experiences the ways in which a particular way to perceive and to think about things is being acquired and how such perceptions point to towards a very specific direction. Throughout Good’s ethnography of American medical school training, it becomes palpable how medical students acquire their “new” way of thinking in terms of pathologies that affect organ systems and to see the body literally as symbolically dissected. This training opens up a new world with an entirely different mode of thinking about *body*, *dysfunction*, *disease*, *human, behavior,* etc. – whichever concept may be at the center of attention at a given time throughout attending medical school and beyond. “[…] The medical world gets built up as a distinctive form of reality for those who are learning to be physicians", Good concludes the introductory section of the chapter in question (B. Good 1993, 67).

According to Good, attending medical school does not only entail acquiring knowledge but also becoming part of and thereby continuously re-establishing a world in which that knowledge is to be acquired. It is a formative process through which medicine creates the world it operates in. A person, a complex cultural construct, is reconstructed appropriately to become subject of a medical gaze and identified as a patient, a body, a case, or a diagnosis. The way medical students learn to interpret the reality according to a certain structure of knowledge, e.g. the disease catalogue for mental disorders, DSM, is depicted as both powerful as well as "often misleading and profoundly ideological" (B. Good 1993, 75–81). Medical education legitimates medical practices in the way it teaches them, constructing the objects of medical attention while reproducing the power relations in which they are embedded – clouding the gaze for alternative practices or dimensions of knowledge. This is closely related to Foucault's work on what he coined to be the "medical gaze", which becomes clear at the latest when Good cites Foucault's famous words: The Medical discourse is not one of "signs (signifying elements referring to contents or representations) but a practice that systematically form[s] the objects of which [it] speak[s]" (Foucault 1972, 49, quoted in Good 1993, 68). In consequence, healing activities are not only scientific practices applicable in case of disease, but they take part in shaping the objects of therapy. The body is then considered an object to be subjected to social practices and biomedicine as an instrument to perform an interaction (e.g., treatment).

When talking about the medical gaze, Foucault states: "The 'glance' has simply to exercise its right of origin over truth" (Foucault 2003, 4). This, of course, contradicts the concept mentioned above, the hypothesis that there is a (pathophysiological) "truth" underlying every illness, an entity that is "there" to be observed by the physician, and the more knowledge is acquired, the more truth can be made visible, through microscopes, through a pathologist chemically dying a certain tissue sample or by simply "knowing" where to look and what to look for. It does, however, emphasize how there is a certain way to look at patients, taught inside institutions which combine "observation, disciplinary control, and teaching" (Foucault 1977, 195–228), nowadays called university hospitals – adjusting what is being looked at to what is expected to be seen.

This is not independent of the power structures and social status the medical profession has achieved over time, a status historically developed along with the profession's bureaucratic structures and a monopoly of knowledge. Adrian Forty, historian of architecture, opens one of his essays on social and medical uses of architecture with a quotation of the French surgeon J. R. Tenon: "Hospitals are in some degree the measure in the civilization of a people" (J. R. Tenon, in Forty 1980, 61). Alongside the architectural history of hospitals, one can deduct paradigm changes as well as changes of power structures within professional (institutionalized) health care as well as a society's moral code. For example, before hospitals became secularized in the 18th century, they used to be mainly religiously motivated charity institutions organized spatially in a way that every patient could witness religious ceremonies from their bed. When Louis Pasteur introduced the "germ theory" and microbes were discovered towards the end of the 19th century, the previously suspected cause and spreading of infectious diseases became scientifically manifest and eventually translated into the creation of separate wards in the hospital (Prior 1988). Subsequently, the physically open spaces in hospitals intended to observe patients and enable them to hear prayers were abolished to separate infectious from non-infectious patients. Scientific advances led to a change in health care practice, that had until then been dominated by religious beliefs and the power of the church (Forty 1980, 68–72). Thus, secularization was an important step towards a more modern version of the hospital. Due to a lack of prestige and comparably low social standing at the time, doctors, however, still had very little authority in hospitals (Forty 1980, 70–72). Later on in the 19th century, doctors started to use hospitals for improving skills, clinical experience and for doing research and hospitals became an important site for institutionalized learning. As medical knowledge evolved and the medical profession achieved a distinct identity in society through obligatory registration[1], the medical lobby

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[1] The foundation of the British Medical Association in 1856 and the Medical Act of 1858 obligating physicians to formally register constitute important landmarks in the profession's increased visibility and social recognition. The development of the first specialized journal, *The Lancet*, in 1823 and the

became more powerful and gained more influence over the organization and structuring of hospitals. The resulting creation of a monopoly in this branch of knowledge further increased doctors' influence.

Patients are luckily not being punished with food restriction anymore as it used to happen in the 18th and 19th century, nor are they subject to disciplinary measures if they didn't obey the doctor's rules. However, the objectifying medical gaze, the medical profession's social hegemony and sovereignty of interpretation regarding matters of health care continued to be prominent into the 20th century. It became part of the social system studied and criticized in academic fields like the sociology of medicine and medical anthropology as mentioned in the beginning of this chapter.

Good does not entirely agree with Foucault. He goes further to state that while the medical gaze refers to a specific perception of reality, medical knowledge is more than just that, it is a "dialogical medium, one of encounter, interpretation, conflict and at times transformation" (B. Good 1993, 68), meaning that it is much more interactive and based on engagement with the world than the concept of a passive gaze would suggest. Medical school is, then, a way of learning how to interact with a specific part of that world, inside the walls of health care institutions.

The Looping Effects of Human Kinds and Metaphysical Motivation

Another central concept in this thesis are the so-called "looping effects of human kinds", a concept introduced by philosopher Ian Hacking. He differs between "human kinds" and "natural kinds" as particular kinds referring to a system of classification. In his work, although the definition can be conceived a bit blurry in parts, "human kinds" are "kinds of people and their behavior which (it is hoped) can enter into practical laws – laws that if we knew them we would use to change present conditions, and predict what would ensue" (Hacking 1995, 360). In other words, he refers to the human sciences or sciences that focus on human organization and human behavior in the broadest sense. According

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progress of a more organized scientific medical community further enhanced public respect for, and influence of, the medical profession. (Forty 1980, 80–81).

to Hacking, all human kinds have a looping effect – a feedback effect that occurs when a classification (e.g. a diagnosis) affects the behavior of those classified (e.g. a patient that consciously or unconsciously acts in expectation of his diagnosis). This, in turn, leads to a "biased" subject behavior (e.g. the patient) that can result in a change or further development of the classification. Or, as Hacking puts it:

> "There is a looping or feedback effect involving the introduction of classifications of people. New sorting and theorizing induces changes in self-conception and in behavior of people classified. Those changes demand revisions of the classification and theories, the causal connections, and the expectations. Kinds are modified, revised classifications are formed, and the classified change again, loop upon loop." (Hacking 1995, 370)

The natural kinds, in contrast, do not have a looping effect, according to Hacking, as the objects of study are "natural", as opposed to human, they are not aware of their classification and thus cannot show biased or different behavior due to that knowledge. He differentiates between natural and human kinds explicitly when stating that human kinds are "loaden with values" (Hacking 1995, 366). Biologizing or medicalizing human kinds function as attempts to free human kinds from moral values, a sign of striving for relief because e.g. neither an alcoholic nor society can carry blame if dysfunctional neurons were to cause his behavior, neurons that can potentially be medicalized into functioning properly.

Hacking emphasizes that there is an obvious tendency in scientific fields to favor a biological approach, a "thrust of human kinds towards the biological" (Hacking 1995, 372). However, this only creates "biologized" kinds rather than natural kinds. Most importantly, he notes, biologizing human kinds does "not make them immune to looping effects" (Hacking 1995, 372), as one might hope because they nonetheless deal with humans to a certain degree being aware of "their" category. He writes this in relation to genetic research, for example, while strongly questioning whether it is possible to attribute human behavior entirely to genes, no matter how much it might be a human desire to be able to do so. In this sense, it seems to be much more an artifact of science than an actual approximation to reality. But why? Hacking attempts to give a reason for where this motivation to biologize human behavior might originate. He describes the idea of acquiring knowledge about humanity by "replacing human kinds by physiological or mechanical or neuroelectric or biochemical ones" as "old", yet, "powerful" (Hacking 1995, 353). The motivation behind this, according to Hacking, is bigger than curiosity or the desire for "completeness" of knowledge could account for. Instead, he writes: "This is not just a tradition of research but also represents metaphysics." […] One solution is to make psychology, and all else that is human or social, into biology. That is, a built-in metaphysical motivation for biologizing human kinds" (Hacking 1995, 353). What Hacking calls the "metaphysical motivation" can be considered a belief that there is something beyond the observable, that is yet to be made observable. An almost spiritual striving for the reality in front of us, a causal connection that will give us relief once we find out about it, but the relief begins, sort of, with believing in the causality that will be obvious eventually, less complex than the intertwined relation of social, moral, cultural and biochemical factors that influence the behavior of a person. It is understandable, and other people beside Hacking have observed this. In Good's book mentioned above, a similar concept can be found, something he refers to as the "soteriological" in medical practice (B. Good 1993, 83–85). Ideas of redemption or salvation are a central element in civilization, he states, something to be found in many philosophers' or sociologists' works. The desire for salvation is closely connected to the finitude of life, the finite nature of our being. Therefore, it is not at all far-fetched to state that this is a motive also appearing in biomedicine, where healing can be read as an almost literal version of salvation. In an essay on religion, sociologist Max Weber wrote that "one could wish to escape being incarcerated in an impure body and hope for a purely spiritual existence. […] One could wish to be redeemed from the barriers to the finite, which express themselves in suffering, misery and death, and the threatening punishment of hell, and hope for an eternal bliss in an earthly or paradisical future existence" (Weber 1946, 280–81). This concept is represented in different ways almost cross-culturally, and Good points out that Foucault also references a spiritual, "metaphysical" component in modern medicine. In the concluding chapter of his book *The Birth of the Clinic,* Foucault turns to the motive of finitude in medicine and how its (in-)surmountability is implicated in medicine's structures and aspirations:

> "[…] positive medicine marked, at the empirical level, the beginning of that fundamental relation that binds modern man to his original finitude. Hence the fundamental place of medicine in the over-all architecture of the human sciences: it is closer than any of them to the anthropological structure that sustains them all. Hence, too, its prestige in the concrete form of existence: health replaces salvation […]." (Foucault 2003, 197–98)

He first establishes the significance modern medicine has in relation to the perception of man's own finitude, to then explain the almost "intrinsic" motivation this relation holds. Modern medicine, Foucault goes on to argue,

> "offers modern man the obstinate, yet reassuring face of his finitude; death is endlessly repeated, but it is also exorcized; and although it ceaselessly reminds man of the limit that he bears within him, it also speaks to him of that technical world that is the armed, positive, full form of his finitude" (Foucault 2003, 198).

Foucault stresses the ambiguous metaphysical connection between modern medicine and men facing finitude: Humans are being constantly forced to acknowledge death when confronted with disease or a corpse – they may even be considered representations of finitude. Meanwhile, medicine offers means to escape finitude, at least temporarily, and salvation is in a way exercised through technical efficacy and constant advances and innovations of modern medicine (see also B. Good 1993, 86–87).

Healing a disease today admittedly may be a materialistic practice of salvation, and a supposedly basic human right one might simply say. However, the seemingly inexhaustible belief in an underlying biological causality for every bodily or psychological "dysfunction" can serve as a driving force for a biologistic science to continue to shift in research towards this almost positivist direction, to acquire funds and to invest into decades of research. Knowing about the complexity of diseases, the multiplicity of factors that may cause a mental disorder and nevertheless pushing biological (e.g. genetic) research in disproportionally, makes Hacking's claim that there is a metaphysical motivation when biologizing the human kinds by, e.g., exclusively locating the origin of human behavior in the DNA, seem very adequate.

Science, Paradigms and Outlook for this Thesis

In his aforementioned book *The Structure of Scientific Revolutions*, the physicist and philosopher of science – or historian of science, it remains a debatable designation – Thomas S. Kuhn challenges the concept of scientific progress occurring in a linear way through experimentation and the resulting accumulation of new data as a representation of the reality that was to be discovered by the experiment. Kuhn describes revolutions that fundamentally alter the way in which reality is perceived by a given scientific community. According to Kuhn, this is usually the consequence of a "crisis", following the assumption that "crises are a necessary precondition for the emergence of novel theories" (Kuhn 1996, 77). Crises happen when scientists are "confronted by severe and prolonged anomalies" (Kuhn 1996, 77) that lead to the doubt of a certain scientific *paradigm* leading to this crisis. Eventually, a paradigm may be rejected and usually replaced by another – a revolution of this scientific community's structure. The scientific community then alters the ways in which experiments are conducted and new "ground rules" are established. These revolutions, according to Kuhn, happen with a certain regularity and follow a certain pattern, they exhibit an underlying structure. This is, of course, a very simplified summary of Kuhn's ideas elaborated in this book. As his work is based on physics as a sort of prototype for science, its applicability to other fields remains limited and is not simply transferable to psychiatric research. However, some of his ideas seem worthwhile to be examined in more detail in the scope of this thesis and kept in mind throughout the following chapter. For example, the opening sentence of Kuhn's book is illuminating:

> "History, if viewed as a repository for more than anecdote or chronology, could produce a decisive transformation in the image of science by which we are now possessed. That image has previously been drawn, even by scientists themselves, mainly from the study of finished scientific achievements, as these are recorded in the classics and, more recently, in the textbooks from which each new scientific generation learns to practice its trade." (Kuhn 1996, 1)

That image, he goes on, is comparable to a tourist brochure's image of a national culture, a misleading excerpt that cannot claim to be what it is: An adequate representation of what is to be "known". Also, this may serve as a cautious reminder that *paradigms* do not equal the truth and that the paradigms a certain scientific community's research is based on, may change as they have changed throughout history. This is not at all exclusive to physics. Medicine in particular constitutes a scientific discipline that has always also been a practical discipline, evolving while being faced with its limitations (e.g. with an unknown disease or its respective cure that has yet to be discovered) has passed through almost countless shifts in paradigms throughout history, most commonly when new knowledge had come to light.

However, caution is advised when considering medicine as a science like physics, and especially when considering psychiatry, a branch of medicine, as a science. This thesis is based on the presumption that psychiatry is not a mere science like physics is, and its "objects", the people and their behavior that are being studied, should not be treated as such. Psychiatry is, for one part, a discipline in which symptoms expressed by the patients as well as clinical data, not necessarily hierarchically organized, are being correlated and interrelated with different fields of knowledge like neurobiology, behavioral psychology, psychoanalysis or psychopharmacology. Additionally, the "objects" to be studied simultaneously are subjects as well, an important aspect that has already been addressed above with the introduction of Hacking's theory regarding the looping effects of human kinds. Hacking also emphasizes this in his essay "Making up People" when he states: "The category and the people in it emerged hand in hand" (Hacking 1999, 165). The following chapter on the history of mental disorders and their categorization as well as the reasons for changes – *paradigm shifts* – will seek to clarify this as well.

Against the historical background of medical anthropology and its contemporary scientific debates, this thesis focuses on biomedicine as it takes a closer look at psychiatry and bipolar disorder in particular. In its attempts to analyze the power relations and historical conditions manifested in contemporary psychiatry, this thesis proceeds to study and "dissect" the ways in which illness, disease, and health care translate into particular practices of diagnosis. In the following chapters, this further explores the ways in which perceptions and representations of patients shape and affect real people's lives and well-being.

Bipolar Disorder: Disease Properties, DSM-Classification and its Historical Context

On Classification

Departing from an introductory overview of medical anthropology and philosophy of science as well as a discussion of some of the more prevalent considerations on biomedicine as a sociocultural practice within this field of research, this thesis takes a closer look at the particular subject of this thesis, the psychiatric diagnosis of Bipolar Disorder. A discussion of this diagnosis and its associated research necessitates a more in-depth description of the characteristics that qualify a cluster of specific symptoms to "become" this diagnosis. The rather theoretical considerations of the first chapter shall be fed with concrete practical aspects of diagnosing or being diagnosed. This chapter's intention is not to assess in any way diagnostic criteria – neither on a qualitative nor clinical-psychiatric or therapeutic level. Rather, a kind of bird's-eye view shall be taken, looking at the manner and systematics of the categorization, and subsequently how it is dealt with in the clinical setting and its possible effects on thoughts, feelings, communication, and actions of the people interviewed. Similar to the diagnoses of many other forms of mental illness, the diagnosis Bipolar Disorder was introduced to clinical practice by becoming part of the disease catalogue Diagnostic and Statistical Manual of Mental Disorders (DSM). I will therefore begin by elaborating on its historical and socio-political context. It seems worthwhile for this chapter to consider the 20th-century history in more detail insofar as it serves to show how these historic circumstances influenced and changed scientific priorities as well as medical practice until today.

In her book on the making of DSM-III, the cultural historian of psychiatry, Hannah S. Decker, attempts to pinpoint the difficulties faced when classifying mental disorders:

> "To begin with, an infinite number of variables go into the making and continued existence of the human brain and personality. The factors affecting any human being are an interactive, ever-evolving mixture of genes, biological processes, experiences, surrounding environments, and thoughts, feelings, and passions, some being below the level of awareness. […] Psychiatrists and psychologists, though advancing on

> many fronts, do not yet know the etiologies of many of the mental conditions they are called on to treat." (Decker 2013, xviii–xix).

It seems that the lack of knowledge about the etiology forces the clinician to look for different means to differentiate between different mental conditions, and the multi-faceted appearance of mental disorders requires a complex effort. Later on in her book, when she explores the history of classification in psychiatry, Decker writes that "Classification is a necessary endeavor that human beings automatically carry out from early infancy on in order to comprehend the world they live in" (Decker 2013, 129). Thus, classification seems to be an inherently human necessity and desire. Making a psychiatric classification system more accurate, valid, or meaningful can serve to improve treatment as well as communication between practicing clinicians and researchers. However, there is always the possibility to create artificial divisions and categories where they do not exist or gaps that are unable to cover the vast spectrum of mental conditions. As these categories are artefacts of human taxonomization, they have to be revised over time and adapted, as necessary, especially when new knowledge is introduced into the field.

DSM

The Diagnostic and Statistical Manual of Mental Disorders, commonly referred to in psychiatry by its abbreviation DSM, is a catalogue of diseases that classifies and lists mental disorders. Published by the American Psychiatric Association (APA), the DSM currently exists in its 5th edition (American Psychiatric Association 2013). Its (European) equivalent is the International Statistical Classification of Diseases and Health Related Problems (ICD), published by the World Health Organization (WHO), currently in its 10th edition (World Health Organization 2016). Mental disorders are one part of it, identifiable by the letter "F" in front of a numeric code further indicating the disease – or rather, diagnosis. While I will only focus on details of the DSM, it can be said for both manuals that they are intended to guide clinicians in the process of finding a diagnosis. They are also intended to help with reliability and communication among clinicians

(Vieta and Phillips 2007) to objectify treatments, to make them efficient, measurable, and comparable in the spirit of modern *evidence-based medicine*[2].

