



DIAGNOSTIC FLUIDITY

Working with Uncertainty and Mutability

Nina Nissen & Mette Bech Risør (eds.)

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CONTENTS

Foreword	7
<i>Annemarie Jutel</i>	
Configurations of diagnostic processes and practices: an introduction	11
<i>Mette Bech Risør & Nina Nissen</i>	
PART 1: TENSIONS IN EVERYDAY DIAGNOSTIC WORK	33
A deviant diagnosis? Doctors faced with a patient's diagnostic work. . . .	35
<i>Sylvie Fainzang</i>	
Enacting ADHD diagnosis in the landscape of care in Poland	55
<i>Anna Witeska-Młynarczyk</i>	
Diagnostic uncertainty and pathways to care for migrant and non-migrant families and their children	83
<i>Sylvie Fortin, Annie Gauthier & Liliana Gomez Cardona</i>	
PART 2: DIAGNOSTIC NEGOTIATIONS IN THE CLINIC	
From evidence to experience: the diagnosis of dementia in a US clinic	105
<i>Laurence Tessier</i>	
A desire for knowing: ontological uncertainty, diagnostic evidence and generative affectivity in pre-symptomatic genetic counselling. . . .	129
<i>Bernhard Hadolt</i>	
“I’m here to help with pain”: diagnosing and resolving total pain in hospital palliative care	149
<i>Marian Krawczyk</i>	
The role of pathology in diagnostic work	171
<i>Torsten Risør</i>	

PART 3: THE POWER OF CHANGING DIAGNOSTIC CATEGORIES

Offstage: madness, the ob-scene, and common sense 197

Angel Martínez-Hernández

The medicalization of diagnosis: from cultural and environmental
nosologies to lay medical concerns. 213

Josep M. Comelles & Susan M. DiGiacomo

Afterword 249

Simon Cohn

FOREWORD

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The multiplication of diagnoses, the seepage of diagnostic language into popular culture and the media, the rise of self-diagnosis and the world wide web, all position diagnosis as an important social phenomenon to which anthropology, sociology, and their cognate disciplines must pay particular attention. In order to understand the health goals to which individuals and communities aspire, it is important to know the place that diagnosis plays in understanding health and illness. In order to determine what conditions are of particular public concern, it is also vital to know how those conditions are conceptualised, categorised, and indeed, diagnosed.

Whether it is fibromyalgia, gout, or obesity, each diagnosis is testimony to a particular way of seeing the world and understanding disease. Fibromyalgia, for example, is, as I write these words, a symptom-based diagnosis, established in the presence of a certain number of symptoms assembled in indicative ways. But, at the same time, it is a diagnosis which lacks legitimacy in the eyes of many, for the absence of biological markers providing so-called objective confirmation. This is why clinical researchers, and notably geneticists, are frenetically trying to discern a profile, be it genetic or biologic, which can explain this baffling condition.

Gout is also determinant, but in other ways. It has biological markers, so its existence is not in doubt, but its causes and location raise questions. Does the problem of uric acid build-up in the joints belong to rheumatology, endocrinology or nephrology? Is it a disease of decadence, or one of poverty?

Obesity, on the other hand, says much about who we are, and what a society should look like. In the neo-liberal context of responsabilisation, obesity, like gout, makes social statements about the large body, stigmatising at the same time as it rings alarm bells about the society in which the large individual is situated. The health of a nation is measured in BMI, with rising obesity touted as an alarming trend.

All three of these examples occupy slightly different social and cultural spaces, but wrestle, as do the case studies provided in *Diagnostic fluidity: working with uncertainty and mutability*, with the themes captured in the up-coming chapters: tension, negotiation and power. These themes both influence, and are influenced by diagnosis, yet often remain unelucidated, invisible, in need of exposure.