According to medical historian Edward Shorter, the history of the current DSM-V is shaped by “haphazard science and politically driven choices” (Shorter 2015). Nosology, the science of classifying diseases within medicine began in the late 19th century with German classifiers, the first one to use clinical properties (instead of “biological” ones) to classify diseases was Emil Kraepelin. He started to introduce a classificatory system for diseases in 1893 and is considered to have paved the way for today’s DSM classificatory structure, because he initiated the classificatory system based on observation of symptoms rather than the underlying causes – in psychiatry often unknown. According to Kraepelin, mental diseases were a pathology located in the brain or symptoms caused by faulty metabolic processes (Decker 2013, 131). In contrast, Sigmund Freud, the founding father of psychoanalysis – born in the same year as Emil Kraepelin, in 1856 – did not feel the necessity for categorization of mental disorders, or “superficial” descriptive psychiatry because he saw their etiology in underlying psychological rather than physiological processes. In accordance with this approach, psychoanalysis focuses on the uniqueness of an individual and their biography (Decker 2013, 132).

After World War II, there was a growing interest in mental health following a rising need to provide treatment options – especially in reaction to veterans returning from the war, many of them traumatized. This gave rise to *Medical 203 (Medical Bulletin number 203)*, a manual developed by the US military and published in 1945. The first time a chapter on mental disorders was included in the WHO’s ICD was in its 6th edition in 1949 and

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[2] Evidence-based medicine is a recent concept in medical practice. Its goal is to optimize health care decision-making in a patient-centered, scientific manner based on evidence. Under the assumption that a clinician’s individual opinion is biased, it resorts to “objective” recommendations based on scientific results retrieved from e.g. clinical trials (Guyatt et al. 1992). While this is a helpful and valid gold standard of medical practice preventing individual malpractice, it has many practical problems such as defining evidence in a very narrow way - often not applicable in all situations - as well as being instrumentalized for a neoliberal restructuring of health care for the sake of efficiency.

the APA released the DSM I in 1952. While both, *Medical 203* and DSM-I emerged under the influence of psychoanalysis, where disorders were – as mentioned above – considered psychological reactions to childhood or life events, European psychiatry was dominated by the Kraepelinian concept according to which mental illnesses were diseases located in the brain (Shorter 2015).

In the late 1960s, the Biometrics Unit of the New York State Department of Mental Hygiene and the Institute of Psychiatry in London organized a US-UK Diagnostic Project that sought to compare British and American psychiatric diagnostic systems. The resulting report, published in 1973, showed that American psychiatrists would diagnose in much "broader" terms and did so less reliably than their British counterparts. As it seemed to be "time to tighten up American diagnostics" (Shorter 2015, 64), an APA's commission for the creation of DSM-III was formed in order to create a new manual with consensus-based diagnoses, also introducing a new nosology that was to become the backbone of DSM-III.

In 1980, DSM-III was published. Considered a landmark in psychiatric nosology, it marks a historic turning of the page, pushing psychoanalysis – at the time still dominating American psychiatry – out the door of psychiatric practice and reconciling psychiatry with the rest of medicine, the "organic" medicine, based on the belief that psychiatric diseases were situated in the brain with psychiatry rendered as a medical subdiscipline. This marked the beginning of a more biological tradition of thinking in 20th-century psychiatry that was supported and pushed further by the appearance of the first psychopharmaceuticals for psychiatric disorders that were introduced in the 1960s. The observed success of these drugs served as proof that the brain was involved after all. This substantially changed existing psychiatric treatment patterns. To this point, there was little therapeutic consequence to classifying mental diseases one way or another because of limited treatment options. "Now that a treatment for depression [is] available, diagnosis is essential" (Hoff 1959). As a result, the concept of diagnosis was believed to have specific prognostic and treatment response correlates. Terms such as "specific disease" and "validity" were new to American psychiatry and the beginning of a new empirical future (Shorter 2015; Vahia 2013).

In the Introduction of DSM-III, the authors state:

> “First of all, over the last decade there has been growing recognition of the importance of diagnosis for both clinical practice and research. Clinicians and research investigators must have a common language with which to communicate about the disorders for which they have professional responsibility. Planning a treatment program must begin with an accurate diagnostic assessment. The efficacy of various treatment modalities can be compared only if patient groups are described using diagnostic terms that are clearly defined. […] Finally, interest in the development of this manual is due to awareness that DSM-III reflects an increased commitment in our field to reliance on data as the basis for understanding mental disorders” (American Psychiatric Association 1980, 1).

Aligning with what has been described above, this introduction emphasizes the importance of a common language between clinical practice and research in the psychiatric field as well as a shift towards and implementation of scientific methods based on clearly defined data. This intention is also reflected in the goals defined by DSM-III’s task force that, among others, included the following:

> “[…] reliability of the diagnostic categories; […] acceptability to clinicians and researchers of varying theoretical orientations; […] usefulness for educating health professionals; […] consistency with data from research studies bearing on the validity of diagnostic categories; suitability for describing subjects in research studies; […]”(American Psychiatric Association 1980, 2).

The task force, a group of psychiatrists appointed to produce DSM-III can be considered successors of the “Neo-Kraepelinians”, a current branch of American psychiatry that was influenced by European psychiatry in the Kraepelinian tradition (Decker 2013, 53-55). As psychoanalysis was considered “faith-healing” by a majority of the members of DSM-III’s task force, committed to “remedicalize” psychiatry, they strongly expressed their scientific concerns against a non-material approach to knowledge, thus insisting on empirical psychiatry. Meanwhile, they neglected the possibility that new data might also shed light on the involvement of social factors in mental disorders. Their aim was for psychiatry to gain more professional credibility and to counter the anti-psychiatry movement in the 1960s (Decker 2013, 54-75).

It seems important to note that today, the use of DSM has multiplied, and DSM diagnoses have become extremely relevant for various domains of institutionalized social organization in relation to mental disorders. Being used by different professions of the healthcare system (psychiatrists, psychologists, social workers, etc.), DSM codes are nowadays indispensable when it comes to objectifying illness and treatment: First of all, they are a prerequisite to get reimbursed from health insurance companies. This is a special case in the North American health care system, but many other health care systems require a DSM diagnosis in order to justify treatment within an institution (this includes hospitalization as well as outpatient care) for their statistics and economic control. In medical school or psychological faculties of universities, education is based on learning diagnostic psychiatry from the disease catalogue, as it determines how mental health care facilities operate. Applications for research grants are required to use the DSM's diagnoses in order to qualify for funding. There are countless other occasions for which a DSM diagnosis is key: While occupational disability insurances will exclude responsibility for any mental disorders if they are listed in an individual's medical record, judges and lawyers resort to DSM diagnoses as the common language to justify an insanity defense, for example, or to refer to other entanglements between an individual's mental state and possible legal consequences. (Decker 2013, xviii)

Bipolar Disorder

Bipolar Disorder was one of various innovations and "newly-coined names" (American Psychiatric Association 1980, 1) introduced with DSM-III, a diagnosis that was to become one of the most popular diagnoses in psychiatry (Vieta and Phillips 2007). In addition to being listed in the new disease catalogue's edition, its legitimacy was simultaneously being promoted by the pharmaceutical industry as it was extremely helpful to sell the rise of "mood stabilizers"[3]. With the new nosology of DSM-III, there was a list of symptoms a patient was required to have in order to "get into" a diagnosis

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[3] Although widely used by psychiatrists as well as patients, the term „mood stabilizers“ is not an official term for a designated group of medication. It generally refers to lithium or valproate but has extended to other types of medication since first being used. „Mood stabilizers“ is a term following clinical observation of effects – namely increasing well-being and preventing acute phases of mania or depression in patients with Bipolar Disorder – rather than a testimony to an understanding of the underlying pathophysiology (Malhi and Goodwin 2007).

(Shorter 2015, 65) as a common expression stated. Bipolar Disorder was one of the diagnoses whose creation followed a certain pattern.

In DSM-III, Bipolar Disorder is grouped with Affective Disorders, as part of the subclassification "Major Affective Disorders", further subclassified as Mixed, Manic, or Depressed (American Psychiatric Association 1980, 205). Bipolar Disorder and Major Depression – the 'other' Major Affective Disorder – are characterized by at least one manic or major depressive episode. However, "[…] these major affective episodes are not diagnosed if the affective disturbance is due to an Organic Mental Disorder or if it is superimposed on Schizophrenia" (American Psychiatric Association 1980, 206). After then describing a manic episode and its possible Associated Features, a paragraph on Differential Diagnosis of maniac episode follows, to exclude other "known organic etiologies" (American Psychiatric Association 1980, 208) e.g. substance-induced alterations of mood, or Paranoid Schizophrenia, stating that it may be difficult to distinguish them due to their similar features. Subsequently, the diagnostic criteria for a manic episode are listed. This scheme of categorization not only shows the possible difficulty of coming to an accurate diagnosis, but also holds a contradiction: DSM-III´s descriptive approach – to diagnose a patient based on the observation of symptoms – requires excluding an underlying disease, an *organic* or *biological* cause. This, in practice, can lead to mis-diagnosing a patient or constantly being on the lookout for biological, measurable properties of psychiatric diseases to gain more security in how to interpret symptoms and draw conclusions for therapeutic decisions.

Cognitive deficits or avolition for example are symptoms not at all exclusive to bipolar disorder but also very common in other mental disorders – for example certain types of Schizophrenia or Post-Traumatic-Stress-Disorder (another new Diagnosis of the DSM-III). The problems this poses in practice are various: Some patients do not fit into either category due to artificial boundaries or gaps between diagnoses. Other patients do not achieve the level of severity of a condition to qualify for diagnosis and will be left out. Still others fulfill criteria for multiple conditions due to a symptom overlap (Vieta and Phillips 2007, 888). The diagnostic validity of Bipolar Disorder has thus been questioned by many clinicians over the course of the last four decades and the alteration of criteria in DSM-V can be considered a correction of DSM-III in an attempt to create a more adequate system of categorization and to include cases that do not “fit” in any of the categories established by DSM-III.

Much debate has focused on how to exactly correlate particular criteria with each diagnosis to account for diseases most adequately in the catalogue. However, that there should be any criteria at all, aside from the psychiatrist’s own, possibly idiosyncratic views, was a major change at the time (Shorter 2015, 64-65). This shift deeply affects the relationship between therapist / physician and patient. Rather than relying on the psychoanalyst’s impression resulting from the interaction with the patient, there was a shift towards an external inspection of symptoms, supported by physical findings (e.g. heart rate variability), laboratory data or – more recently – neuroimaging. In an overall retrospective view, DSM-III (re-)introduced a quantifiable, comparable “medical model” into psychiatry that had until then been dominated by a “biopsychosocial” model (Shorter 2015; Vieta and Phillips 2007).

This change in perceiving mental disorders and the resulting change in treatment also influenced medical training and resulted in psychiatrists situating symptoms and the responses to treatment in relation to the brain and the rest of the body. This affected medical practice in various ways. On the one hand, it seemed necessary to make the symptoms “fit” the diagnostic categories, on the other hand, diagnoses were treated with the newly available pharmaceutic interventions.

A significant discrepancy emerged regarding the theory and practice surrounding the DSM’s assessment of psychiatric conditions. Many psychiatrists and philosophers of science are keen to analyze and critique the mode in which the DSM has arrived at criteria. At the same time, the catalogue continues to dominate psychiatric practice in all its domains and guides clinicians on an everyday basis. Recent works in the field of philosophy of science suggest that researchers are fully aware of the DSM’s discrepancies as scholars question its merely descriptive approach and its “function as an administrative constraint”. However, the most frequently offered solutions seem to focus on etiology, the expansion of a biologistic approach in psychiatric research and the associated search for the true, underlying reality of biological properties (see Tsou 2019).

Conducting Qualitative Research in an Institutional Setting – Methods

Research Design, Methods and Intentions

This thesis sought to better understand the lived realities of patients diagnosed with Bipolar Disorder in the context of institutionalized health care in a present-day facility. As previously described, there may be a discrepancy between the perception a patient has of his or her illness and physicians's observation of the symptoms presented to them. This work previously discussed the relationships between different layers of representation and perception along with the communication between health care providers and patients. In an effort to investigate the interplay of these various layers of meaning, perception and knowledge, this thesis opted for case studies of patients with the diagnosis Bipolar Disorder, accompanied by interviews with treating psychiatrist, respectively. The use of semi-structured interviews seemed to be an appropriate method to approach these questions (which I will elaborate on). The interviews took place in the department of psychiatry of the Coimbra University Hospital*, Centro Hospitalar e Universtário de Coimbra* (CHUC), from September to November of 2020.

At the very beginning of this thesis, broad bibliographic research was performed to formulate a research question and to understand more precisely what was of interest in this matter that was also accessible through field work. The further the project progressed, the more systematic and specific the bibliographic research became to be what it is now, as introduced in the first two chapters. Throughout this process, the research explored in this thesis could be situated in the context already established by the investigation of numerous other authors, as introduced in the first two chapters.

It is assumed that qualitative research presents significant advantages when studying humans in their sociocultural context or when studying the context itself. People included in field work are not mere objects that are to be studied but have their own perceptions of the social reality in which they are situated. Often, their own perception matches the broader terms of what is intended to be approached. Qualitative research has a greater capacity to take into account the vast richness of human perception and experience than quantitative research (Becker 1996). It therefore seemed to be an adequate choice of method in order to make room for the core interest for this thesis: The nuances in how people chose to answer the questions asked. What they chose to elaborate on. The emergence of unexpected details. The narratives of suffering as well as stories about treating patient that were not previously considered, etc. The central questions of interest covered in the ethnography centered around the diagnosis, the process of diagnosing, and the impact the construct of a diagnosis has on doctors as well as patients:

- How and when did symptoms first appear? As of when were they considered symptoms? How much time elapsed between this point in time and a diagnosis? Did the diagnosis meet the needs of the patient? Were there doubts?
- Representation of Bipolar Disease in everyday life. How do doctors explain the diagnosis and its prognosis to patients? Do patients seek other explanatory models or further information from different sources? Does the treatment work? Are therapeutic alternatives discussed?
- How did the diagnosis change the patient's life? How did it affect the relationship between patient and psychiatrist?
- Support system and social network to cope with the disease: Family? Friends? Work? Support groups? Do doctors encourage patients to seek this kind of support?
- Cure: Is there hope for a cure? Is the desire or the perspective being communicated from either side? If so, how?

Questions were posed to both patients and psychiatrists in a similar manner, altering respectively to the perspective interviewed, but assuming that both would have a corresponding perspective on the matter at hand (self vs. physician's perspective regarding e.g. effectiveness of treatment or adequateness of diagnosis).

Preparation and Ethical Considerations of the Ethnographic Field Work

The beginning of planning the field work in March and April of 2020 coincided with the onset of what was to become the COVID-19 pandemic. At the time, the decision to conduct interviews with psychiatrists and their patients treated for Bipolar Disorder in the department of psychiatry of the University Hospital in Coimbra had already been made. March an April marked the preparation phase to determine how and when to proceed with the field work. Of course, the pandemic presented an unforeseen obstacle that was luckily overcome or became more manageable. However, it did slow down and complicate the process. For instance, it was necessary to physically enter the hospital to present the research project to the head of the department of psychiatry and ask for permission. One had to seek authorization of the hospital's ethics committee and to establish contact with the psychiatrists and their patients. Although these steps theoretically could have happened online or by phone, the establishment of personal contact turned out to be crucial in the pursuit of making the field work happen. The fact that I had been an employee in the same hospital's emergency room at the time allowed me access to the building without being a patient myself. Physically entering the psychiatry wing, sometimes still wearing the working clothes (at times unavoidable as I would go back and forth between my work in the emergency room and the psychiatric wing until catching the person I needed to speak to) and thereby being identifiable as a "member" of the hospital's team was necessary to proceed to the interviews. Only thereby could I ask direct questions (people would not always be in their offices and pick up their phones) and find out necessary steps along the way without disregarding the working routine of the members of the department of psychiatry. Being a physician myself I was considered a colleague (this would happen independently of my clothing, as being "colleagues" did not seem to require the same workplace but the same profession, something I was unaware of until then). This afforded me the advantage of being considered less of an outsider invading the non-public space of a psychiatric wing which, in my perception, made people less skeptical and more likely to cooperate with me in my undertaking. Being of the medical profession facilitated my access to the institution because I was already somewhat familiar with the hierarchies and the way people interacted in this organization constellation. In light of the all-encompassing impact of the pandemic, it was also the only way I could have performed the interviews at all. Although I was technically not required to enter the psychiatric wing and be a potential additional risk of infection for no reason related to immediate patient care, I benefitted from being granted a "collegial" confidence that I would reduce risk of infection to an absolute minimum. Another part of the cooperative attitude I found in the department of psychiatry, I attribute to the fact that in a university hospital, it is common to conduct research and people are inclined to support each other's projects in the spirit of working constantly towards new knowledge.

The previously performed bibliographic research and the formulation of questions informed the development of a guide for the interviews. This guide was designed to make the interviews somewhat comparable and served as a reminder for the interviewer to cover key aspects that seemed important to talk about with each interviewee. However, the guide was not to be strictly followed during the interview, nor was it shown to the person interviewed to avoid giving the impression interviewees were requested to follow a certain order or to "check boxes" to fulfill a set of expectations they did not yet know. At the same time, patients were given access to the guide when they specifically asked to see it. The idea was not to get too fixated on the set of questions asked, and to make room for interaction or divergence flowing from the conversation.

As the interviews were semi-structured, an interviewee had the necessary time to answer questions. Sometimes, they would divert from the original question and tell me things that may not have been intended with my opening question but were important for them to share. One guide was developed for the patients and a different one for the psychiatrists, with some questions corresponding to the ones for the patients as the issues they were asked to talk about were assumed to correspond as well.

In addition to the guide for the interviews, an informed consent form was prepared. The interview guides and the informed consent form can be found in the appendix of this thesis. As the research was taking place inside the hospital, authorization by the hospital's ethics committee was required. To obtain authorization, an extensive application had to be submitted. The application included my curriculum vitae as well as the one from the professor supervising this thesis. An outline of the project, describing its scientific background, context and intentions as well as a detailed outline of how the interviews would be conducted had to be submitted to and signed by the chief of psychiatry, before being added to the application. The list of documents required for the ethics request can also be found in the appendix. The ethics committee would come together about once a month. The paperwork had to be submitted at least 15 days in advance in a paper file according to the ethics committee's standards outlined in a detailed manner upon request.

Having no experience with the procedure, it was necessary and luckily possible to meet the head of the ethics committee personally to understand the procedures according to which the papers had to be submitted.

Conducting and analysing interviews: Setting, participants and documentation

After having obtained authorization from the ethics committee (see appendix), contact was established with the psychiatrists to whom I had previously introduced myself to. It was also determined whether they patients diagnosed with Bipolar Disorder at the time. Patients were informed about the interviews by their psychiatrists and asked whether they would be willing to participate. Upon agreement, psychiatrists established contact with patients. Usually timed to coincide with a scheduled visit with their psychiatrist, patients would meet with me either in the Coimbra University Hospital's main building, in the psychiatric wing, or in *Hospital Sobral Cid*. The latter was a psychiatric facility just outside of Coimbra but remained part of the organizational structure of the university hospital's Department of Psychiatry. This way, patients were spared an additional trip. Only one patient interviewed was an in-patient[4] at the time of the interview. All others were out-patients coming for their regular appointment every three months. This implies that except for the one patient, they were not in an acute or highly symptomatic phase of their disease. Interviews with psychiatrists were scheduled in their offices during their working hours when they could spare time for an interview.

Every interview began with me introducing myself and my position (student of medical anthropology with a background in medicine as well as practicing physician). Subsequently, I briefly explained the context of the interview and the project's intention. It was made clear to patients that I was bound to confidentiality, that information would only be used after having been anonymized and that participation in interviews would have no consequence for therapy and treatment they were receiving from psychiatrists.

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[4] The term „in-patient" refers to a patient who is staying in a hospital's ward. This generally indicates a more acute or severe phase of a disease that requires more intense care and / or surveillance, as opposed to in an out-patient, who only comes in for scheduled appointments and is in a less severe state of a disease and thus does not require such a high level of intensity of care.

To participating psychiatrists, it was made clear that the intention was not to evaluate or judge their professionality in any way and that confidentiality applied to them as well. Only one patient decided to not participate in the interview after having explained the context because she did not feel like she was in the condition to talk about her diagnosis that day. If the interviewees would agree, they signed the form about informed consent containing everything that had been previously explained and I would ask permission to record the interview. The opening question usually inquired about their name, age and profession. Sometimes, I would take notes during the interviews in addition to recording, but only rarely, e.g., if a facial expression stood out or the body language changed significantly during the interview. The desire to facilitate conversation remained the focus of the interviews. Each interview was limited to 20 minutes, which turned out to be a generally adequate amount of time. A few cases exceeded that timeframe if I felt people were not done talking to me yet. In total, five psychiatrists and six patients were kind enough to participate in my field work. The sixth and last interview with a psychiatrist did unfortunately not happen due to logistic reasons that could not be overcome despite the efforts made.

After conducting the interviews, they were transcribed. Simultaneously as well as after the process of transcription, a qualitative analysis was performed, based on literature regarding field work in anthropology. (For reference, see Chapter 8, *Recording and Analysing Field Data*, in Burgess 1984.) The technique applied in this case was the definition of topics that were expected to come up during the interviews, some previously defined according to my expectations, some added retrospectively if they emerged during the interviews. The topics were codified and sorted by their codification in an excel sheet and grouped with notes taken during and after the transcription process.

The interviews were conducted and transcribed in Portuguese. In the next chapter, when quoting parts of the interviews, an English translation is given. Portuguese expressions are only included when the English translation did not seem to suffice to capture nuances in meaning and cultural specificity. When quoting parts of the interviews, “HK” refers to me, the interviewer. All information was anonymized to avoid recognizability of the interviewees. The names of the psychiatrists and patients were changed to random names without any connection to their real names. A chart of the interviews and the participants can be found in the appendix.

The following chapter will present the outcomes of the interviews relative to a discussion of the literature and theoretical foundations as introduced previously.

Psychiatrists' and Patients' Perspectives on Biopolar Disorder – Analysis

The condition known as Bipolar Disorder presents the core subject of this thesis that examines the diagnosis' history and categorization as a disease as well as its clinical treatment and sociocultural context. This study further explores the effects that Bipolar Disorder has on people diagnosed with this disorder and how the diagnostic processes unfold in the institutional settings of aa present-day psychiatric clinic. The analysis presented in this chapter breaks down into three parts.

The first part discusses the process of diagnosing Bipolar Disorder and how it affects people during the course of the condition. It will focus on the necessity and process of classifying the disorder while also considering any obstacles that may delay diagnosis. The second part takes a closer look at how the diagnosis is communicated. I will focus on the images and narratives that are shared with patients, how patients can relate to the disease, and what perspectives emerge from that. The third part discusses the impact of the institutional setting on the diagnosis. It examines how psychiatrists observe and describe their patients and how such practices rely on the disease catalogue as a foundation. Although the issues covered in this analysis are highly intertwined, the chapter proposes to study the issues according to these separate sections. This approach allows to address the benefits and shortcomings of categorizing the condition as Bipolar Disorder while also making the subject more accessible to the reader.

The Diagnosis: An Element Associated with Relief or Stigma?

The process a patient has to go through from the onset of symptoms until diagnosis can be a long and windy road. It is the process through which an illness becomes a disease, in which two different perspectives amalgamate into a diagnosis, a name, a designation, a drawer into which an experience is placed or discarded entirely, depending on the circumstances. The Dutch anthropologist and philosopher Annemarie Mol approaches this ambiguity in her book *The Body Multiple: Ontology in Medical Practice*, where she states that "However shared or solitary perspectives may be, the practice of diagnosing and treating diseases inevitably requires cooperation" (Mol 2002, 21). This is crucial, as there are (at least) two perspectives that come together, the patient's one and the treating physician's one. In order to make a diagnosis, neither one functions without the other. They shape the process – as do other factors that will be discussed later – and both contribute to this shape individually as well as in dialogue with each other. This can be seen in reference to Ian Hacking's concept of "looping effects" of "human kinds" introduced earlier, when observing that patients behave differently according to what they believe is expected from them, for example. Furthermore, the diagnosis marks a crucial moment in a patient's disease that has consequences for the course of treatment while also reflecting the events leading up to it. When Hahn and Kleinman describe a dialectic of nature and culture and consider it "to be one of the primary theoretical problematics of medical anthropology", they go on to state that it "acts as a vital intersection of body, mind, and community" (Hahn and Kleinman 1983, 321). This dialectic can be recognized, in parts, in the moment of diagnosis, when body, mind and culture meet in the form of social practices within biomedicine and define the shape a disease takes on.

A question that emerged while conducting the interviews was whether something as simple as a clear diagnosis of Bipolar Disorder really existed in the first place, partially due to the reasons previously elaborated (overlap of diagnosis criteria, necessity of a certain degree of severity in order to qualify as "symptom", etc., see Vieta and Phillips 2007). In my perception, there has been a very prominent desire throughout all interviews to establish a clear, "textbook-style" case. However, in reality this never seemed to be the case. A number of phrases used by diagnosticians, the psychiatrists interviewed, point to the absence of clearly identifiable cases of Bipolar Disorder, for example "Well, he did not have a *clean* mania, …" (Dr. Luísa, Interview 2.3) or "[…] he had manic episodes, but there you go, it is a picture that is *contaminated* by post-traumatic stress disorder […]" (Dr. Mafalda, Interview 2.4). These expressions show that there is an underlying template of a textbook diagnosis serving as reference while the complex reality of a clinical situation frequently 'clouds' or even "contaminates" the possibility of a clear diagnosis. The desire for certainty of a diagnosis is disturbed by the presence of "other" symptoms that may not belong to the category Bipolar Disorder.

In almost all cases, diagnoses were significantly delayed, a fact that prolonged patients' suffering and the time without appropriate treatment. Sometimes, the delay only became apparent retrospectively, when the diagnosis shed a different light on adolescence, for example. All patients told me about problems in their younger years. Many referred to high school as a time and place associated with feelings of being marginalized or not being a good fit in other ways ("something never felt quite right"). Often, the diagnosis occurred much later in life, usually after periods of clinical decompensation, thus, passing the threshold *into* a diagnosis. The case of Joana documents this pattern in the most explicit way (Interview 1.1). Her psychiatrist had been treating her for several years at the time of our interview after the initial diagnosis had been made previously by a different psychiatrist when she was 20 years old. When I asked the psychiatrist, Dr. Maria (Interview 2.1), whether she could tell me what she knew about the diagnostic process in this patient's case, she answered:

> Dr. Maria: "Well, for many years I have treated her now, she already came to me diagnosed and on mood stabilizers5, and I agreed with the diagnosis. She had a very early onset of the disease, and she sought help of a specialist relatively soon, and went to see a psychiatrist, which was good, and she has a good prognosis. She was diagnosed right away and adhered to the medication prescribed. She never had to be an in-patient in the hospital."

She then goes on to describe this patient's story as a very classical case of Bipolar Disorder. She states that it was a smooth process finding the appropriate diagnosis, which led to treatment right away. However, the patient presents a different perspective on the matter:

> HK: "Can you tell me about when you had the first symptoms, how they showed and how you sought help?" – Joana: "My first really visible outbreak, really clear, was when I was 20, I completely decompensated, it was when I went into mania that you really realized I was sick. […] I went into the emergency room on a Thursday, before that I had been fully aware that I wasn't well, and I went to the doctor who was accompanying me, a neurologist, and he told me that I didn't want to work, that I didn't

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[5] The term mood stabilizers refers to different kinds of medication prescribed for patients with bipolar disease to stabilize the mood between the two „extremes", mania and depression in preventing their outbreaks and/ or their severity. See also foot note on mood stabilizers in chapter 2. In this case, the patient was taking lithium, a common treatment for the disease.

> want to study, that life wasn't like that and that I had to go to work because I had a very difficult presentation at university the next day and he said that I didn't want to work, and then I was hospitalized and stayed there for some time."

This comparison shows the differences in perspectives. In a way, the patient is her own best observer as her memories may be clearer and more immediate. Meanwhile, the psychiatrist has had numerous patients over the years and does not necessarily remember all of their stories in detail. It is significant that that the *illness* perspective, the patient's perspective, begins – as it is the case most of the times – before the onset of the disease. Joana's account suggests that the patients' complaints were stigmatized and invalidated. She is only taken seriously when her suffering has become too great to be ignored. Hospitalization occurred because the patient was not able to manage her symptoms anymore as they reached a level of severity that undoubtedly met the criteria for diagnosing Bipolar Disorder. The fact of such a severe outbreak of mania at the early age of 20 strikes the psychiatrist in retrospective as a positive thing. Joana had only once been institutionalized initially without recurrence. This observation has been attributed to her adherence to the medication prescribed. It is also seen as evidence of her understanding and acceptance of the illness as a chronic condition. She therefore has a good prognosis. When asked whether she had seen physicians before being diagnosed by a psychiatrist, she answers:

> Joana: "Yes, I did, I complained to my parents, we went to the family doctor and his stance was that I was a spoiled little girl and then I didn't have access to more help. […] The process of diagnosis is so long. You keep expressing it, and well, a mania is something that everyone realizes is out of place and has to be fixed, but there were many "intermediate" symptoms that they [the parents] got a little tired of - I mean, I never lied from the beginning to the end, I was always truthful about everything I felt. It makes it very hard. It's a lot of days, it's a very long process."

I observed that the patient repeatedly felt compelled to justify herself in different ways: How she had felt initially in clinical settings but also during the interview with me. She further emphasized that she had never lied. She had been accused of exaggerating by various doctors she saw before (and even after) she decompensated. These episodes prompted her having to go to the emergency room, especially when expressing the "intermediate" symptoms, the ones not deemed severe enough for her to be recognized as a patient with Bipolar Disorder in need of treatment. When Dr. Maria and Joana met, the diagnosis and the severity of her outbreaks were already an established part of her medical history. But prior to being considered symptoms of Bipolar Disorder, the symptoms had fallen through the cracks of the health care system. The symptoms had not yet manifested themselves sufficiently in ways that aligned with Bipolar Disease. They did not seem distinct enough to be grasped by a medical gaze. Such occurred perhaps due to a lack of knowledge, interest or time on the part of the family doctor or the neurologist who had dismissed her symptoms as the fancies of a "spoiled girl". Throughout the process of diagnosis, this patient, like the other ones interviewed, had experienced stigmatizing episodes both inside and outside the health care system in different ways.

The sociologist Erving Goffman describes the term stigma as being used "to refer to an attribute that is deeply discrediting" (Goffman 1963, 3) and that has to be considered in relation to the context rather than as the attribute itself being the stigmatizing element. In Joana's case, her complaints were stigmatized relative to her presumed laziness (when being told that she did not want to work for university) or to her supposed dramatizing her situation by blowing it out of proportion (when being called a "spoiled little girl" during the doctor's visit with her parents). In his book *Stigma: Notes on the Management of Spoiled Identity*, Goffman initially introduces concepts of society before approaching a definition of the term stigma. He states: "Society establishes the means of categorizing persons and the complement of attributes felt to be ordinary and natural for members of each of these categories" (Goffman 1963, 2). The word stigma has a Greek origin and means *brand*, referring to the physical branding that was done (in ancient Greece) to a person to "expose something unusual and bad about the moral status of the signifier" (Goffman 1963, 1). Two things matter in this context: All of the interviewed patients experience mental illness, something that unfortunately still carries great stigma in society. Bipolar Disorder, for instance, is not generally visible at first sight when first meeting a person. It does, however, "brand" the people afflicted with this disorder in a different way, due to e.g., deviant behavior, sick days or absenteeism at the workplace, not holding steady relationships throughout their lives, etc. (These are all attributes with which the patients described themselves during the interviews or were descriptive terms that had been applied to them by their psychiatrists.) However, before being diagnosed with a mental disorder – and possibly being stigmatized for it – patients have to have certain attributes that allow them to be part of that category and that are "felt to be ordinary and natural" for the people in this category as described by Goffman (see above). The interviews revealed that the stigma did not begin with the label of the diagnosis but that different kinds of stigma prevented the correct categorization of the complaints presented by the patients. For instance, three patients were not assessed further after having been diagnosed with substance abuse or alcoholism. These patients were usually advised to stop consuming or drinking in order for their problems (symptoms) to stop. The following cases present another way in which a heterogenous appearance of symptoms associated with Bipolar Disorder can disturb the clear vision that is deemed necessary to facilitate a diagnosis. Emanuel (Interview 1.3), a patient, shared his story as follows:

> "The doctor who treated me in the very beginning, she exaggerated, I think due to some consumption of hashish that was never very big, but it was daily, because it was what I did with my brother[...]. This doctor, I think she saw this as a huge problem, maybe due to her age, [...] and treated me like a drug addict. […] She was a psychiatrist and she medicated me for six months, until I was able to get out of there[6]. I remember taking so many medications until I weighed a hundred and something kilos. I remember the first exam I took at university, I had studied all the material, but I couldn't write. My head was empty from the medication. I was 21 years old! I wasn't a drug addict!"

Another patient, Francisco (Interview 1.2), who was treated for alcoholism for 20 years before having an episode of manic decompensation, told me a similar story, as did a third one, Pedro (Interview 1.4), who felt like he was stuck in a "drawer" for addicts due to his consumption of cannabis.

All three patients were first diagnosed with Bipolar Disorder when they were hospitalized for several weeks due to manic decompensation. When sharing their story retrospectively at a later point, during the interview, after having been treated for several weeks with adequate medications, they described their consumption of cannabis or alcohol as a necessary substance for social interaction, for managing their emotional helplessness, or to compensate for similar conditions. They report multiple visits to doctor's offices throughout the years. Each offer stories about these visits in which they describe not being properly listened to as soon as their diagnosis "substance abuse" appeared on an old

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[6] Out of the ambulatory treatment, he was not hospitalized during this period.

record or surfaced in their file. Of course, there is, generally speaking, an overlap of symptoms between addiction and other mental disorders. Such makes it often difficult to distinguish between cause and effect. Evidence of addiction or substance abuse may itself be a diagnosis as well as a symptom of another condition, generally referred to as comorbidity. It takes great effort and is sometimes nearly impossible to decipher symptoms such as sadness, loss of joy, insomnia, mania, etc. and to distinguish them from regular or excessive consumption of alcohol or other substances. I would like to emphasize here that it is not my intention to judge the doctors who misdiagnosed the patients as I am neither qualified to make the diagnosis nor was I present at the time to evaluate how possible symptoms of Bipolar Disorder were presented or even detectable. I was nevertheless struck by what appeared to be the sheer impossibility of re-evaluating an existing diagnosis over time, or to thoroughly questioning whether smoking cannabis equals substance abuse in ways that would disqualify and prevent the "making" of different diagnoses subsequently. It may not have been obvious at the time that patients were suffering from Bipolar Disorder (in two of them the diagnosis was still being questioned at the time of the interview). Therefore, the complexity of taking a patient seriously without jumping to preliminary conclusions is not to be underestimated. Especially when a number of factors (e.g., altered behavior due to regular substance consumption or having more than one mental disorder) appear to be "contaminating" the clear vision a diagnostician would need. The necessity to produce a clear diagnosis may be one of the reasons that misleads physicians. According to Arthur Kleinman, as mentioned in the introduction, biomedicine "presses the practitioner to construct disease […] as the object of study and treatment" and that there is little space in the "narrowly focused therapeutic vision for the patient's experience of suffering" (Kleinman 1997, 31). This, according to Kleinman, leads the practitioner of biomedicine to "discount the moral reality of suffering" (Kleinman 1997, 32) and to discredit it. This applies in different situations and not only to misdiagnosis. In this case, however, the oversight and misrecognition of Bipolar Disorder, a severe form of chronic mental illness, can for one part be attributed to the absence of symptoms, which would be the easiest answer. Nonetheless, it seems that giving a diagnosis based on superficial observation is a course of action that is often expected from a "practitioner of biomedicine". Such is frequently seen as more feasible in everyday practice than questioning and reversing a preliminary judgement call, expressing doubt, or simply hearing more details of a patient's history.

Kleinman writes: “The doctor is expected to decode the untrustworthy story of illness as experience for the evidence of that which is considered authentic, disease as biological pathology. In the process, the doctor is taught to regard experience – at least the experience of the sick person – as fugitive” (Kleinman 1997, 32).

Going back to the aspect of stigma: When I asked Dr. Maria during the interview whether she considers the moment of diagnosis as helpful or rather stigmatizing, she answers that the disease itself, the condition, not only the diagnosis, has a very negative impact on people’s lives, that can isolate them as well as stigmatize them. She elaborates the consequences and their stigmatizing effect:

> Dr. Maria: “[…] and so if we think about a person who works, the person will be absent from work for at least 3 or 4 months. For the treatment, the recovery. […] It highly disturbs the professional life. Because when they start any of the phases [mania or depression], people, colleagues, will see that they have a problem. And then the stigma begins. When they are in the hospital and then return to work, they are a person who has been hospitalized in psychiatry. This is very bad [and] I feel their discomfort. It’s a disease, like any other disease, they have to take medication, sometimes we have this discourse of diabetes, the diabetic has to take medication as well. We want as much as possible that the patient perceives and understands their illness as any other illness, it needs treatment because they have episodes that disturb work and, in fact, their families as well. Normally these are people who have... many relationships... but sometimes not very long-lasting...it’s not... if the disease is not controlled, probably they also have an instability at the affective level.”

The absence of functioning normally in professional life and the “visibility” of the disease have a negative effect because people are stigmatized for that. Hence, it is never just a disease, it is a malfunction of the entire person in his or her social environment, which causes stigmatization to be much more common in psychiatric diseases than in other medical conditions (Hinshaw and Stier 2008). Also, the stigma is explained relative to work, which functions as an indicator of a presumed stability in life, a continuity that is disturbed by Bipolar Disorder’s “extremes”. Work seems to be a strong indicator of normality, which is also consistent with a study conducted by psychiatrists and anthropologists on the personal and societal construction of illness in Bipolar Disorder (Sajatovic et al. 2008). In this study, numerous patients interviewed mention the lack of a stable, consistent professional life as one of the main, most visible disturbances in life and refer to it as a consequence of their suffering from Bipolar Disorder, one of them stating that “Having a profession is so associated with having a life” (Sajatovic et al. 2008, 721).

Another important information implied by Dr. Maria’s words is the fact that the diagnosis itself does not necessarily carry the stigma. It is also the symptoms, the fact that other people will notice an “abnormality” in behavior. It therefore makes sense that the diagnosis is also considered a great relief. This was another common finding throughout all interviews. It means that what people have been experiencing becomes associated with a name, they are taken seriously, and they may receive help. For instance: Pedro (Interview 1.4), whose diagnosis was substance abuse for many years, told me:

> “After the hospitalization I calmed down more. And from then on, I started to have a more stable life. […] Until then it was all based on assumptions. [...] In an attempt to experiment, but without certainty of the problem that was being treated.”