Diagnoses are not simply names. They shape the way we think of disease, and they determine our public actions. They are both categories and processes—a diagnosis is the classification tool, at the same time as it is the means by which the classification is conferred upon an individual. That diagnosis is both category and process means that the consideration I call for in the opening paragraph must think broadly about how a diagnosis is arrived upon, whose interests are served by particular configurations and symptom arrays, and whose are silenced. As Thomas Arnold, head master of Rugby School, in England, wrote in the great age of classification, “We are not to suppose that there are only a certain number of divisions in any subject, and that unless we follow these, we shall divide it wrongly and unsuccessfully: on the contrary every subject is as it were all joints, it will divide wherever we choose to strike it, and therefore according to our particular object at different times we shall see fit to divide it very differently” (ARNOLD, 1839).

ARNOLD spoke these words before the theory of social construction had been developed, yet they presage important precepts of contemporary social and cultural theory. These words should give pause to the medical anthropologist or sociologist whose research can be just as often critical of, as it is useful to, the contemporary practice of medicine. What ARNOLD highlights in the quaint language of yesteryear is not that things are simply imagined and have no substantive content. They are “real” in material and tangible ways. However, their labels, and how they are understood is determined by the institutions that negotiate them, by the place they assume in the cultural landscape. Institutions and culture then determine to a great degree how we approach the materiality of everyday life.

If we extend this to diagnosis, it highlights the fact that even while disease and dysfunction are real, material challenges, diagnosis is separate from—yet of course, related to—human suffering. Diagnosis is the social action related to disease. It is in its pursuit, often, that the lay person will enter the world of medicine. It is also the way in which medicine decides

what matters, both taxonomically and clinically. But finally, it is how symptoms are explained, resources are allocated, the future is predicted, behaviours are legitimised, and people make sense of their dysfunction.

Diagnosis does more than just determine how diseases are organised, it organises medicine as well, determining what conditions are seen by which specialists, and which specialists have the most status and prestige. It serves a didactic purpose: students learn diagnosis and study diagnostic manuals. Despite these important social functions, diagnosis has only recently come to the attention of scholars as a social or cultural object. It has been consistently seen as a simple label of mainly uncontroversial disorders, rather than as a highly-complex process involving hierarchies, interests, paradigms and power.

And, even as diagnosis has started to surface as a topic of interest to social and cultural scholars, it has often done so in the context of particular diagnoses, or of particular disorders. Calls surface in academia for attention to be paid to a particular diagnosis, citing the specific and particular contexts in which this diagnosis is experienced, its unequal distribution, its consequences on its sufferers. Less frequent are those calls to consider diagnosis in a more general sense, of which this diagnosis, or that diagnosis, is simply a poignant example amongst many.

The *Medical Anthropology at Home* conference, held in Tromsø, Norway, in June 2016, which was the starting point for *Diagnostic fluidity: working with uncertainty and mutability*, moved forward towards considering the more general import of diagnosis. Nina Nissen and Mette Bech Risør have pulled together in this volume a collection which should take an important early step in considering the broader implications of diagnosis in culture and of culture in diagnosis.

In its pages, one will find important concepts which capture the way diagnosis is either practiced or understood. There are the tensions in diagnostic work. These can be between patient and doctor, between specialists. They are related to the nature of the diagnosis, and the degree to which it legitimises or explains dysfunction; the resources to which it gives access; the stigma with which it might be associated. But these are also related to the patient group. To be positioned culturally in a different place than one's doctor creates other kinds of tensions, not all of which result in optimal care, or optimal diagnosis.

At the same time, these tensions give rise to different forms of negotiation, particularly in the presence of uncertainty, and power. The authority to name and label confers the labeller with extensive power: to decide who is normal and who is not, to determine what counts as sick and what counts as mad. When the label itself is linked variably to resources and legitimisation, or to stigma and rejection, the negotiation of power has more gravitas. How does diagnosis cement a particular organisation of power? Of care? What tensions are present in the diagnostic process, and what are the work-arounds implemented by lay person as well as by clinician? How do social class, gender, context, and culture shape, or indeed, diffuse, these tensions; change the configurations of power?