In similar ways, all patients described this shared experience. Psychiatrist Dr. Mafalda (Interview 2.4) also emphasizes the aspect of relief associated with a diagnosis and the need for transparency towards the patients:

> HK: “Do you think the process of diagnosing and naming is a relief to the patient? Does it help to objectify the situation?” – Dr. Mafalda: “I think it does. And I’ve had patients, for example, with personality disorders, who we are always very afraid to diagnose because the name itself is very... unpleasant... it has a very stigmatizing component. And it’s easily noticeable that the person thinks that we’re saying that the person is disturbed. But I think when we tell them [their diagnosis] and we relate their symptoms to the diagnosis, people sometimes look at you and say: “Man, that’s it! And my whole life I’ve been thinking that I was the only person in the world, and it turns out to be something that’s been described!” I think sometimes people feel some relief in realizing what it is that they have. So, I try not to keep diagnoses to myself. When we have them, we should share them with the patient.”

This shows the significance of giving and communicating a diagnosis in clear and transparent ways. Having a name for what has been experienced subjectively is a relief. It is part of the initiation of adequate treatment – sometimes adequate treatment can also be part of the diagnosing process – that also offers relief in the consequence. The moment of diagnosis carries more weight than the subsequent treatment. It appears to enable people to feel that they were not lying, after all, that they were “right” all along. The reference to a diagnosis being a condition described elsewhere, something that “exists” e.g. in scientific literature, something the psychiatrists recognize, means that people feel less alone with it. Although mental disorders can still be, and often are, a heavy burden even after the correct diagnosis has been made, the moment of naming it releases some of the tension. The feeling of being secluded from “the others” is alleviated, because the feeling of “abnormality” being recognized as a condition in the shape of a diagnosis means that there are “other” people with it as well. In that moment, the very human desire for categorizing and naming things, in order to understand them, materializes. It seems as though historian Hannah Decker, introduced in chapter two, identifies this importance when she states that classification, thus, organizing and naming what surrounds us, “is a necessary endeavor that human beings automatically carry out from early infancy on in order to comprehend the world they live in” (Decker 2013, 129).

How the Disease is Being Communicated to Patients – and vice-versa

Departing from the discussion above of how the process of diagnosis of Bipolar Disorder unfolds itself, this section shifts focus to the narrative of Bipolar Disorder and how it is being approached by psychiatrists and patients. The way an illness narrative is being transformed into a disease, and how the disease is communicated to the patient has a great effect on the course of the disease. For instance, it might determine whether patients will adhere to medication or what impact it has on their lives. Such communication takes place in two directions as the perspective of the clinician and observer is confronted with the perspective of the patient, who experiences the symptoms. As they encounter each other and try to find a common and objective language, they draw from different experiences and points of reference involving cultural, biological, and physiological factors. Anthropologist Byron J. Good states:

> „[…] medicine formulates sickness from a materialist and individualizing perspective. Disease is resident in the individual body, and the goal of treatment is to understand surface phenomena with reference to a deeper ontological order, to link symptoms and signs to physiological structure or functioning and to intervene at that level. Disease has a natural course; the story of the disease is one without a personalized agent. The narrative and phenomenological structure of

> illness experience, and the person who is agent of suffering, are relevant to routine clinical practices only insofar as they reveal the pathophysiological order, enabling the physician to formulate and document the case as a medical project. The clinical narrative [...] most often conceive[s] the patient as person and actor only so far as patients are seen as morally responsible for their diseases – the despised alcoholic's esophageal bleed – or as willing agents in conforming to recommended treatments." (B. Good 1993, 83)

This quotation insinuates the different levels of communication that come into play the clinical narrative. A good example for talking about disease in a medical context are the hospital's morning rounds in which the patient is referred to as the "agent" of "illness experience". The patients talk about their emotional state, their problems, their biography which constitute the surfacing symptoms – the "phenomenological structure" of what is to be called disease. This has in part already been shown by the quotations of patients interviewed above. The psychiatrists, then, will combine these symptoms and translate them into a disease. They translate them into their own language as well as into what Kleinman calls "culturally meaningful" syndrome, towards the patient. Dr. Maria describes this process, the psychiatrist's work, as follows:

> Dr. Maria: "What is most important is a thorough assessment of the patient. This involves a lot of careful interviewing [*entrevista cuidada*] of the psychiatrist for the diagnosis. Sometimes the symptomatic picture doesn't appear that way to the patient, it's not in the book, so we have to understand the psychopathology. To do this translation."

She describes psychiatric practice as a translation of a patient's symptoms into a diagnosis and treatment, respectively. Especially in psychiatry, language has great significance, as it is the main arena in which symptoms manifest themselves and diagnoses are made. When asked how she explained the disease to the patients, she answers:

> Dr. Maria: "I explain it exactly how it is. I explain how it [the disease] behaves, how to prevent relapses and that there is no cure. I really just display how it is, I emphasize the need to take the medication, and generally focus on the psycho-education.[7]"

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[7] Psycho-Education is a concept that is part of treatment. Its intention it to educate a patient and their relatives about their disease, approaching issues like communication or the prevention of possible

In her explanation, I noted the absence of mentioning or relating to the patient's emotional state, which I assumed to be intentional. She refers to the disease as having its own behavior, one that is detached from the "personalized agent", that is, according to Good, the patient. The non-verbalization of a patient's suffering was coherent throughout all the interviews conducted with the psychiatrists. It was never verbalized directly towards me. It seemed that the language used was intended to name arguments that a complaint objectively qualifies as a symptom. Another similarity I observed throughout the interviews was the comparison of Bipolar Disorder to diabetes, something already touched above, when Dr. Maria refers to Bipolar Disorder as a disease like any other, for instance, diabetes. Almost all psychiatrists used diabetes as an example of a disease easily relatable and being fairly common. One of the psychiatrists, Dr. Marta (Interview 2.2) put it like this: "There is no blame in diabetes, just like there is no blame in Bipolar Disorder!" In evoking the comparison with diabetes – a lifelong condition characterized by the lack of insulin that the people have to substitute or treat with other types of medication – psychiatrists try to relieve the stigma from patients, to locate it in their body as a dysfunction and that they should not feel responsibility for or be ashamed of. Patients could relate to this, as they told me, and felt relief for being informed about the chemical imbalance in their brain and underlying the genetic causes for Bipolar Disorder. It was, after all, their brain that was responsible for everything. Ian Hacking refers to this as biologization, a "thrust of human kinds towards the biological" (Hacking 1995, 372). Biological in this context may refer to "biochemical, neurological, electrical or whatever is the preferred model of efficient causation in a given scientific community or era" (Hacking 1995, 372). Dr. Marta (interview 2.2) gave the following explanation:

> Dr. Marta: "The example I always give is that of diabetes, i.e. you already had the genetics for Bipolar Disorder, it only expressed itself now at the age of 20-25, but you would have the disease anyway, and it is true that Bipolar Disorder is caused by a combination of genetics and external precipitants."

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triggering factors and is thus a helpful tool in the prevention of relapses, aggravation of symptoms and creating a more understanding environment for the disease.

She speaks of a “chemico-cerebral disbalance” that has to be combatted with medication and that, unfortunately, “we still don’t have diagnostic biomarkers in Bipolar Disorder, we are sometimes just looking a little bit at the psychopathology, looking at the symptoms… but cannot draw blood and measure a biomarker yet…”

When looking at the current state of scientific literature on Bipolar Disorder and its causes, it seems to be common ground that it does not have a single etiology but is a multi-factorial disease. Biological factors such as structural changes in the brain and genetic components are strongly assumed, but environmental factors that trigger the disease are also suggested (for reference, see Carvalho, Firth, and Vieta 2020; Ghoryani et al. 2019; Mayo Clinic 2021; National Institute of Mental Health 2021). Such references to an underlying biological cause surfaced frequently during the interviews, a point stressed more often by the psychiatrists but communicated by the patients as well. Such references seem to be connected to various aspects: For one part, there is the question of insecurity and uncertainty of the diagnosis. The long time it might take to diagnose Bipolar Disorder as some of the patients’ stories have already shown could be avoided if functional MRIs[8] were able to show an altered metabolism that proved Bipolar Disorder, many psychiatrists hope. The future prospect of a biomarker or imaging techniques that accelerate the diagnostic process and eliminate doubt is tempting. This temptation has been described by Ian Hacking as the “built-in metaphysical motivation” (Hacking 1995, 353) when looking for the biological cause that can account for everything. I believe this aspect of this motivation is also connected to the other facets that are figured prominently in the communication about Bipolar Disorder during the interviews: responsibility, guilt, and shame. Previously, the statement about the absurdity of blaming a diabetic for his or her condition – which nevertheless happens occasionally – had been applied to Bipolar

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[8] MRI stands for Magnetic Resonance Imaging, an imaging technique that is mainly used to create images of soft tissues in the body, e.g., the brain. It is so far the most precise way to obtain images of the brain, depending of what one is looking for. Functional MRIs measure brain activity (e.g. blood-oxygen levels) usually in specific parts of the brain and make them visible them in the MRI, producing colorful pictures of where the brain activity is the highest at a given moment, filling “a previously vacant niche in the educational armamentarium of students and professors of cognitive neuroscience” (Singleton 2009)

Disorder as well, emphasizing the pointlessness of feeling guilty for one's diagnosis of Bipolar Disorder. Here, I want to recall the patient who stated that she had never lied about her symptoms, a fact that indirectly points to her possibly having been accused of such. It also evokes the patients who had been stigmatized for their substance abuse. These scenarios foreground the question of responsibility. In the almost metaphoric description of future biomarkers, a desire for separating the disease from a person becomes apparent. Again, it seems adequate to refer to Ian Hacking's words:

> „Of course, biology is not a foolproof excuse; Susan Sonntag has written about how people are made to feel as morally involved in their cancers as others once were in their tuberculosis. […] However, by and large, biology is exculpating. […] In this [biological] view the alcoholic has a disease for which he is not responsible, and is required to follow a regimen chiefly in the way in which someone with high blood pressure follows a regimen. The scientific (biological) knowledge about alcoholics produces a different kind of person.“ (Hacking 1995, 373)

The way in which a disease is communicated to a patient has a great effect on how the person with that disease will be looked at and treated by family and friends. It will also affect the way they feel about themselves. It further explains the relief people feel when learning about their diagnosis so as to assume a malfunction located in their bodies. This constitutes a different framework of mental disorders, one that is being reorganized by technological advances like deciphering DNA for instance. Such allows to steer away from moral judgements about people with behavioral or emotional disorders as was very prominent the case in the 18th and 19th century (and before that, but then in a non-institutionalized way), when mentally ill people were considered morally corrupt or tainted rather than sick. When conceived in relation to nature, "[d]isease breaks away from the metaphysics of evil, to which it had been related for centuries" (Foucault 2003, 197). This is, of course, still an issue today, although in a different shape and scale. In this sense, this naturalization and, thus, kind of reorganization carries great benefits, however, it can also cause the previously discussed dehumanization of medicine and the patient may be deprived of being a subject.

I noticed yet another layer of communication during the interviews when one of the psychiatrists referred to a diagnosis as a "working hypothesis", hence, relativizing the significance of the diagnosis for treatment and the interaction with the patient. Dr.

Mafalda (Interview 2.4), for instance, told me when asked about the significance of communicating the diagnosis:

> Dr. Mafalda: "At the beginning I thought things were the way they were and diagnoses were like that, only one way. Nowadays sometimes I worry less about the diagnosis and more about the symptoms that the patient has. For the symptomatic relief of the patient and for his recovery I think sometimes it is more important to focus on what the patient presents, because things don't always fall right in the box we are looking for and it makes things more difficult."

She made it clear to her patient that her main goal was to make him feel better. If one medication did not work, they would switch to different ones. Close interviews with patients would lay the ground for deciding how to proceed with treatment. Several psychiatrists reiterated this. Some of the patients also made an effort to let me know that their psychiatrists would change the frequency of their appointments, if necessary, adapt medication or be available over the phone. In spite of contradicting experiences shared by all interview partners, it seemed, that in the end, personalized communication on an individual level was given high priority.

How is all this shaped by the institutional setting?

As mentioned before, the interviews were conducted in the Department of Psychiatry of the Coimbra University Hospital, a present-day health care institution affiliated with the University of Coimbra, therefore also a teaching hospital. To gain access, various barriers had to be overcome, some already described in the methodological chapter, e.g., entering the hospital during the pandemic, obtaining authorization from the psychiatry's head of department and subsequently the ethics committee to conduct interviews within the hospital, and contacting possible volunteers to ask them for cooperation in my field work. These steps are part of the methods used, but they also become part of the analysis as well, as all of these steps are shaped by an institution's character and, in turn, shape the situation in which the interview is conducted. Everyone in the interviews had to overcome certain barriers in order to sit in the room of the interview, a doctor's office. I could only be there because this field work was happening in the framework of a master's thesis, thus benefitting from the oversight of a different institutional framework, i.e. an educational setting abiding by certain scientific standards that were shared – to a great extent – by the hospital's scientific standards. After having established the context of my field work, I followed the rules and declared my intentions to the ethics board, an established institution inside the hospital, overseeing all research that happens inside or is affiliated with the hospital. The ethics board considered my research to be ethical and granted permission.

The psychiatrists I subsequently interviewed had all attended medical school and passed an exam to enter residency in psychiatry. In the process, they acquired knowledge, passed exams, became physicians, registered with the Portuguese Medical Board (in Portugal: *Ordem dos Médicos*)[9] and were socialized in the context of medicine along every step of the way. This process and its effect of shaping medicine through shaping the professionals in it is referenced in Good's work on several occasions, very prominently when he describes attending medical school as a "process of coming to inhabit a new world" (B. Good 1993, 72), as mentioned in the introduction. The "new world" is shaped by the education the people (medical students) receive to get there and is subsequently reshaped and constituted by their practice that adheres to the institution's *paradigms*. One of the psychiatrists referred to the hospital as being a "home" (*"é casa"*) to them, a place where they studied and then practiced for all of their "medical life", where they had been taught and grown to be a psychiatrist, therefore constituting a professional "home".

The patients' journey into the institutionalized setting was already described above. Although they may not have had to undergo medical school training and pass exams,

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[9] A country's Medical Board or Medical Association is an institution of professional self-administration overseeing all practicing physicians. After graduating from medical school, one has to be registered there and pay a yearly contribution or fee. The Medical Board is thus in control of who is allowed to practice medicine and has the authority to exclude physicians for medical malpractice or other abuse of their position. Medical Boards were formed in the 19th century and exist in most countries today. With the previously mentioned foundation of the British Medical Association in 1856, for instance, the UK was one of the first countries to introduce obligatory registration for physicians (Forty, 1980, pp. 80-81). This constituted an instrument of control as well as one of power, as from then on, the monopoly of medical knowledge and practice was restricted to the board-registered physicians. This is a common structure among other professions as well, e.g., lawyers, architects, or craftsmen, who hold high social status.

patients also had to overcome obstacles and meet certain criteria, as discussed in chapter two, to have regular appointments in a doctor's office during the course of their treatment for Bipolar Disorder.[10]

Various aspects of the institutional setting became apparent during the interviews. Probably the most prominent one was the handling of the disease catalogue DSM or ICD as introduced in the second chapter. The disease catalogues shape the psychiatrist's perception to what is considered a disease and the subsequent course of treatment insofar as that they serve as a (diagnostic, clinical or legal) reference that is implicit in all interviews with the psychiatrists. When asked about her opinion and attitude towards the disease catalogues, Dr. Mafalda (Interview 2.4) describes her approach to the DSM as follows:

> HK: "How do you use the diagnostic criteria to for the diagnosis?" – Dr. Mafalda: "When it's obvious, I don't look them up. But if there are things on the edge... I usually look at [the disease catalogue] and make sure that everything is there. But even when I don't look it up, every diagnosis is based on them." – HK: "What is your opinion on them?" – Dr. Mafalda: "I think right now, this is what we have. And for clinical practice it's going to be very difficult to get out of here, because it's very simple, you have people in boxes and they stay there. I think that from the point of view of understanding the disease, it's not what makes the most sense. […] There are many people who vary from one diagnosis to another throughout their lives, not only because they vary from one doctor to another, because this is very subjective, unfortunately, but also because there are alterations and it's much more dynamic than we initially think, it's not that categorical. But I think that for clinical practice it's going to be difficult to get out of here."

She describes the disease categories as something very present in clinical practice, although not necessarily being the best solution. Her statement "right now, this is what we have" was similar to what almost all psychiatrists said. No one thought the disease

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[10] Another threshold to be passed in order to receive treatment in a health care facility is usually to be registered in a country's health care system, as it defines who is eligible for health care. Statehood, a recognized residency status or professional affiliation with the health care system are crucial and differ depending on a country's legal and health care system. This aspect is not being discussed in this thesis, however, it is of great importance in the question of who can receive adequate and institutionalized health care and should therefore not remain unmentioned.

categories were representative of reality nor the most reasonable way to differentiate the complexity of mental disorders. All of them agreed, however, on the disease catalogue being “the best so far” in its practical application, yet, giving enough room for the psychiatrist’s individual assessment of a patient’s state. It seemed to be an important guideline for treatment and a helpful orientation. This changed, according to the psychiatrists interviewed, during their years of professional practice. Dr. Maria (Interview 1.1), a psychiatrist for about 25 years, stated: “When we leave medical school, we leave with a lot of baggage. But things are more complicated than they are in the books.” This sentence is a very sincere statement after decades of practice and professional experience, where one has learned to differentiate between the knowledge internalized in medical school and the medical practice, in which that knowledge is applied and adjusted due to the fact that reality is more multifaceted than textbooks could ever account for. The younger psychiatrists did not exactly phrase it like that, but their critical distance towards the disease categories showed a differentiated understanding of their benefits as well as their limitations. For instance, Dr. Catarina (Interview 2.5) expressed her attitude in the following way: “I don’t like to get stuck on what the classifications tell us, and I don’t see diseases, I see patients. […] naturally, for me it’s important to have a diagnosis […] but I also have this flexibility to adapt myself to what the needs of his therapeutic approach may be.” In her patient’s case, Emanuel (Interview 1.3), it was particularly difficult to find a diagnosis due to a symptom overlap with schizophrenia, substance abuse and a complicated biography of psychiatric treatment with varying diagnoses and medications.

Benefits named were the ability to communicate according to the standards of the disease catalogue among health care professionals – in chapter two referred to as inter-reliability – and to have the treatment guidelines that they can resort to but that also hold them accountable for their actions. The latter is another important aspect to take into account. Dr. Maria pointed this out when she affirmed that psychiatrists also have to be able to justify their diagnoses to other health care professionals, to the patients, for doing research, and sometimes in front of a court (see her quotation below). The necessity of being able to substantiate a diagnosis and subsequent treatment can be seen as factor that serves the patient’s protection and prevents medical malpractice, as it creates a certain degree of transparency in medical practice. It may also be considered expression of a "bureaucratic rationality" that is subjected to economic and political priorities that constitute a regulatory element in the postmodern state, according to Kleinman (1997, 38–40) and, in a wider frame, Foucault, who describes a connection between social control and bureaucratic regulatory mechanisms that are politically legitimated[11].