In this context, the book *Diagnostic fluidity: working with uncertainty and mutability* does the important work of locating diagnosis in different cultures, in different settings, and in different conditions. In so doing, it provides a way of thinking more generally about diagnosis and its role in understanding health, illness and disease.

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CONFIGURATIONS OF DIAGNOSTIC PROCESSES AND PRACTICES: AN INTRODUCTION

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Diagnoses are inherently social realities, linking the individual and the social system, while also being actors that “configure and reconfigure the lives of real men and women” (ROSENBERG, 2002: 250). Considering the abundance of stories, studies and projects on diagnosis from the social sciences to social media, one could argue that nowadays almost any person in a high income society seems to juggle, use, be concerned about and engaged in diagnostic processes, and in so doing draws on a diagnosis (or diagnoses) as a compass for how to organize and perceive his/her life, health and body. In a medical sense, diagnoses are overall confined to classificatory terms, but the ways that patients perceive diagnoses and make them meaningful transform them into individual illness explanations and socially adaptable frameworks. One may consider, for example, the patients (most often women) who receive a diagnosis of chronic fatigue syndrome and struggle to find social acceptance (SACHS, 2016); the gendered differences in the experiences of a diagnosis of Multiple Sclerosis and associated sense-making processes (FROST, GROSE & BRITTEN, 2017); patients’ experiences of receiving a cancer diagnosis (e.g. TOBIN & BEGLEY, 2008; JOHNSON, AUS & BERTERÖ, 2009; EDMONDSON, BIRTWISTLE, CATTO *et alii*, 2017); and studies on risk assessment, such as coming to terms with screening results indicating prenatal diagnoses that are severe or fatal (LOU, JENSEN, PETERSEN *et alii*, 2017). Diagnosis pervades and expands into numerous areas of life, and as ROSENBERG (2002) argues, the tyranny and prominence of diagnosis has increased despite a strong distinction between disease entities and unique manifestations of illness in particular men and women.

This increase has prompted researchers to discuss whether the proliferation of diagnoses is real and how it may be judged as real. Suggesting the notion of “diagnostic culture”, BRINKMANN (2010), for example, asks whether there is indeed a growth in ill health, or whether the proliferation of diagnoses, supported by new diagnostic practices and technologies, reflects a tendency to pathologize certain behaviors as disease. Irrespective of the explanatory framework, disease categories have always linked knowledge and practice, and have long been used to determine, modify and exert designation, prognosis and treatment through medical authority. But the separation of place and person from disease, that is, the idea that disease mechanisms exist somehow outside the body, is more recent (ROSENBERG, 2002). This development is supported by the standardization of a nosology that aligns with innovations in technology and shifting bureaucratic structures and practices, making further inroads towards a supposedly value-free biomedicine that exerts increasing influence on perceptions of what a disease is and how diagnoses prosper.

This anthology brings together a selection of papers that were presented at the IX biennial Medical Anthropology At Home (MAAH) conference, entitled *Configurations of Diagnostic Processes, Practices and Evidence*, held in Tromsø in Northern Norway from June 2nd-5th 2016 under the auspices of UiT, The Arctic University of Norway.

We, the conference organizers, saw a need to critically engage with and analyze the configurations of diagnostic processes, practices and evidence, given the ongoing medical developments and the concurrent changing social realities for patients, relatives, healthcare professionals and others. The aim of the conference was to critically explore the many dimensions of diagnosis, its functions and consequences, and to uncover the centrality of diagnosis for research in medical anthropology and diverse forms of medicine. The conference addressed four interrelated themes: *a*) Symptoms and diagnoses, *b*) Diagnoses and biopower, *c*) The enactment and becoming of a diagnosis within medicine, and *d*) Intersubjective experiences of diagnostic processes. We envisaged the conference to provide insights into existing and changing values, configurations, structures and contexts that surround and implicate diagnostic processes, practices and evidence, and in so doing to contribute towards rethinking empirical and conceptual phenomena on technology, regulations, power relations and the interactions of the many parties involved in defining and responding to diagnoses.

The papers presented at the conference covered a wide range of topics within these themes, and addressed both theoretical and methodological issues pertaining to studies of diagnostic work, categories, practices and processes. Salient in the many papers, and constituting the core of this collection, was the importance of spatial and temporal dimensions as well as a demonstration of the fluid and often unruly processes of diagnosis, both concerning classificatory work and the everyday practices when dealing with diagnoses. The emotional work and the performative and intersubjective practices especially were ongoing issues of the anthropological field studies presented, as will be shown in the chapters that follow.

Several issues concerning diagnosis and diagnostic processes have been dealt with in anthropology and sociology. In this introduction, we do not mean to reiterate or synthesize these contributions; rather we wish to build on previous research to expand and complement ongoing developments. We thus see this introduction as a contemplation on diagnostic issues emerging from these contributions and our reading of them. What follows below are reflections on diagnosis as both category and process, on debates that concern the concept of risk and of medicalization, and on the pervasive impression from the papers of seeing diagnoses as fluid, being worked on and able to invoke emotional dimensions of intersubjective relations.

Process within classification and framing

Notions of subjectivity, intersubjectivity and diagnostic process within and beyond clinical settings are key to this collection. In one way, diagnosis is both a category and a process (BLAXTER 1978; JUTEL & NETTLETON 2011). This distinction provides a useful analytical perspective, bearing in mind that diagnosis in real life encompasses a combination of both category and process, and the separation of the two may obscure important aspects of diagnosis.

Diagnosis as category often refers to classification structures and nosology, exemplified by international classification systems such as DSM V (Diagnostic and Statistic Manual of Mental Disorders), ICD 10 (International Classification of Diseases) and ICPC (International Classification of Primary Care). In principle, diagnostic categories

work as vehicles to capture a person's distress and align this to existing nomenclatures of disease. Categories therefore are an attempt to arrange diseases in specific groups according to clear boundaries. The history of how classification systems have developed is long and shifting, pointing to changes in epistemology, causation and the sociopolitics of health.

Several researchers have scrutinized the aims and principles of classification. JUTEL (2011a), for example, identified two major trajectories in medical classification, the statistical and the nosological, and links these to their social embeddedness. This highlights the way in which the establishment of a classification is modulated by social, political and technological factors, whereby "classifications give voice to certain perspectives and silence others" (BOWKER & STAR, 1999, paraphrased by JUTEL 2011a: 198).

Drawing on medical history, ARMSTRONG has demonstrated how nosology in primary care has changed according to the problems presented by patients. The ICD system originally classified illness according to pathological types and causes of death. However when attributed to illness patterns and symptoms in general practice, health problems and symptom presentations did not seem to fit the pathological classifications and a new system was developed, the ICPC (ARMSTRONG, 2011). ARMSTRONG's point of this observation is that: "Major changes in medical classification demonstrate that there are no diseases waiting in nature to be discovered; there are no diagnoses which capture an immutable illness state. Diseases and diagnoses only become apparent through the contemporary classifications systems" (ibid.: 806). ROSENBERG (2006) points to another aspect of medical history and shows how the attempt to legitimate behavioral ills in psychiatry is dominated by a search for somatic mechanisms, a reductionism which defines specific disease entities and thus creates a specificity of diseases with consequences for psychiatry as discipline. Ultimately, disease categories are about classification, of suffering but also of ourselves. The examples illustrate that the medical reality created through classification has a history that follows the social and cultural developments of society as much as developments and processes in medicine (ARMSTRONG, 2011). Josep COMELLES & Susan DIGIACOMO (Chapter 9) contribute to these debates. With an emphasis on the cultural context of classification history, they guide us through the development of historical concepts of diseases. The authors connect nosology and classification systems with the very practices of doctoring