The psychiatrists agreed that it was useful and necessary to have guidelines for diagnosis and treatment, particularly in a discipline like psychiatry that was already based on assumptions drawn from subjective statements – even if it was not the best possible system. Dr. Maria's words reflect this ambivalence very well:

> Dr. Maria: "[the disease catalogue] has its defects, but we don't have a better one. In psychiatry, which is already so subjective, there has to be something to give us a basis. Of course, from that point on we are free. We can escape the criteria. But this comes from the beginning of the DSM, the criteria for diagnosis, for example in matters of the court, have to be well justified, the diagnosis well discussed. It is very important to have a classification – God help us if we didn't – of course it's not the best, it never is. But it is also dynamic. But we also have to justify a diagnosis."

Being able to justify a diagnosis includes possibly being held accountable for one's actions. This can have a positive effect on the patients because it carries the potential to protect them from arbitrary or careless treatment. It also carries the potential for an overly narrow-minded observation, a medical gaze trained to see specific criteria that is unable to grasp symptoms if they do not sufficiently match the criteria required for a diagnosis.

One case that stood out from the other cases was José (Interview 1.5), an elderly man who had served in "the war" (referring to one of the wars in the former Portuguese colonies) and whose condition had begun shortly thereafter. He had returned to Portugal as a war veteran in his early 20s and suffered from Post-Traumatic Stress Disorder that, according to his medical record, in later years transformed into Bipolar Disorder. At the time of his first appointments with a psychiatrist, in the mid-70s, neither Bipolar Disorder nor post-traumatic stress disorder existed as diagnoses. Nonetheless, he was suffering and

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[11] Bureaucracy is a recurring motive in many of Foucault's writing. For reference in this context see (Foucault 1978)

unable to work. He and his wife, who was present during the interview, draw the picture of a desperate situation. His wife states:

> “He, poor thing, ... began to feel like he was losing everything and we went from doctor to doctor and they didn’t give [his symptoms] much value. Until one doctor here in Coimbra, a psychiatrist named [she emphasizes the name of the psychiatrist, her husband repeats the name as well as if to agree] he listened to him. And it was because of him that he could retire because until then he was at home and not earning anything!”

José’s wife describes how having been diagnosed marked a new chapter for them and how existentially threatening it was to not have a diagnosis. Similarly, in court, a recognized diagnosis is key for somebody to gain access to the social security system. In the case of above patient that meant being able to retire and receive a pension. His case exemplifies the ways in which the health care system is closely tied to society’s other social or legal institutions and how the diagnosis is the mean and prerequisite for communication between those institutions. Arthur Kleinman also describes this when characterizing biomedicine’s distinctive properties as introduced in chapter one. He states that many of the structures inherent to biomedicine that ought to be followed (e.g. following certain standards such as labeling a set of symptoms with a diagnosis in order for a patient to find recognition in the health care system) is not only characteristic to biomedicine, but to other institutions in modern societies as well, i.e. “[…] the sources of these qualities are societal rather than strictly medical. […] In this sense, biomedicine is, like other forms of medicine, both the social historical child of a particular world with its shape of experience and an institution that has developed its own unique form and trajectory” (Kleinman 1997, 40).

According to Foucault, power is omnipresent, it is “produced at every moment, in every point, or rather in every relation from one point to another” and it is everywhere because “it comes from everywhere” (Foucault 1978, 93). Although the hospital and the health care system in general are not unique in this sense, the hospital is one of the institutions in which this becomes very palpable, as parts of this analysis have shown. Patients have to submit themselves to the institution’s regulations in order to receive treatment. This becomes apparent in different ways, for instance in the delegitimization of complaints that the patients received when not being considered sick enough to “deserve” treatment, thus being deprived of it for what in some cases turned into several years without adequate treatment. It is defined by the institution under which conditions one receives health care. The power relations also become apparent when the psychiatrists describe how they are very conscient that the diagnostic categories "are guidelines, above all, [they are] not a bible, [they are] not an absolute truth […] and often, there are patients who do not fit into any of these drawers" (Dr. Luísa, Interview 2.3) – but they do have to justify their diagnoses and their treatment nonetheless due to the structures they are embedded in. Although Foucault's concept of power is very broadly formulated, it is important for this context as the power referred to is expressed in the relations between the different elements of a given situation that affects all of the elements in it, in different ways. The psychiatrists, here, are a subject of power in relation to the patients due to a disbalance of knowledge, sovereignty of interpretation of symptoms, etc. At the same time, they are subjected to the power of institutionalized structures, e.g. diagnostic categories, taught in medical school and demanded for by legal, social or political institutions, thus maintaining significant influence on shaping (their) biomedical practice.

It was consistent throughout all interviews with the psychiatrists that they considered the criteria for diagnosing Bipolar Disorder as a help and not as a law. However, I found that the more professional experience a psychiatrist had, the longer he had been out of medical school, the more independent and critical they were of the criteria for Bipolar Disorder. This is in line with Good's description of the influence medical school has on individuals as observed in his field work mentioned above. He, too, found that the strict adherence to or search for textbook cases applies stronger in medical students than it does in experienced physicians. He further states:

> "The elemental practices of clinical work absorb the attention of the student, who must learn the simplest procedures, forms of reasoning, and ways of speaking and acting, while these quickly fade into the background for the skilled clinician, allowing for a different kind of attending - at least ideally - to the person who is ill. [O]ur research [shows] how medical students learn lays bare those elemental practices and shows them to provide the skeleton of medical activity and medical knowledge." (B. Good 1993, 83–84)

None of the psychiatrists interviewed used the image of a skeleton, but that is what they meant when referring to the disease catalogue as a "help", "guiding principles", or "basic structure" from where to come to own conclusions based on detailed evaluation of a patient's complaints.

Diagnosing patients can, then, be a result of both things: Of being embedded in and subjected to relations of power expressed in the regulatory elements of the various institutions where often only one seems visible (the biomedical standard) and a reflection and relativization of these relations that lead to more independence and space for inter-individual exchange and decisions.

Considerable Aspects not included in the analysis

There were many more aspects that came up throughout the interviews and that would also be interesting to discuss. Despite that, I decided not to include them in the analysis for various reasons: Some were only mentioned by one or two people interviewed, thus making it difficult for me to make statements about them as they would be based on only little representation in the field work's findings and my assumptions drawn from them. Others I did not include for reasons of capacity, as the abundance of topics that could be discussed further would exceed the capacity of this thesis, or because they were not directly related to the core issues discussed in this thesis. I do not, however, want to leave them without mentioning.

One interesting point raised by the psychiatrist Dr. Marta (Interview 2.2) was what she called "literacy of mental health". She suggested that a better literacy of mental health, meaning a more competent way of "reading" mental health and being aware of problems that could indicate a mental disorder, would improve many things. It would reduce stigma and encourage people to seek professional help sooner because they would recognize symptoms in themselves or in family members earlier and feel less shame or guilt for them, which could reduce a diagnostic delay. It could also be helpful if family doctors or general practicians were trained more carefully in mental health issues, as they share great responsibility in recognizing symptoms and transferring patients to psychiatrists. As some of the cases presented have shown, the symptoms are often misread or failed to be taken seriously and one of the reasons may be lack of specific knowledge.

Another aspect that was interesting was the potential of support groups as foundation for integrating Bipolar Disease into one's life and talking to other people affected by it. Only two patients had at one point in their life participated in support groups and there were a lot of logistic hinderances (e.g. very few groups existed and only in Coimbra, in the evening, making it difficult for people living in the periphery or countryside to reach them with public transport). There are studies who focused more specifically on the potential of patient support groups for people diagnosed with Bipolar Disease and generally found them to be very beneficial for the patients' stability and well-being (for instance, see Sajatovic et al. 2008).

Conclusion

This thesis investigated the interactions and unfolding tensions between institutionalized patterns of mental health care and the experience of stigma and relief in Bipolar Disorder in the context of a present-day psychiatric facility. Based on the assumption that biomedicine is not only a scientific practice but also a sociocultural one, the history and social context of diagnostic category Bipolar Disorder and its way of being inserted in medical teaching were juxtaposed with the experiences of patients with Bipolar Disorder and their psychiatrists during the diagnostic process. The diagnosis represents a crucial moment for the course of a disease as well as the intersection of a dialogue between the patients' *illness* experience and the psychiatrists observation of *disease*, two concepts established in the respective literature of Medical Anthropology. It constitutes the moment – that is the result of a process – where the two perspectives come together and shape what is then called a *disease* through an institutionalized 'medical gaze'.

To explore the abundant nuances of the experience regarding institutionalized health care, ethnographic field work was conducted in the form of semi-structured interviews organized in case studies with patients diagnosed with Bipolar Disorder and their treating psychiatrists in the Coimbra University Hospital. The subsequent qualitative analysis was focused on three core questions elaborated during the process of this thesis: How does the process of diagnosis affect the course of disease and people diagnosed with it? How is the diagnosis communicated and what do the narratives used insinuate? And how is all this shaped by the institutional setting, referring to the location as well as the institutionalized knowledge and procedure?

Without any motive to evaluate diagnostic criteria and treatment for Bipolar Disorder or the biomedical realities from a scientifically medical point of view, the thesis' investigation was focused on the sociocultural aspects of biomedicine in psychiatry as a cultural practice from an observer's perspective not involved in the treatment.

The analysis of the interviews conducted showed that the very present desire for a "clear" diagnosis was confronted with the complexity of individual realities of *illness* experience which in many cases led to a significant delay in the appropriate diagnosis. In almost all of the cases observed, the symptoms had initially not been severe enough to pass as what was perceived as a threshold *into* a diagnosis or was misinterpreted until a clinical decompensation happened, usually due to mania, leading to hospitalization as the precipitant of the diagnosis Bipolar Disorder. This was due to the fact that patients had either not seen a specialist sensitive enough to the complaints they presented or to a symptom overlap with other diagnoses, e.g. substance abuse and/or addiction.

When exploring the aspect of stigma, it became obvious that stigma was experienced not only in relation to the diagnosis, but also beforehand. It happened inside and outside the health care system. For one part, people were stigmatized by the doctors they went to see before having a diagnosis and their complaints were discredited as laziness, exaggeration or substance abuse, thus, not recognized as symptoms of Bipolar Disorder. Simultaneously, patients experienced a feeling of "abnormality" and inability to feel well throughout the years preceding their diagnosis, generally expressed in the relation to family, friends and their work environment. These findings showed that stigma does not begin with a diagnosis, although it can contribute to the experience of stigma, but that it happens before, due to behavior perceived as deviant. A continuous workplace was considered an indicator of stability in life, an element contributing to "normality" by both patients and psychiatrists. This was a common parameter with the result of another study investigating the effects of Bipolar Disorder on people's lives.

In the process of diagnosis, the patients as well as the psychiatrists referred to the diagnosis as being relieving. Once the condition they had been experiencing throughout many years was given a name and shaped into a diagnosis, it had a different quality. For one part, they would receive adequate treatment which improved their quality of life. Additionally, a strong component was seen in the labeling of their complaints as a mental disorder described in scientific literature and thus, not being an entirely individual problem. Psychiatrists stated that this was a reason to always communicate the diagnosis transparently, considering the stigmatizing effect smaller in comparison to the effect of relief. It constituted a possibility to feel less alone or secluded, feelings that were described by almost all patients prior to their diagnosis. In the consequence of a diagnosis, their suffering was perceived as legitimate, and they received help in dealing with it through medication and regular appointments with their treating psychiatrists.

Focusing on the communication of the diagnosis and the narratives that shape it, I found that the disease was generally perceived as having a natural course. The psychiatrists would explain the disease “as it is”, by referring to the conceptions of the common explanatory models of current scientific literature, Bipolar Disease being a biological disease with a genetic component, triggered by external factors such as stress and social circumstances.

The perception of the disease and the way it was communicated was crucial to the way patients dealt with it, e.g., adhering to medication prescribed, as well as to the way they would communicate the disease with their social environment, e.g., Bipolar Disorder being a condition they were not to blame for. The psychiatrists considered their work as a translation from a patient’s complaints into symptoms and into a diagnosis, emphasizing consistently the great significance language carried to a practice unfortunately already very subjective. The way the disease model was explained to the patients as a biological disorder located in the patients bodies, in the brain, had the effect of relieving them from guilt and to some degree of shame, as it was communicated as being a part of them, but a separate one. The question of responsibility was a reappearing motive in the interviews and the biological explanation of Bipolar Disorder, thus, separating the disease form the person carrying it, was conceived relieving. I assume that this also explains part of the relief patients and psychiatrists reported in relation to giving or receiving the diagnosis. The biological explanation of the disease was emphasized multiple times through a comparison to other diseases, diabetes being a common point of reference throughout the interviews. This constitutes a reorganization of the framework of mental disorders in comparison to their more distant history, when they were more commonly connected to a metaphysical perception of evil. The moral judgement of a person carrying a mental disorder breaks away when their cause is attributed to genetics, nevertheless, the aspect of stigma is still present in the patients’ experiences. The naturalization of a disease is therefore to be considered beneficial, as it exculpates its carriers from being morally corrupt, however, it can lead to a dehumanizing practice promoted by institutionalized biomedical standards, resulting in no longer considering a patient a subject and treating them as such.

Despite all standardized treatment and disease explanatory models, however, high priority was given to communication and the individual case, e.g., adapting frequency of appointments according to a patient's needs and switching medication if the result was not satisfactory. This was emphasized from both patients and psychiatrists. In conclusion, I observed that despite all regulation and diagnostic templates followed by standardized treatment, all of the interviewed were prioritizing the individual features of a given case to be decisive for how to proceed, within the framework of the institutionalized setting, of course.

It was discussed how everyone, including me, had their affiliations with the institutionalized setting as well as their own barriers for them to be in the situation when the interviews were conducted. One of the main elements in which the institutionalized setting materializes, is the Diagnostical and Statistical Manual of Mental Disorders, the DSM, as it exemplifies the institutionalized education psychiatrists had undergone as well as representing a structure defining standards for daily practice, i.e., the diagnosis and treatment of a given mental disorder. The psychiatrists perceived the DSM as beneficial in regard to facilitating communication among health care professionals through standardized terms or for conducting research. Overall, however, I observed great ambivalence towards the disease catalogue. It served as a helpful guide providing structure in a field of medicine already perceived as unfortunately subjective, but at the same time its limitations were very apparent, and the diagnostic categories perceived as too narrow to truly illustrate the complexity of Bipolar Disorder in this case. The influence the diagnostic criteria had on the psychiatrists' decisions and daily practice were found to be smaller in more experienced physicians.

Ambivalence was also present in my observation that psychiatrists were subjects exercising control, hence, power, in their sovereignty of the interpretation of symptoms leading to a possible diagnosis, as well as being subjected to power themselves, having to act according to institutionalized structures, e.g., justifying a diagnosis to other social or legal institutions if society. This yearn for objectivity of a diagnosis was often complicated by complex individual complaints and biographies.

The field work was conducted in Coimbra, Portugal and has to be interpreted in its cultural context. However, implications highlighted in this work can be extended to other contexts as well, as great parts of Europe and North America and beyond share similar social constructions.

Aspects that surfaced during the interviews but were only briefly discussed in the analysis like the concept of an improved literacy of mental health in the general population as well as within the medical profession as a preventive measure for recognizing symptoms earlier could be investigated in the future, as it seemed to be a promising approach given the results of this thesis. Patient support groups as a resource for dealing with mental health issues also carry great potential for future research. The component of a personal identity and the degree of identifying oneself with a particular diagnosis in order to integrate a chronic mental disorder into life's trajectory, came short in the framework of this thesis but seems to be a crucial issue to create perspectives for people after being diagnosed with Bipolar Disorder.

What came to my mind during the process of this thesis was the German expression *Krankheitsbild*, the image of a disease, an expression commonly used by medical professionals in medical teaching and medical communication. It seems as though the image of a disease, a systematized set of symptoms, an attribute one can be stigmatized for, or a malfunction of the body, rather than the "self", defines the course a disease can take and should therefore be painted carefully and with attention to detail. It has to, however, always remain a mere image, a representation of a subjective experience perceived by a medical gaze.

Regarding biomedical practice, it can be concluded that both the psychiatrists' perspectives of *disease* as well as the patients' *illness* experience are embedded in a sociocultural context, a cultural practice, but in different ways. Reaching true objectivity for the sake of improving health care seems far-fetched, especially in psychiatry. The health care system appears to function as a net, like a net used for fishing: It is a structure supposed to catch anyone falling, in need of support. In this metaphorical image, the net's meshes are the gate keepers of who is caught and who falls through the net. Ideally, the meshes – in the context of the thesis they may be represented by diagnostic categories for Bipolar Disorder – are just big enough to let fall through what is not be caught in the net and become entangled, e.g., lighter mood swings like enthusiasm, sadness or doubt, or personality traits that can have very different individual appearances but do not necessarily have pathological value. At the same time, the net carries the responsibility to catch anyone who is suffering from a mental disorder and will profit from not being left alone to fall.

This thesis has shown the complexity of the diagnostic process in Bipolar Disorder, how it is shaped by historical and sociocultural constructs as well as the difficulty of recognizing clinically apparent symptoms when they are not (yet) what is considered "valid". Institutionalized health care has shown to protect people from suffering as well as to stigmatize and discredit their complaints. Space for critical reflection in medical teaching and medical practice, close attention to the diagnostic process and course of disease as well as an awareness of its deficits will be necessary to better integrate the versatility and multiplicity of people's lived experiences into everyday biomedical practice in the future.