across rural Europe and in overseas colonies, presenting early attempts to systematize what was observed and learnt from peoples' local illness presentations. From an emic gaze, we gain a vivid and differently angled story of how doctors developed terminology ranging from "ethnic pathology", "folk medicine", and "culture-bound syndromes" to "medical concerns". The authors argue that "medical diagnosis is no longer based exclusively on responding to illness but increasingly on responding to medical concerns," and that this contemporary folk nosology has impacted already on both medical constructs and medical anthropology. Such historically detailed and empirical accounts of local disease nosology make an important addition to other, more classic presentations of disease categorization.

Inevitably, an emphasis on the historical development of a diagnosis and disease nosology leads to considerations of diagnosis as a process. Processes of diagnosis include any activity surrounding investigations, assessments and negotiations pertaining to clinical and non-clinical judgments of ill health. Different actors with their skills, experiences and sensing bodies are involved in these processes, in conjunction with technology and instruments of measurement. Studies of such processes have explored the enactment and the making of a diagnosis with particular focus on subtle intersubjective processes between health professionals and patients (Büscher, GOODWIN & MESMAN, 2010; GARDNER, DEW, STUBBE *et alii* 2011; MOL, 2002). For instance, Allan Young, in his seminal study *The Harmony of Illusions. Inventing Post-Traumatic Stress Disorder* (YOUNG, 1995), critically scrutinizes how a specific disorder is made and has come to encompass certain disorders and symptoms. He describes the practices, technologies and narratives that support the proliferation of the diagnosis of PTSD (Post-Traumatic Stress Disorder) and demonstrates how it acquires facticity.

More recently, in an anthology entitled *Ethnographies of Diagnostic Work. Dimensions of Transformative Practice* (Büscher, GOODWIN & MESMAN, 2010), the editors and authors depart from an understanding of diagnosis as predominantly associated with health care situations, and extend diagnosis to a broad spectrum of spaces and practices of deciphering and enacting situations that call on both professional and mundane judgments, sense-making, assessment and action. To substantiate the argument, the contributions in this volume range from explorations of prison officers reading prisoners' behavior, call centre workers trying

to troubleshoot problems of technological devices, and the evaluation of videoelectroencephalography used for assessing epileptic seizures or pseudoseizures. In challenging the conventional boundaries and use of the term diagnosis, the authors move from a focus on diagnosis as such to diagnostic *work* as a collaborative social and technological process, to understand how this work is done and to present the transformative potential of such analyses. This offers an inspiring and transgressive input to the making of a diagnosis, which is deeply anchored in the subtle practices of assessment while moving beyond linear cognitive notions of rationality. In addition, these studies take into account space, setting and the transformative role of instruments and other non-human factors as pertaining to the process of diagnosis rather than existing outside it.

Other studies point to the negotiation of what constitutes a diagnosis, how it is evidenced and how the evidence is interpreted. This is illustrated in a study of prenatal screening results (LOU, NIELSEN, HVIDMAN *et alii*, 2015), where diagnosis is not a fixed category, but involves multiple fluid processes of knowledge production and results in varied consequences for the diagnosed. The consequences of a diagnosis may also pertain to those who are not (yet) diagnosed or are “in the waiting”, including parents whose newborn babies are genetically screened or tested (TIMMERMANS & BUCHBINDER, 2010). The processing of diagnoses, in other words, takes place and continues both within and beyond clinics, for example when screening may bring muddy results, placing a person between health and disease with a specific social significance in terms of, for example, illness trajectory.