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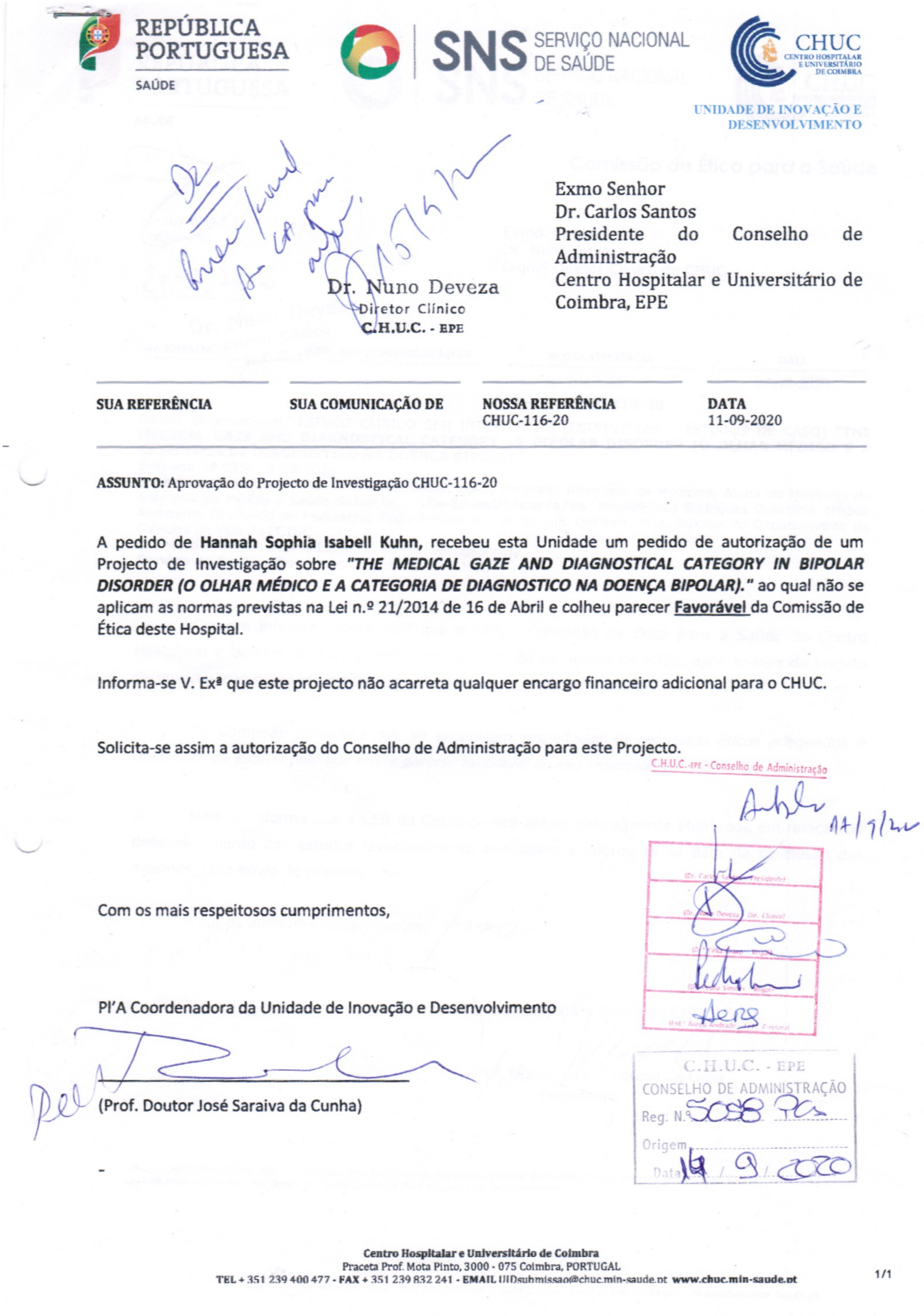
Appendix

Authorization of the Coimbra University Hospital Ethics Committee



REPÚBLICA PORTUGUESA
SAÚDE
SNS SERVIÇO NACIONAL DE SAÚDE
CHUC CENTRO HOSPITALAR E UNIVERSITÁRIO DE COIMBRA
UNIDADE DE INOVAÇÃO E DESENVOLVIMENTO

Dr. Nuno Deveza
Diretor Clínico
C.H.U.C. - EPE

Exmo Senhor
Dr. Carlos Santos
Presidente do Conselho de Administração
Centro Hospitalar e Universitário de Coimbra, EPE

SUA REFERÊNCIA	SUA COMUNICAÇÃO DE	NOSSA REFERÊNCIA	DATA
		CHUC-116-20	11-09-2020

ASSUNTO: Aprovação do Projecto de Investigação CHUC-116-20

A pedido de **Hannah Sophia Isabell Kuhn,** recebeu esta Unidade um pedido de autorização de um Projecto de Investigação sobre ***"THE MEDICAL GAZE AND DIAGNOSTICAL CATEGORY IN BIPOLAR DISORDER (O OLHAR MÉDICO E A CATEGORIA DE DIAGNOSTICO NA DOENÇA BIPOLAR)."*** ao qual não se aplicam as normas previstas na Lei n.º 21/2014 de 16 de Abril e colheu parecer Favorável da Comissão de Ética deste Hospital.

Informa-se V. Exª que este projecto não acarreta qualquer encargo financeiro adicional para o CHUC.

Solicita-se assim a autorização do Conselho de Administração para este Projecto.

C.H.U.C.-EPE - Conselho de Administração

11/9/20

(Dr. Carlos Santos - Presidente)
(Dr. Nuno Deveza - Dir. Clínico)
(Dr.ª Célia [illegible] - Vogal)
(Dr. Pedro Simões - Vogal)
(Enf.ª Áurea Andrade - Enf.ª Diretora)

Com os mais respeitosos cumprimentos,

Pl'A Coordenadora da Unidade de Inovação e Desenvolvimento

(Prof. Doutor José Saraiva da Cunha)

C.H.U.C. - EPE
CONSELHO DE ADMINISTRAÇÃO
Reg. N.º 5058 PCs
Origem
Data 14 / 9 / 2020

REPÚBLICA PORTUGUESA
SAÚDE

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CHUC
CENTRO HOSPITALAR E UNIVERSITÁRIO DE COIMBRA

Comissão de Ética para a Saúde

Visto/ À U.I.D.
para difusão

25, 8, 2020

Dr. Nuno Deveza
Diretor Clínico
C.H.U.C. - EPE

Exmo. Senhor
Dr. Nuno Deveza
Digmº Diretor Clínico do CHUC

SUA REFERÊNCIA	SUA COMUNICAÇÃO DE	NOSSA REFERÊNCIA	DATA
		N.º 204/CES	27-08-2020

Proc. N.º **CHUC-116-20**

Estudo Observacional: ESTUDO CLÍNICO SEM INTERVENÇÃO (ENTREVISTAS – ESTUDOS DE CASO) **"THE MEDICAL GAZE AND DIAGNOSTICAL CATEGORY IN BIPOLAR DISORDER (O OLHAR MÉDICO E A CATEGORIA DE DIAGNOSTICO NA DOENÇA BIPOLAR"**
Entrada na CES: 14-08-2020
Investigador/a/es: Hannah Sophia Isabell Kuhn, Mestrado Integrado de Medicina, Aluna do Mestrado de Antropologia Médica e Saúde Global UC **Co-Investigador/a/es**: Manuel João Rodrigues Quartilho, Médico Assistente Graduado de Psiquiatria, Prof. Auxiliar da FMUC; Luís Quintais, Prof. Auxiliar do Departamento de Ciências da Vida da FCTUC
Promotor: Hannah Sophia Isabell Kuhn (a investigadora)
Serviço de Realização: Serviço de Psiquiatria, CHUC

Cumpre informar Vossa Ex.ª que a CES - Comissão de Ética para a Saúde do Centro Hospitalar e Universitário de Coimbra, reunida em 26 de agosto de 2020, após análise do projeto de investigação supra identificado, emitiu o seguinte parecer:

"A Comissão considera que se encontram respeitados os requisitos éticos adequados à realização do estudo pelo que emite parecer favorável ao seu desenvolvimento no CHUC".

Mais se informa que a CES do CHUC deverá ser semestralmente atualizada em relação ao desenvolvimento dos estudos favoravelmente analisados e informada da data da conclusão dos mesmos, com envio de relatório final.

Com os melhores cumprimentos,

A Comissão de Ética para a Saúde do CHUC, E.P.E.

Prof. Doutor João Pedroso de Lima
Presidente

CES do CHUC: Prof. Doutor João Pedroso de Lima, Prof. Doutora Margarida Silvestre, Enfº Adélio Tinoco Mendes, Dra. Cláudia Santos, Dra. Isabel Ventura, Dr. José António Feio, Rev. Pe. Doutor Nuno dos Santos, Dr. Pedro Lopes, Dra. Teresa Monteiro

List of documents to be submitted to the Ethics Committee

CHUC CENTRO HOSPITALAR E UNIVERSITÁRIO DE COIMBRA	Estudo Observacional Estudo sem intervenção medicamentosa	IM- 11- 00 **Próxima Revisão:** **04/2020**
Unidade de Inovação e Desenvolvimento		Página 1 de 1

Identificação do estudo clínico

Número Interno do protocolo:

IDENTIFICAÇÃO DO PROJECTO: O Olhar Médico e a Categoria de Diagnóstico na Doença Bipolar

("The Medical Gaze and Diagnostic Category in Bipolar Disorder")

ITEM	DESCRIÇÃO	N.º Exemp.	Confirmado Pela UID
1	Pedido de autorização do estudo	**1**	
2	Identificação do Investigador	**1**	
3	Curriculum do investigador e co-investigadores (Datado e assinado)	**1**	
4	Autorização do Diretor do Serviço	**1**	
5	Parecer científico dado pelo Diretor do Serviço	**1**	
6	Modelo específico da Comissão de Ética (preenchido no que for aplicável)	**1**	
7	Documento de Informação ao doente e consentimento informado, em português	**1**	
8	Projeto de Investigação (assinado pelo IP)	**2**	
9	Caderno de registo de dados	**1**	
10	Declaração de que não constitui encargos financeiros adicionais para o Hospital	**1**	
11	Contrato Financeiro e Clínico (se aplicável)	**3**	
12	Documentação em Suporte Informático (Pen)	**1**	

PARECER DA UNIDADE DE INOVAÇÃO E DESENVOLVIMENTO

__/__/__

Pl'A Coordenadora da Unidade de Inovação e Desenvolvimento

____

(Prof. Doutor José Saraiva da Cunha)

***NOTA*:**

Todos os Documentos devem estar em Português.

Na apresentação do projecto de investigação deverá ser constituído um "dossier" com separadores identificadores dos pontos previstos no presente modelo. Esta documentação deve ser enviada também em suporte informático, em formato editável (WORD) – Itens 6, 7 e 8.

Project information submitted to the Ethic Committee

Antes de preencher este formulário, leia atentamente as respetivas instruções de preenchimento

Todos os campos são de preenchimento obrigatório

IDENTIFICAÇÃO DA EQUIPA DE INVESTIGAÇÃO

1.1 IDENTIFICAÇÃO DO(A) INVESTIGADOR(A)

Nome (completo): Hannah Sophia Isabell Kuhn

Morada: Couraça de Lisboa 41, 2° andar

C. Postal: 3000 - 435 **Localidade:** Coimbra

Telemóvel: 925949456 **Endereço de e-mail:** Hannah.Kuhn@gmail.com

1.2. IDENTIFICAÇÃO DO INVESTIGADOR COORDENADOR *(se aplicável)*

Nome (completo):

Telemóvel: **Endereço de e-mail:**

1.3. IDENTIFICAÇÃO DO(S) CO-INVESTIGADOR(ES) (se aplicável)

Nome (completo): Manuel João Rodrigues Quartilho

Telemóvel: 932908914 **Endereço de e-mail:** mjquarti@ci.uc.pt

Nome (completo): Luís Quintais

Telemóvel: - **Endereço de e-mail:** LFGSQ@CI.UC.PT

Nome (completo):

Telemóvel: **Endereço de e-mail:**

Nome (completo):

Telemóvel:		**Endereço de e-mail:**	

1.4. IDENTIFICAÇÃO DO PROMOTOR

Hannah Sophia Isabell Kuhn (a investigadora)

IDENTIFICAÇÃO DO PROJETO

Título do projeto:	THE MEDICAL GAZE AND DIAGNOSTICAL CATEGORY IN BIPOLAR DISORDER (O OLHAR MÉDICO E A CATEGORIA DE DIAGNOSTICO NA DOENÇA BIPOLAR)
Tipo de estudo:	*ESTUDO CLÍNICO SEM INTERVENÇÃO (ENTREVISTAS – ESTUDOS DE CASO)*
Finalidade do estudo:	*ACADEMICA – RECOLHA PARA DISSERTAÇÃO DE MESTRADO DE ANTROPOLOGIA MÉDICA E SAÚDE GLOBAL*

Serviço(s) onde o projeto será executado:

Serviço de Psiquiatria, CHUC

Existem outros centros, nacionais ou não, onde a mesma investigação será feita?

☐ Sim X Não

Em caso afirmativo indique qual/quais:

JUSTIFICAÇÃO CIENTÍFICA DA INVESTIGAÇÃO

A Doença Bipolar foi introduzida com a terceira edição do catálogo de diagnóstico em 1980, o DSM-III, que é considerado um marco histórico na nosologia psiquiátrica exemplificando uma mudança no ideal de tratamento (Shorter, 2015). Subsequentemente, a Doença Bipolar viria a tornar-se num dos diagnósticos mais populares na psiquiatria (Vieta & Phillips, 2007), sendo simultaneamente promovida pela indústria farmacêutica, dada a dua utilidade para vender os "mood stabilizers" em ascensão (Shorter, 2015). De modo a "entrar" num diagnóstico, como uma expressão comum declarava (Shorter, 2015), o DSM-III estabeleceu critérios para os sintomas que um doente ter deveria apresentar.

Como estes critérios seguem um certo padrão, e estão sujeitos a uma série de fatores que mudam com a evolução de uma doença tal como dependem da situação individual, este projeto de investigação pretende realizar uma etnografia baseada em estudos de casos de indivíduos diagnosticados com Doença Bipolar e dos médicos-psiquiatras que os tratam ou trataram. A Doença Bipolar foi escolhida porque é especialmente interessante neste aspeto. É classificada como uma "perturbação afetiva", uma categoria que depende sempre também do contexto sociocultural e da expressão subjetiva de sofrimento do indivíduo. Além disso, é uma perturbação geralmente tratada com medicamentos, que permite uma investigação que a aborde neurobiologicamente em termos de validade e eficácia de medição do tratamento tal como a procura de causas biológicas para a perturbação. Aqui pretende-se, no entanto, examinar a tese de que a biomedicina não é apenas uma ciência dedicada à investigação e cura de doenças, mas um sistema sociocultural. Não se trata simplesmente de observar e estudar cientificamente o corpo humano como um fenómeno natural, mas sim, tal como foi descrito por Arthur Kleinman e Robert Hahn, um "[…] artefacto da sociedade humana, fundado num quadro cultural de valores [...], ensinado pelas comunicações da interação social e depois posto em prática numa divisão social do trabalho em contextos institucionais".(Hahn & Kleinman, 1983, p. 306) Por outras palavras: Não se trata apenas de uma acumulação de propriedades biológicas que podem ser percebidas como saúde ou doença no corpo humano, trata-se, também, de uma prática cultural inserida num contexto social e histórico - como qualquer outra ciência.

Um conceito fundamental em que se baseia a investigação deste projeto é um fenómeno descrito pelo filósofo Ian Hacking. Ele chama-lhe "looping-effects of human kind" (efeitos de looping da espécie humana), um efeito de feedback que ocorre quando o significado da classificação (por exemplo, um diagnóstico de uma doença psiquiátrica) afeta o comportamento de quem é classificado (por exemplo, um doente que atua de acordo com o seu diagnóstico e as expectativas do mesmo). (Hacking, 2004) Esta questão é crucial para o assunto em discussão, porque como a biomedicina frequentemente "[…] pressiona o profissional a construir a doença, [um] processo biológico desordenado, como objeto de estudo e de tratamento […]" (Kleinman, 1997, p. 31) isto influencia o próprio sujeito, neste caso, o percurso da doença, tal como o doente que vive com a doença. Segundo Kleinman, há muito pouco ou nenhum lugar para o sofrimento do paciente nesta visão terapêutica estrita e "[…] as queixas da família são consideradas como auto-relatos subjectivos, relatos tendenciosos de uma pessoa vendo de um sítio demasiado pessoal […]" (Kleinman, 1997, p. 32), enquanto na prática o médico volta a ter a tarefa de substituir estas observações tendenciosas por "[…] dados objectivos: o único sinal válido de processos patológicos […]" (Kleinman, 1997, p. 32). Isto afeta um doente antes e depois do seu diagnóstico. Além disto, na prática existem vários problemas com a forma como a categorização e validação dos sintomas definem o sofrimento: Alguns pacientes não se enquadram em nenhuma das categorias devido a limites artificiais ou lacunas entre vários diagnósticos; outros pacientes não atingem o nível de gravidade de uma condição para se qualificarem para o diagnóstico; outros ainda preenchem critérios para condições múltiplas devido a uma sobreposição de sintomas (Vieta & Phillips, 2007, p. 888). Este projeto irá tentar analizar mais profundamente onde e como acontecem os fenómenos acima descritas e procurar possíveis causas tal como possíveis soluções para eles.

PARTICIPANTES ABRANGIDOS NA INVESTIGAÇÃO

4.1. Grupo de estudo

Número: **8-12**

Critérios de inclusão/exclusão utilizados:

Inclusão: Grupo de doentes diagnosticados com Doença Bipolar; Médicos que tratam / trataram destes doentes

Exclusão: Doentes que tem menos de 18 anos

Indique como se processará o seu recrutamento:

ESTABELECER CONTACTO ATRAVÉS DOS PROFISSIONAIS DE SAÚDE DO SERVIÇO DE PSIQUIATRIA DO CHUC (ENTRANDO DIREITAMENTO EM CONTACTO PARA EXPLICAR O ESTUDO E PROPOR A ENTREVISTA APÓS CONCORDAREM SER CONTACTADOS PELA INVESTIGADORA)

4.2 Grupo de controle

Número: -

Critérios de inclusão/exclusão utilizados:

-

Indique como se processará o seu recrutamento:

-

Especifique se o estudo abrange grávidas, maiores incapazes e/ou menores de idade:

-

OUTROS DADOS SOBRE O PROJETO

a) A Investigação envolve a realização de exames complementares?

☐ Sim [✓ Não]

- Em caso afirmativo, por favor, indique:

Tipo:	
Frequência:	
Especifique se estes procedimentos são feitos especialmente para esta investigação ou são executados no âmbito dos cuidados médicos habituais a prestar aos doentes:	

b) A Investigação proposta envolve Questionários?

X Sim ☐ Não

- Em caso afirmativo, por favor, indique:

A quem são feitos?	SÃO FEITOS AOS DOIS GRUPOS, AOS DOENTES TAL COMO AOS MÉDICOS. HÁ DOIS GIÕES DE ENTREVISTAS DIFERENTES COM PONTOS DE INTERESSES COMPARÁVEIS
Como são aplicados?	O QUESTIONNÁRIO É UM GIÃO DE PERGUNTAS QUE DÁ ESTRUTURA À ENTREVISTA QUE ACONTECERÁ DE FORMA SEMI-ESTRUTURADA E DÁ ESPAÇO PARA OS ENTREVISTADOS ELABOREM A SUA HISTÓRIA COM A DOENÇA / COM O TRATAMENTO DO/DA DOENTE. O LIMITE DA ENTREVISTA É 45-50 MINUTOS E NÃO SERÁ OBRIGATÓRIO RESPONDER A TODAS AS PERGUNTAS SE FOR INCONVENIENTE.

*(NOTA: **Junte 1 exemplar** do questionário que será utilizado).*

A Investigação proposta envolve outros procedimentos?

☐ Sim X Não

- Em caso afirmativo, por favor, indique:

Tipo:	
Frequência:	
Especifique se estes procedimentos são feitos especialmente para esta investigação ou são executados no âmbito dos cuidados médicos habituais a prestar aos doentes:	

DESCRIÇÃO RESUMIDA DO PLANO E METODOLOGIA DE INVESTIGAÇÃO

Inicialmente será realizada uma análise bibliográfica sistemática que terá como obectivo posicionar a investigação deste projeto no contexto da investigação já efectuada por outros autores.

A recolha de dados será efectuada através de estudos de caso em forma de entrevistas qualitativas semi-estruturadas. Serão estabelecidos dois grupos de pessoas entrevistadas: Psiquiatras do Serviço de Psiquiatria do Centro Hospitalar e Universitário de Coimbra, e doentes com o diagnóstico Doença Bipolar por eles tratados. O objetivo é realizar uma análise qualitativa profunda, de aproximadamente dez casos, baseada na informação adquirida nas entrevistas. A realização e análise dos estudos de caso baseia-se na literatura relativa ao trabalho de campo em antropologia. (ver Burgess, 1984; Mills et al., 2010)

As entrevistas seguirão um guião de perguntas, embora se garanta espaço e liberdade suficiente para divergir de modo a que o entrevistado possa elaborar a sua experiência. O guião de perguntas foi criado com base na análise bibliográfica anteriormente realizada.