In this anthology, we are primarily concerned with the processes surrounding diagnoses, with diagnostic work and the making of a diagnosis. Thus, explorations of diagnostic processes predominate in the chapters that follow, both methodologically and theoretically. Although one can speak of classification systems as objective standards, void of temporality and space, it is only when enacting these standards that they become meaningful, disputed or ambiguous, and open to scrutiny. With JUTEL & NETTLETON we may say: “Diagnosis serves thus as an analytic device that can explore the way classifications and labels are constructed, framed and enacted” (2011: 798). Critical examinations of these processes are therefore central to this anthology, and we wish to emphasize how individuals, patients, relatives, and health professionals participate in the activity of processing diagnosis, with the diverse trajectories and

consequences such engagement may have for each actor. Diagnosis as an epitome or imaginary of illness and disease could be said to be the point of contact between medical anthropology and (bio)medicine – where both disciplines contribute to discussions of diagnosis and diagnostic processes, practices and work from different perspectives.

By adopting a process-oriented approach, we move beyond a strictly structural approach and the social constructionism found in several earlier studies (e.g. ARONOWITZ, 2001; BROWN, 1995; LOCK & KAUFERT, 2001; RAPP, 1993; YOUNG, 1980). We seek to highlight the processes of intersubjectivity surrounding diagnostic activities. We see a possibility for further theoretical development and a deeper understanding of re/actions, emotions and roads taken by the actors involved in diagnostic processes. At the same time, we attend to the space and temporality of negotiations as influential dimensions, thus building on previously documented cultural, social and medical mechanisms of diagnostics. In this way, social framing remains a key concept underpinning this anthology. However, the contributions mainly present how people frame or enact their dealings with diagnosis, more than they show how people are passively framed. As JUTEL says, “diagnoses are not prior, ontological entities but social categories that organize, direct, explain, and sometimes control our experience of health and illness” (2011b: 34). Our interest lies in what this “direction, control and explanation” consists of, and how such an interest may evoke the subtleties of immediacy and simultaneousness in a diagnostic process and look to the capacities of framing and directing hopes, wishes and intentions not only of professionals but also of those being diagnosed or affected by a diagnosis.

Anthropological and ethnographic studies on health and illness certainly address diagnostic processes as a core issue, but this attention can circumscribe analyses of doctor-patient relationships, illness experiences and the production of medical knowledge. Diagnosis per se and its enactment at the level of scientific production of diagnosis and at the level of clinical interaction, professional performance or the self-diagnosis in everyday life, are less often seen. Exceptions of course exist, such as early deconstructionist analyses of the procedures and styles of reasoning which underpin the establishment of the menopause as a medical diagnosis (LOCK & KAUFERT, 2001), and the detailed ethnography of hospital clinical performance when “doing disease”, for example, in the case of atherosclerosis (MOL, 2002).

More recently, some medical anthropologists have explicitly taken up the critical examination of diagnosis, with the aim to “look beyond social issues and clinical challenges” (SMITH-MORRIS, 2015). With a focus on diagnostic conflicts, SMITH-MORRIS and colleagues present a meta-analysis of diagnosis in terms of patterns, designs, impacts and structures of authority, in an anthology entitled *Diagnostic Controversy. Cultural Perspectives on Competing Knowledge in Healthcare* (2016). This focus is substantiated by in-depth ethnographic explorations of the many ways in which social factors in diagnosis interact and produce broader issues, including processes of medicalization and resistance, and the transforming and transformative position of diagnosis for 21st century global health. The authors brought together in this anthology question specific diagnoses (such as Parkinson’s disease, andropause, psychosis), and scrutinize the structural and epistemological elements behind the naming and experience of a disease. Thus, the shared impact of a diagnostic event unifies the discussions in this volume, while also capturing some of its complexity and controversy in real-world settings. In this way, SMITH-MORRIS and colleagues allow the critical study of biomedical praxis to emerge, contributing a coherent and thought-provoking critique of the process and wider implications of diagnosis.