As entrevistas serão realizadas apenas após a obtenção do consentimento informado dos entrevistados por escrito. A informação obtida será posteriormente utilizada de forma anónima de modo a não permitir, em momento algum, a rastreabilidade dos sujeitos entrevistados.

AVALIAÇÃO DE RISCO/BENEFÍCIO

Que riscos ou incómodos podem ser causados aos participantes pelo estudo?

NÃO SÃO ESPERÁVEIS RISCOS CAUSADAS PELO ESTUDO. PODIA HAVER UM CONFRONTE DESCONFORTÁVEL PARA OS DOENTES COM A EXPERIÊNCIA DA DOENÇA, COM UMA PESSOA (A INVESTIGADORA) QUE DEPOIS NÃO OS CONTINUA A ACOMPANHAR. PODIA SURGIR A SENSAÇÃO DE SER QUESTIONADO NO SEU JULGAMENTO PROFISSIONAL QUE NÃO É DE NENHUMA FORMA INTENCIONADA PELA INVESTIGADORA.

Que benefícios imediatos poderão advir para os participantes pela sua anuência em participar no estudo?

PODE SER UM MOMENTO DE PARTILHA, DE REFLEXÃO SOBRE A EXPERIÊNCIA COM A DOENÇA DENTRO E FORA DE UMA INSTITUIÇÃO (SENDO INTERNAMENTO OU CONSULTA EXTERNA)

PODE SER UMA ESPÉCIE DE ALÍVIO PARA OS DOENTES TAL COMO PARA OS MÉDICOS FALAR COM UMA PESSOA “NEUTRA” (NÃO ENVOLVIDO NO TRATAMENTO, OBRIGADA A CONFIDENCIALIDADE) SOBRE A EXPERIÊNCIA.

PROTEÇÃO DE DADOS DOS PARTICIPANTES

Medidas tomadas para assegurar a proteção de dados.

8.1 Responsável pelo tratamento de dados

Nome (completo): **Hannah Kuhn**

Telemóvel: **925949456** **Endereço de e-mail:** **Hannah.Kuhn@gmail.com**

8.2. Categoria de Dados Pessoais

Identifique todos os dados pessoais e/ou especiais a que pretende ter acesso:

Nome, Idade, Profissão / Formação, Estado Civil, Diagnóstico se for aplicável, Dados de contacto (nomeadamente número de telefone para estabelecer contacto para a entrevista). Além disto, o que os entrevistados queiram partilhar durante a entrevista (Vê guião de perguntas).

8.3 Colheita/Recolha de Dados Pessoais

Direta (ao próprio):

x Presencial ☐ Por impresso x Telefone ☐ Inquérito on-line ☐ Outro (especificar):

Indireta:

☐ Processo Clínico ☐ Registos de outras Instituições ☐ Familiares ☐ Outro (especificar):

Tratamento de Dados Pessoais

Indicar a forma como são armazenados ou gravados os dados recolhidos:

Haverá uma recolha de dados em forma de entrevista presencial ou via telefone. As entrevistas serão gravadas com o telemóvel da investigadora para ser transcritos para um documento WORD anteriormente a apagar a gravação, se os participantes concordam. Se não, haverá apenas apontamentos de memória posteriormente a entrevista. Os dados serão guardados no computador privado da investigadora de forma anonimizada.

Medidas de segurança

Indicar as medidas técnicas e organizativas adotadas para segurança dos dados pessoais:

8.5.1.O participante é identificado por código especificamente criado para este estudo?

x Sim ☐ Não

8.5.2. Em caso afirmativo, quem realiza a codificação dos dados?

x Investigador ☐ Promotor ☐ Outro (especifique)

8.5.2. Onde ficam os dados pessoais tratados?

x numa base de dados / ficheiro do Investigador

☐ numa base de dados / ficheiro do CHUC

☐ numa base de dados / ficheiro do Promotor

☐ numa base de dados / ficheiro fora da União Europeia

8.5.3. É criado um biobanco?

☐ Sim x Não

8.5.4. Existe Comunicação de Dados Pessoais a terceiros?

☐ Sim x Não

8.5.5. Existem Fluxos de Dados Pessoais transfronteiriços para fora da EU/EEE?

☐ Sim x Não

8.5.6. Indicar o Prazo Máximo de Conservação dos Dados

Até a data de entrega da dissertação, que está prevista para Junho 2021.

CONFLITO DE INTERESSES

A investigadora e os co-investigadores declaram que a investigação será realizada na ausência de quaisquer relações comerciais ou financeiras que pudessem ser interpretadas como um potencial conflito de interesses. Além disto, como a investigadora não está envolvida no tratamento dos doentes, não haverá conflito que resulta em alteração do tratamento dos doentes participantes.

CONSENTIMENTO

A expressão do consentimento informado terá forma escrita, conforme a Lei.

*Nota: Deverá juntar um exemplar do **Texto de Consentimento Informado** a assinar pelo participante ou representante(s) legal(is).*

Descreva resumidamente o conteúdo da informação a transmitir ao participante:

O estudo tem por objetivo investigar o aspeto sociocultural da biomedicina, o efeito de epistemologia/funcionamento de ciência e relações de poder na perceção de saúde, de doença e de tratamento biomédico. A aparente necessidade de categorizar a experiência humana em gavetas muito mais pequenas do que a realidade vivida pelas pessoas, pode limitar a comunicação e interação com os doentes de uma forma pouco saudável: Perde-se informação, o sofrimento torna-se estigmatizado e reações emocionais a eventos da vida são medicalizadas, as vezes de forma inadequada, em doenças psiquiátricas. Olhando ao diagnostico Doença Bipolar fazendo entrevistas que dão espaço para o participante partilhar a sua experiência pessoal e subjetiva, este projeto pretende investigar o contexto e efeito da nosologia (classificação) na psiquiatria através deste diagnóstico.

A recolha de dados será efectuada através de estudos de caso em forma de entrevistas qualitativas semi-estruturadas. Serão estabelecidos dois grupos de pessoas entrevistadas: Psiquiatras do Serviço de Psiquiatria do Centro Hospitalar e Universitário de Coimbra, e doentes com o diagnóstico Doença Bipolar por eles tratados. O objetivo é realizar uma análise qualitativa profunda, de aproximadamente dez casos, baseada na informação adquirida nas entrevistas. As entrevistas seguirão um guião de perguntas, embora se garanta espaço e liberdade suficiente para divergir de modo a que o entrevistado possa elaborar a sua experiência.

RELATIVAMENTE AO ESTUDO

Data prevista de início: : 15/09/2020 **Data prevista de conclusão: 15/12/2020**

Existe reembolso e/ou ressarcimento aos participantes

Pelas deslocações: ☐ Sim x Não

Pelas faltas ao serviço: ☐ Sim x Não

Por danos resultantes da sua participação no estudo: ☐ Sim x Não

Em caso afirmativo especifique a entidade que assume a responsabilidade pelo reembolso e/ou ressarcimento das despesas:

--

Existe um Seguro afeto a este Projeto de Investigação (especifique):

não

Do estudo resulta alguma espécie de benefício financeiro ou outro para o investigador e/ou instituição?

☐ Sim x Não

Em caso afirmativo especifique: -

Os dados obtidos constituirão propriedade exclusiva de companhia farmacêutica ou de outra entidade?

☐ Sim x Não

Em caso afirmativo especifique a entidade: -

TERMO DE RESPONSABILIDADE

Eu, abaixo assinado(a), declaro por minha honra, na qualidade de investigador, que as informações prestadas neste questionário são verdadeiras.

Comprometo-me a respeitar o direito à privacidade e à proteção dos dados pessoais dos participantes, vinculando-me ainda ao estrito cumprimento do dever de sigilo e de confidencialidade a que me encontro legalmente obrigado.

Declaro também que durante o estudo serão respeitadas todas as disposições legais em vigor e as recomendações constantes da Declaração de Helsínquia (1964 e subsequentes revisões) e da Organização Mundial de Saúde.

Data do pedido de aprovação: 11/08/2020

____

(assinatura)

PARECER DA COMISSÃO DE ÉTICA

A Comissão,

Reunião de ___/ ___/____

____

Interview Guide – Psychiatrists

Guião da entrevista - Médicos

Perfil do informante:
- Nome
- Idade
- Profissão/formação (especialidade)

Início/Primeiros episódios da doença:
- Como foi o processo de diagnóstico? Houve dúvidas no diagnóstico? Se sim, quais e como foram resolvidas até chegar ao diagnóstico final?
- Quais foram os primeiros sintomas do seu doente?
- Foi o próprio doente quem pediu ajuda ou foi outra pessoa? Quando tempo julga que demorou até o doente procurar ajuda?

Representação da doença bipolar:
- O que significa para si, enquanto profissional, a doença bipolar?
- O que é que considera estar na origem da doença, neste doente?
- O que acha que o seu doente sentiu quando lhe disseram que tinha Doença Bipolar? Como é que ele reagiu?

Avaliação do conhecimento sobre a Doença Bipolar:
- Como explicou a doença ao doente? Fez alguma prescrição no início? Se sim, o quê e com que objectivo?
- Discutiu com o doente outro tipo de acompanhamento paralelo? (e.g., psicoterapia, grupos de pares)
- Qual a sua opinião sobre o enquadramento de sintomas no padrão de diagnóstico do ICD ou DSM?

Impacto do diagnóstico na relação médico-doente:
- O que passou a ser diferente na sua interação com o doente desde que o diagnosticou?
- Sente que a qualidade da relação médico-doente alterou após início do tratamento?
- Que impacto lhe parece ter tido a doença do doente nas pessoas mais próximas (família, amigos)?
- Identifica alguma mudança na relação do doente com essas pessoas?
- Mantém contacto com o doente depois da fase aguda? Com que regularidade? O doente pode contactá-lo fora do horário das consultas? Se sim, de que forma?

O futuro:
- Comunica ao doente alguma esperança da doença algum dia passar? (e.g., espécie de “cura”?)

Interview Guide – Patients

Guião da entrevista

Perfil do doente:
-Nome
-Idade
-Profissão/formação
-Estado civil

Primeiros episódios da doença:
-Quais sente que foram os primeiros sintomas a surgir?
-Quem tomou a decisão de procurar ajuda profissional (o próprio ou outro)?
-Quando foi tomada essa decisão?
-Como foi o processo de diagnóstico?
-Quantos médicos consultou?
-Já sabia da existência desta doença?

Representação da doença bipolar:
-O que significa para si a doença bipolar?
-O que é que considera estar na sua origem?
-O que sentiu quando lhe disseram que tinha doença bipolar?
-Como reagiu?

Avaliação do conhecimento sobre a Doença Bipolar:
- Como é que o médico lhe explicou a doença?
- De que forma foi tratado com medicação? (Que tipo de medicação / quanto tempo / resultou em melhorar ?)
- Para além da informação disponibilizada pelo médico sobre a doença procurou outras fontes de informação?

Impacto da doença na sua vida:
-O que é que passou a ser diferente no seu dia-a-dia desde que teve este diagnóstico?
-Sente que o início do tratamento interferiu qual a sua qualidade de vida? De que forma? (e.g., ter um nome para o que se passa ajudou?)
-Qual o impacto que considera que a sua doença teve na sua rede de familiares e amigos próximos?
-Identifica alguma mudança na sua relação com essas pessoas?

Apoios para lidar com a doença bipolar:
-Que tipo de acompanhamento tem para lidar com a doença? Psiquiátrico, psicológico e/ou ambos? Apoio social?
-Toma medicação? Que tipo de medicação e com que frequência?
-Procurou medicinas alternativas?
-Mantém contacto com pessoas com a mesma doença? Se sim, em que contexto? Se não, já teve vontade de ter? (e.g. Grupos de Pares/Apoio)

A cura:
-Tem esperança que algum dia a doença passe? Ou que seja encontrada uma „cura"?

Informed Consent – Interview Psychiatrists

	INFORMAÇÃO AO PARTICIPANTE E FORMULÁRIO DE CONSENTIMENTO INFORMADO	IM-02.01 **Próxima Revisão: Junho/2023**
Comissão de Ética para a Saúde		Página **1** de **5**

TÍTULO DO PROJETO DE INVESTIGAÇÃO:

O OLHAR MÉDICO E A CATEGORIA DE DIAGNOSTICO NA DOENÇA BIPOLAR
(THE MEDICAL GAZE AND DIAGNOSTICAL CATEGORY IN BIPOLAR DISORDER)

PROMOTOR:

Hannah Kuhn

INVESTIGADOR COORDENADOR:

Luís Quintais / Manuel Quartilho

CENTRO DE ESTUDO CLÍNICO:

Serviço de Psiquiatria, CHUC / Faculdade de Antropologia, DCV, Universidade de Coimbra

INVESTIGADOR:

Hannah Kuhn

MORADA:

CONTACTO TELEFÓNICO:

NOME DO PARTICIPANTE:

É convidado(a) a participar voluntariamente neste estudo porque é Médico no Serviço de Psiquiatria do Centro Hospitalar e Universitário de Coimbra e trata / tratou doentes diagnosticados com Doença Bipolar e assim qualifica como participante do grupo de estudo.

As informações que se seguem destinam-se a esclarecê-lo acerca da natureza, alcance, consequências e risco do estudo, de modo a permitir que, depois de esclarecido, se encontre capaz de decidir participar, ou não, neste estudo.
Caso não tenha qualquer dúvida acerca do mesmo, deverá tomar a decisão de participar ou não. Se não quiser participar não sofrerá qualquer tipo de penalização. Caso queira participar, ser-lhe-á solicitado que assine e date este formulário.
Após a sua assinatura e a do Investigador, ser-lhe-á entregue uma cópia, que deve guardar.

1. INFORMAÇÃO GERAL E OBJETIVOS DO ESTUDO

Este estudo irá decorrer no Centro Hospitalar de Coimbra em colaboração com o Departamento das Ciências da Vida da Faculdade de Ciência e Tecnologia da Universidade de Coimbra e tem por objetivo investigar o aspeto sociocultural da biomedicina, o efeito de epistemologia e relações de poder na perceção de saúde, de doença e de tratamento biomédico. Como descrito por vários autores, a aparente necessidade de categorizar a experiência humana em gavetas muito mais pequenas do que a realidade vivida pelas pessoas, pode limitar a comunicação e interação com os doentes de uma forma pouco saudável: Perde-se informação, o sofrimento torna-se estigmatizado e reações emocionais a eventos da vida são medicalizadas, as vezes de forma inadequada, em doenças psiquiátricas. Olhando ao diagnostico Doença Bipolar, este projeto pretende investigar o contexto e efeito da nosologia na psiquiatria através desta classificação, tendo em consideração a história do diagnóstico, como e quando surgiu, bem como o desenvolvimento e o contexto sociocultural da classificação de doenças mentais em geral.

Trata-se de um estudo clínico sem intervenção, com finalidade académica, de realizar a dissertação da tese de mestrado.
Este estudo foi aprovado pela Comissão de Ética do Centro Hospitalar e Universitário de Coimbra (CHUC), de modo a garantir a proteção dos direitos, segurança e bem-estar de todos os participantes incluídos e garantir prova pública dessa proteção.

2. PLANO E METODOLOGIA DO ESTUDO

A RECOLHA DE DADOS SERÁ EFECTUADA ATRAVÉS DE ESTUDOS DE CASO EM FORMA DE ENTREVISTAS QUALITATIVAS SEMI-ESTRUTURADAS. SERÃO ESTABELECIDOS DOIS GRUPOS DE PESSOAS ENTREVISTADAS: PSIQUIATRAS DO SERVIÇO DE PSIQUIATRIA DO CENTRO HOSPITALAR E UNIVERSITÁRIO DE COIMBRA, E DOENTES COM O DIAGNÓSTICO DOENÇA BIPOLAR POR ELES TRATADOS. O OBJETIVO É REALIZAR UMA ANÁLISE QUALITATIVA PROFUNDA, DE APROXIMADAMENTE DEZ CASOS, BASEADA NA INFORMAÇÃO ADQUIRIDA NAS ENTREVISTAS. A REALIZAÇÃO E ANÁLISE DOS ESTUDOS DE CASO BASEIAM-SE NA LITERATURA RELATIVA AO TRABALHO DE CAMPO EM ANTROPOLOGIA.
AS ENTREVISTAS SEGUIRÃO UM GUIÃO DE PERGUNTAS, EMBORA SE GARANTA ESPAÇO E LIBERDADE SUFICIENTE PARA DIVERGIR DE MODO A QUE O ENTREVISTADO POSSA ELABORAR A SUA EXPERIÊNCIA. O GUIÃO DE PERGUNTAS FOI CRIADO COM BASE NA ANÁLISE BIBLIOGRÁFICA ANTERIORMENTE REALIZADA.

3. PROTEÇÃO DE DADOS DOS PARTICIPANTES

3.1 Responsável pelos dados

Hannah Kuhn

3.2 Recolha de dados

Hannah Kuhn

3.3 Categorias de dados

Nome, Idade, Profissão / Formação, Estado Civil, Diagnóstico se aplicável, Dados de contacto (nomeadamente número de telefone para estabelecer contacto para a entrevista). Além disto, o que os entrevistados queiram partilhar durante a entrevista.

3.4 Tratamento de dados

Haverá uma recolha de dados em forma de entrevista presencial ou via telefone. As entrevistas serão gravadas com o telemóvel da investigadora para ser transcritos para um documento WORD anteriormente a apagar a gravação, se os participantes concordam. Se não, haverá apenas apontamentos de memória posteriormente a entrevista. Os dados serão guardados no computador privado da investigadora de forma anonimizada.

3.5 Medidas de proteção adotadas

O participante é identificado por código especificamente criado para este estudo, a codificação realizada pela investigadora. Os dados ficarão guardados nos dispositivos pessoais (telemóvel em caso de gravação, computador) as quais apenas a investigadora tem acesso.

3.6 Prazo de conservação dos dados

Prazo máximo de conservação de dados é até data de entrega da dissertação, prevista para Junho 2021.

3.7 Informação em caso de publicação

Se os resultados forem publicados, os participantes serão informados. A investigadora compromete-se também neste caso de assegurar a confidencialidade da sua identidade e dos seus dados.

4. RISCOS E POTENCIAIS INCONVENIENTES PARA O PARTICIPANTE

PODIA HAVER UM CONFRONTE DESCONFORTÁVEL COM A EXPERIÊNCIA DA DOENÇA, COM UMA PESSOA (A INVESTIGADORA) QUE DEPOIS NÃO OS CONTINUA A ACOMPANHAR. PODIA SURGIR A SENSAÇÃO DE SER JULGADO PELA INVESTIGADORA.

5. POTENCIAIS BENEFÍCIOS

A ENTREVISTA PODE SER UM MOMENTO DE PARTILHA, DE REFLEXÃO SOBRE A EXPERIÊNCIA COM A DOENÇA DENTRO E FORA DE UMA INSTITUIÇÃO (SENDO INTERNAMENTO OU CONSULTA EXTERNA).
PODE SER UMA ESPÉCIE DE ALÍVIO PARA OS PARTICIPANTES DO ESTUDO FALAR COM UMA PESSOA "NEUTRA" (NÃO ENVOLVIDO NO TRATAMENTO, OBRIGADA A CONFIDENCIALIDADE) SOBRE A EXPERIÊNCIA VIVIDA.