In the specific field of medically unexplained symptoms, the lack of a diagnosis has prompted scholars from different academic backgrounds to examine diagnostic issues and their consequences (DUMIT, 2006; KARTERUD, RISØR & HAAVET, 2015; RISØR, 2009). This fundamental questioning and the workings of a diagnosis, whether named or not, are also explored in studies of chronic fatigue syndrome and Lyme’s disease in the above-mentioned anthology (DAVIS & NICHTER, 2016; SACHS, 2016). These and several other studies produce new entrances to investigating diagnostic processes and stimulating theoretical reflections that may be applied to other fields of diagnostic work, not merely where diagnoses are absent or contested.

We perceive the examination of diagnostic processes as a window to exploring, for example, the often medically defined boundaries of social life and health where several actors participate and disciplines intersect, thus showing the diverse ways in which subjectivity, intersubjectivity and diagnostic processes are mediated and configured. Here, the contestations, enactments, extensions and changes of diagnoses surrounding the multiple perspectives invested in these negotiations come to the fore.

Diagnoses under the auspices of biopolitics and risk technology

A diagnostic development that seems to stem from the more frequent and increasing specificity of diagnosing via technological and scientific achievements (ROSENBERG, 2006) is the focus on pre-illness states and the fine differentiation of particular diseases. Surveillance technology, testing and genetic and molecular profiling has directed attention to the huge numbers of at-risk factors for otherwise healthy people, shaping the lives of those affected as well as transforming what counts as disease (JUTEL, 2011b). Not only does the surveillance and detection of at-risk conditions configure the illness trajectories of people at risk for heart disease, diabetes or cancer, but new diagnoses enter the stage through complex blood tests, genetic testing, and biomarkers that establish novel disease scenarios, such as pre-diabetes. This is made possible by technological innovations aimed at disease prevention, technologies which are embedded in the paradigm of evidence-based medicine with its emphasis on biology and biopolitics (ROSE, 2007). This embeddedness impacts on everyday living, making us seemingly willing to explore and receive the technology offered by biomedicine. For instance, we follow calls for screening and we undergo genetic tests, sometimes deliberately, sometimes merely out of fear, or at times based on the rationale that “I better do it, because if....” (LOU, DAHL, RISØR *et alii*, 2007). The focus on symptoms and the general context of risk discourses related to the abundance of screening programs, testing and use of technology are modes of creating diagnostic evidence that medical anthropologists often study critically. Some medical specialties such as family medicine and community medicine too have recently begun to focus on overdiagnosis as a central phenomenon. Overall, these positions critically view the volume of biodata that govern ordinary people’s lives through self-monitoring via counting, weighing and numbering. They also consider technology to enable diagnosis through the increasing use of testing and regard the excessively widened disease definitions as key contributors to a culture of diagnosis and pathologization.

Similarly, but arguing from a more discursive position for a “somatic ethics” that governs bodies and lives, Nikolas Rose’s (2007) work is central to an understanding of disease in terms of biopolitics. According to ROSE, we interpret our lives based on an understanding of bodies as biological entities. This basic orientation relates to a dominant discourse of molecules and biomarkers and to the optimization of lives (not only

the treatment of diseases) through, for example, the monitoring of bodies. In turn, this prompts the proliferation of professionals with somatic expertise. ROSE's arguments sustain the idea that biomedicine contributes to pathologization (cf. BRINKMANN, 2010), while also making it possible to see the part played by multiple actors in this process, including the pharmacoindustry, patients, and patient organizations. Notably, the ways in which complex diagnostic processes configure new subjectivities under the influence of biopolitical bureaucracy also take place at a more individual and practice-oriented level (ANDERSEN & VEDSTED, 2015).