6. NOVAS INFORMAÇÕES

Não é previsto haver novas informações que possam ser relevantes para a sua condição ou participação no estudo. Caso se verifique qualquer alteração nas finalidades do estudo, procede-se à recolha de novo consentimento de modo a contemplar a alteração às finalidades inicialmente propostas.

7. RESPONSABILIDADE CIVIL

O estudo não implica intervenções fora dos cuidados habituais ou deslocações específicas para a realização do estudo.

8. PARTICIPAÇÃO / RETIRADA DO CONSENTIMENTO

É inteiramente livre de aceitar ou recusar participar neste estudo. Pode retirar o seu consentimento em qualquer altura, através da notificação ao investigador, sem qualquer consequência, sem precisar de explicar as razões, sem qualquer penalização ou perda de benefícios e sem comprometer a sua relação com o investigador que lhe propõe a participação neste estudo.
O consentimento entretanto retirado não abrange os dados recolhidos e tratados até a essa data.
O investigador do estudo pode decidir terminar a sua participação neste estudo se entender que não é do melhor interesse continuar nele. A sua participação pode também terminar se o plano do estudo não estiver a ser cumprido. O investigador notificá-lo-á se surgir uma dessas circunstâncias.

9. CONFIDENCIALIDADE

Será garantido o respeito pelo direito do participante à sua privacidade e à proteção dos seus dados pessoais; devendo ainda ser assegurado que será cumprido o dever de sigilo e de confidencialidade a que se encontra vinculado, conforme disposto no artigo 29.º da Lei n.º 58/2019, de 08/08.

10 – DIREITO DE ACESSO E RETIFICAÇÃO

Pode exercer o direito de acesso, retificação e oposição ao tratamento dos seus dados. Contudo, este direito pode ser sujeito a limitações, de acordo com o disposto no artigo 31.º, n.º da Lei n.º 58/2019, de 08/08.

11. REEMBOLSO E/OU RESSARCIMENTO DO PARTICIPANTE

Este estudo é da iniciativa do investigador e, por isso, solicita-se a sua participação sem uma compensação financeira para a sua colaboração.

12. COMPENSAÇÃO DO CENTRO DE ESTUDO / INVESTIGADOR

O Centro de Estudo não receberá uma compensação financeira pela realização do estudo. A Investigadora não receberá uma compensação financeira pelo seu trabalho na realização do estudo.

13. CONTACTOS

Se tiver questões sobre este estudo deve contactar:

Investigador	HANNAH KUHN
Morada	COURAÇA DE LISBOA 41, 3000-435 COIMBRA
Telefone	925949456
Email	HANNAH.KUHN@GMAIL.COM

Se tiver dúvidas relativas aos seus direitos como participante deste estudo, poderá contactar:

Presidente da Comissão de Ética do CHUC
Centro Hospitalar e Universitário de Coimbra
Praceta Mota Pinto, 3000 075 Coimbra
Telefone: 239 400 400
e-mail: secetica@chuc.min-saude.pt

NÃO ASSINE ESTE FORMULÁRIO DE CONSENTIMENTO INFORMADO A MENOS QUE TENHA TIDO A OPORTUNIDADE DE PERGUNTAR E TER RECEBIDO RESPOSTAS SATISFATÓRIAS A TODAS AS SUAS PERGUNTAS.

CONSENTIMENTO INFORMADO

Título do Projeto de Investigação

O OLHAR MÉDICO E A CATEGORIA DE DIAGNOSTICO NA DOENÇA BIPOLAR

Nome do Participante:

BI / CC: **Contactos:**

Nome do Investigador: Hannah Kuhn

No âmbito da realização do Projeto de Investigação acima mencionado, declaro que tomei conhecimento:

a. do conteúdo informativo anexo a este formulário e aceito, de forma voluntária, participar neste estudo;

b. da natureza, alcance, consequências, potenciais riscos e duração prevista do estudo, assim como do que é esperado da minha parte, enquanto participante;
c. e compreendi as informações e esclarecimentos que me foram dados. Sei que a qualquer momento poderei colocar novas questões ao investigador responsável pelo estudo;
d. que o investigador se compromete a prestar qualquer informação relevante que surja durante o estudo e que possa alterar a minha vontade de continuar a participar;
e. e aceito cumprir o protocolo deste estudo. Comprometo-me ainda a informar o investigador de eventuais alterações do meu estado de saúde que possam ocorrer *(quando aplicável);*
f. e autorizo a utilização e divulgação dos resultados do estudo para fins exclusivamente científicos e permito a divulgação desses resultados às autoridades competentes;
g. que posso exercer o meu direito de retificação e/ou oposição, nos limites da Lei;
h. que sou livre de desistir do estudo a qualquer momento, sem ter de justificar a minha decisão e sem sofrer qualquer penalização. Sei também que os dados recolhidos e tratados até a essa data serão mantidos;
i. que o investigador tem o direito de decidir sobre a minha eventual saída prematura do estudo e se compromete a informar-me do respetivo motivo;
j. que o estudo pode ser interrompido por decisão do investigador, do promotor ou das autoridades reguladoras.

Local e data:	***Assinaturas***
	Participante:
	Representante legal:
	Representante legal:
	Investigador (*):

(*) Confirmo que expliquei ao participante acima mencionado a natureza, o alcance e os potenciais riscos do estudo acima mencionado***.***

Informed Consent – Interview Patients

	INFORMAÇÃO AO PARTICIPANTE E FORMULÁRIO DE CONSENTIMENTO INFORMADO	IM-02.01 **Próxima Revisão: Junho/2023**
Comissão de Ética para a Saúde		Página **1** de **5**

TÍTULO DO PROJETO DE INVESTIGAÇÃO:

O OLHAR MÉDICO E A CATEGORIA DE DIAGNOSTICO NA DOENÇA BIPOLAR
(THE MEDICAL GAZE AND DIAGNOSTICAL CATEGORY IN BIPOLAR DISORDER)

PROMOTOR:

Hannah Kuhn

INVESTIGADOR COORDENADOR:

Luís Quintais / Manuel Quartilho

CENTRO DE ESTUDO CLÍNICO:

Serviço de Psiquiatria, CHUC / Faculdade de Antropologia, DCV, Universidade de Coimbra

INVESTIGADOR:

Hannah Kuhn

MORADA:

CONTACTO TELEFÓNICO:

NOME DO PARTICIPANTE:

É convidado(a) a participar voluntariamente neste estudo porque tem o diagnóstico de Doença Bipolar tratado no Serviço de Psiquiatria do Centro Hospitalar e Universitário de Coimbra e assim qualifica como participante do grupo de estudo.

As informações que se seguem destinam-se a esclarecê-lo acerca da natureza, alcance, consequências e risco do estudo, de modo a permitir que, depois de esclarecido, se encontre capaz de decidir participar, ou não, neste estudo.

Caso não tenha qualquer dúvida acerca do mesmo, deverá tomar a decisão de participar ou não. Se não quiser participar não sofrerá qualquer tipo de penalização. Caso queira participar, ser-lhe-á solicitado que assine e date este formulário.

Após a sua assinatura e a do Investigador, ser-lhe-á entregue uma cópia, que deve guardar.

1. INFORMAÇÃO GERAL E OBJETIVOS DO ESTUDO

Este estudo irá decorrer no Centro Hospitalar de Coimbra em colaboração com o Departamento das Ciências da Vida da Faculdade de Ciência e Tecnologia da Universidade de Coimbra e tem por objetivo investigar o aspeto sociocultural da biomedicina, o efeito de epistemologia e relações de poder na perceção de saúde, de doença e de tratamento biomédico. Como descrito por vários autores, a aparente necessidade de categorizar a experiência humana em gavetas muito mais pequenas do que a realidade vivida pelas pessoas, pode limitar a comunicação e interação com os doentes de uma forma pouco saudável: Perde-se informação, o sofrimento torna-se estigmatizado e reações emocionais a eventos da vida são medicalizadas, as vezes de forma inadequada, em doenças psiquiátricas. Olhando ao diagnostico Doença Bipolar, este projeto pretende investigar o contexto e efeito da nosologia na psiquiatria através desta classificação, tendo em consideração a história do diagnóstico, como e quando surgiu, bem como o desenvolvimento e o contexto sociocultural da classificação de doenças mentais em geral.

Trata-se de um estudo clínico sem intervenção, com finalidade académica, de realizar a dissertação da tese de mestrado.
Este estudo foi aprovado pela Comissão de Ética do Centro Hospitalar e Universitário de Coimbra (CHUC), de modo a garantir a proteção dos direitos, segurança e bem-estar de todos os participantes incluídos e garantir prova pública dessa proteção.

2. PLANO E METODOLOGIA DO ESTUDO

A RECOLHA DE DADOS SERÁ EFECTUADA ATRAVÉS DE ESTUDOS DE CASO EM FORMA DE ENTREVISTAS QUALITATIVAS SEMI-ESTRUTURADAS. SERÃO ESTABELECIDOS DOIS GRUPOS DE PESSOAS ENTREVISTADAS: PSIQUIATRAS DO SERVIÇO DE PSIQUIATRIA DO CENTRO HOSPITALAR E UNIVERSITÁRIO DE COIMBRA, E DOENTES COM O DIAGNÓSTICO DOENÇA BIPOLAR POR ELES TRATADOS. O OBJETIVO É REALIZAR UMA ANÁLISE QUALITATIVA PROFUNDA, DE APROXIMADAMENTE DEZ CASOS, BASEADA NA INFORMAÇÃO ADQUIRIDA NAS ENTREVISTAS. A REALIZAÇÃO E ANÁLISE DOS ESTUDOS DE CASO BASEIAM-SE NA LITERATURA RELATIVA AO TRABALHO DE CAMPO EM ANTROPOLOGIA.
AS ENTREVISTAS SEGUIRÃO UM GUIÃO DE PERGUNTAS, EMBORA SE GARANTA ESPAÇO E LIBERDADE SUFICIENTE PARA DIVERGIR DE MODO A QUE O ENTREVISTADO POSSA ELABORAR A SUA EXPERIÊNCIA. O GUIÃO DE PERGUNTAS FOI CRIADO COM BASE NA ANÁLISE BIBLIOGRÁFICA ANTERIORMENTE REALIZADA.

3. PROTEÇÃO DE DADOS DOS PARTICIPANTES

3.1 Responsável pelos dados

Hannah Kuhn

3.2 Recolha de dados

Hannah Kuhn

3.3 Categorias de dados

Nome, Idade, Profissão / Formação, Estado Civil, Diagnóstico se aplicável, Dados de contacto (nomeadamente número de telefone para estabelecer contacto para a entrevista). Além disto, o que os entrevistados queiram partilhar durante a entrevista.

3.4 Tratamento de dados

Haverá uma recolha de dados em forma de entrevista presencial ou via telefone. As entrevistas serão gravadas com o telemóvel da investigadora para ser transcritos para um documento WORD anteriormente a apagar a gravação, se os participantes concordam. Se não, haverá apenas apontamentos de memória posteriormente a entrevista. Os dados serão guardados no computador privado da investigadora de forma anonimizada.

3.5 Medidas de proteção adotadas

O participante é identificado por código especificamente criado para este estudo, a codificação realizada pela investigadora. Os dados ficarão guardados nos dispositivos pessoais (telemóvel em caso de gravação, computador) as quais apenas a investigadora tem acesso.

3.6 Prazo de conservação dos dados

Prazo máximo de conservação de dados é até data de entrega da dissertação, prevista para Junho 2021.

3.7 Informação em caso de publicação

Se os resultados forem publicados, os participantes serão informados. A investigadora compromete-se também neste caso de assegurar a confidencialidade da sua identidade e dos seus dados.

4. RISCOS E POTENCIAIS INCONVENIENTES PARA O PARTICIPANTE

PODIA HAVER UM CONFRONTE DESCONFORTÁVEL COM A EXPERIÊNCIA DA DOENÇA, COM UMA PESSOA (A INVESTIGADORA) QUE DEPOIS NÃO OS CONTINUA A ACOMPANHAR. PODIA SURGIR A SENSAÇÃO DE SER JULGADO PELA INVESTIGADORA.

5. POTENCIAIS BENEFÍCIOS

A ENTREVISTA PODE SER UM MOMENTO DE PARTILHA, DE REFLEXÃO SOBRE A EXPERIÊNCIA COM A DOENÇA DENTRO E FORA DE UMA INSTITUIÇÃO (SENDO INTERNAMENTO OU CONSULTA EXTERNA).
PODE SER UMA ESPÉCIE DE ALÍVIO PARA OS PARTICIPANTES DO ESTUDO FALAR COM UMA PESSOA "NEUTRA" (NÃO ENVOLVIDO NO TRATAMENTO, OBRIGADA A CONFIDENCIALIDADE) SOBRE A EXPERIÊNCIA VIVIDA.

6. NOVAS INFORMAÇÕES

Não é previsto haver novas informações que possam ser relevantes para a sua condição ou participação no estudo. Caso se verifique qualquer alteração nas finalidades do estudo, procede-se à recolha de novo consentimento de modo a contemplar a alteração às finalidades inicialmente propostas.

7. RESPONSABILIDADE CIVIL

O estudo não implica intervenções fora dos cuidados habituais ou deslocações específicas para a realização do estudo.

8. PARTICIPAÇÃO / RETIRADA DO CONSENTIMENTO

É inteiramente livre de aceitar ou recusar participar neste estudo. Pode retirar o seu consentimento em qualquer altura, através da notificação ao investigador, sem qualquer consequência, sem precisar de explicar as razões, sem qualquer penalização ou perda de benefícios e sem comprometer a sua relação com o investigador que lhe propõe a participação neste estudo.
O consentimento entretanto retirado não abrange os dados recolhidos e tratados até a essa data.
O investigador do estudo pode decidir terminar a sua participação neste estudo se entender que não é do melhor interesse continuar nele. A sua participação pode também terminar se o plano do estudo não estiver a ser cumprido. O investigador notificá-lo-á se surgir uma dessas circunstâncias.

9. CONFIDENCIALIDADE

Será garantido o respeito pelo direito do participante à sua privacidade e à proteção dos seus dados pessoais; devendo ainda ser assegurado que será cumprido o dever de sigilo e de confidencialidade a que se encontra vinculado, conforme disposto no artigo 29.º da Lei n.º 58/2019, de 08/08.

10 – DIREITO DE ACESSO E RETIFICAÇÃO

Pode exercer o direito de acesso, retificação e oposição ao tratamento dos seus dados. Contudo, este direito pode ser sujeito a limitações, de acordo com o disposto no artigo 31.º, n.º da Lei n.º 58/2019, de 08/08.

11. REEMBOLSO E/OU RESSARCIMENTO DO PARTICIPANTE

Este estudo é da iniciativa do investigador e, por isso, solicita-se a sua participação sem uma compensação financeira para a sua colaboração.

12. COMPENSAÇÃO DO CENTRO DE ESTUDO / INVESTIGADOR

O Centro de Estudo não receberá uma compensação financeira pela realização do estudo. A Investigadora não receberá uma compensação financeira pelo seu trabalho na realização do estudo.

13. CONTACTOS

Se tiver questões sobre este estudo deve contactar:

Investigador	HANNAH KUHN
Morada	COURAÇA DE LISBOA 41, 3000-435 COIMBRA
Telefone	925949456
Email	HANNAH.KUHN@GMAIL.COM

Se tiver dúvidas relativas aos seus direitos como participante deste estudo, poderá contactar:

Presidente da Comissão de Ética do CHUC
Centro Hospitalar e Universitário de Coimbra
Praceta Mota Pinto, 3000 075 Coimbra
Telefone: 239 400 400
e-mail: secetica@chuc.min-saude.pt

NÃO ASSINE ESTE FORMULÁRIO DE CONSENTIMENTO INFORMADO A MENOS QUE TENHA TIDO A OPORTUNIDADE DE PERGUNTAR E TER RECEBIDO RESPOSTAS SATISFATÓRIAS A TODAS AS SUAS PERGUNTAS.

CONSENTIMENTO INFORMADO

Título do Projeto de Investigação

O OLHAR MÉDICO E A CATEGORIA DE DIAGNOSTICO NA DOENÇA BIPOLAR

Nome do Participante:	
BI / CC:	**Contactos:**
Nome do Investigador: Hannah Kuhn	

No âmbito da realização do Projeto de Investigação acima mencionado, declaro que tomei conhecimento:

a. do conteúdo informativo anexo a este formulário e aceito, de forma voluntária, participar neste estudo;

b. da natureza, alcance, consequências, potenciais riscos e duração prevista do estudo, assim como do que é esperado da minha parte, enquanto participante;

c. e compreendi as informações e esclarecimentos que me foram dados. Sei que a qualquer momento poderei colocar novas questões ao investigador responsável pelo estudo;

d. que o investigador se compromete a prestar qualquer informação relevante que surja durante o estudo e que possa alterar a minha vontade de continuar a participar;

e. e aceito cumprir o protocolo deste estudo. Comprometo-me ainda a informar o investigador de eventuais alterações do meu estado de saúde que possam ocorrer *(quando aplicável);*

f. e autorizo a utilização e divulgação dos resultados do estudo para fins exclusivamente científicos e permito a divulgação desses resultados às autoridades competentes;

g. que posso exercer o meu direito de retificação e/ou oposição, nos limites da Lei;

h. que sou livre de desistir do estudo a qualquer momento, sem ter de justificar a minha decisão e sem sofrer qualquer penalização. Sei também que os dados recolhidos e tratados até a essa data serão mantidos;

i. que o investigador tem o direito de decidir sobre a minha eventual saída prematura do estudo e se compromete a informar-me do respetivo motivo;

j. que o estudo pode ser interrompido por decisão do investigador, do promotor ou das autoridades reguladoras.

Local e data:	***Assinaturas***
	Participante:
	Representante legal:
	Representante legal:
	Investigador (*):

(*) Confirmo que expliquei ao participante acima mencionado a natureza, o alcance e os potenciais riscos do estudo acima mencionado***.***

Declaration of Additional Financial Charges

Projeto de investigação
Dissertação de tese de Mestrado em Antropologia Médica e Saúde Global, DCV / UC

O Olhar Médico e a Categoria de Diagnostico na Doença Bipolar
("The Medical Gaze and Diagnostic Category in Bipolar Disorder")

Declaração de encargos financeiros adicionais

Venho por este meio declarar que este projeto de investigação não constitui encargos fincanceiros adicionais para o Centro Hospitalar e Universitário de Coimbra.

A investigadora,

Hannah Kuhn

Table of Interview Codes and Interview Participants

	Interview Code – Psychiatrists	**Interview Code – Patients**
Case 1	2.1 Dra Maria	1.1 Joana
Case 2	2.2 Dra Marta	1.2 Franscisco
Case 3	2.5 Dra Catarina	1.3 Emanuel
Case 4	2.3 Dra Luísa	1.4 Pedro
Case 5	2.4 Dra Mafalda	1.5 José
Case 6	n.a.	1.6 Isabel

All names were anonymized. No additional information was included to prevent any possible implication of the interview participants' identity.