Technology not only frames new types of diseases; it also differentiates diseases like breast cancer into new layers of specificity, according to tissue, tumor size or gene expression (JUTEL, 2011b). Risk detection, the increase of disease specificity and new diagnoses are expansions of the biomedical regime and knowledge approaches related to processes of medicalization. According to Peter CONRAD "medicalization" describes a process by which nonmedical problems become defined and treated as medical problems, usually in terms of illness and disorders" (CONRAD, 2007:4). Medicalization however can comprise more than these processes, as detailed above. It can encompass diagnostic fine-tuning and its impact on the persons being examined, permeating the lives of people and their understanding of health and disease. Biomedicine considers many individuals to be at the edge of a disease and at risk; many are pre-diagnosed or being given test results in a grey zone. New technologies, biomarkers and the ability or wish to know and map our bodies play a decisive role in diagnostic work and processes. Once the specificity of discerning bodily malfunction increases, it is likely that more "patients in the waiting" will be produced (TIMMERMANS & BUCHBINDER, 2010).

As stated by ARONOWITZ (2009), medicalization has expanded due to transformations in the labeling and the production of ill health. ARONOWITZ considers chronic disease to be a special case when compared to individuals with an "at risk for" disease, arguing that the experience of chronic disease and its management resembles the experience of being at risk (ibid.). People living with chronic disease, he suggests, are exposed to the same risk approach composed of preventive measures used for supposedly healthy people – for example the adoption of new clinical interventions that change the natural history of disease, greater knowledge of risk for the already chronically ill, and larger and more intensive screening programs and testing. This has led to the emergence

of new types of biomedical disease management but also to an increasing attention and experience by the chronically ill towards surveillance and their often highly professional understanding of elaborate laboratory tests and the reading and interpretation of symptoms. Such processes form part of the ongoing diagnostic work, at the levels of both scientific achievements and in everyday life —making looping effects from one to the other.

However, nosological categories at work do not necessarily present as appropriate or compatible. Angel MARTÍNEZ-HERNÁEZ (Chapter 8) departs from a historical analysis of madness and asks why it is always associated with the social practices of movement and confinement. Through his reflections on madness as “ob-scene” we gain a glimpse into the life of Babu, a patient in a residential treatment centre for people with chronic psychosis. MARTÍNEZ-HERNÁEZ elaborates, with inspiration from GEERTZ’s (1983) notion of common sense as a cultural system, how madness defies common sense rather than reason. This again permeates treatment approaches trying to domesticate patients and, notably, reducing social dialogue since madness is refractory and denied any social use. In attending to the power of societal values on the conceptualization of disease, and the impact this may have on objectifying human suffering, MARTÍNEZ-HERNÁEZ adds to the critical examinations of a specific process of medicalization.

Expanding how to think about and conceptualize such processes, both for people who are chronically ill and those who are not yet ill, the term biomedicalization encapsulates an extra dimension: “...the increasingly complex, multisited, multidirectional processes of medicalization that today are being both extended and reconstituted through the emergent social forms and practices of a highly and increasingly technoscientific biomedicine” (CLARKE, SHIM, MAMO *et alii*, 2003: 162). Despite these developments in biomedicine, we also witness processes of demedicalization as Sylvie FAINZANG illustrates (Chapter 1). FAINZANG offers an example of patient agency whereby a patient challenges the medical advice of his doctor and engages in personal diagnostic activity, over time and in interaction with the doctors involved in his care. Through a meticulous description of the patient and his health complaints as they developed over years, FAINZANG analyzes the turns and deliberations made on medication and diagnosis by the patient, and focuses on how he decides to discontinue a specific medication, against the advice of the

doctor. The paper speaks to de-medicalization and discusses authority, risk and pharmacovigilance in a system of hegemonic biomedical discourses where knowledge, diagnosis and social positions are challenged by patient agency. This example complements, but also differs from, instances where the biomedical narrative and medical diagnosis do not resonate with the patient's experience (JUTEL, 2011b).

Fluidity in diagnostic time and space

The focus and interest in diagnostic processes enables us to scrutinize what we perceive as fluidity in several modalities of diagnostic work. This fluidity is linked with the temporality and spatiality of multiple diagnostic processes, and belies the apparent stability of diagnostic categories. Medical categories are an attempt to grasp and pin down shifting illness phenomena, in order to manage and treat systematically. Yet, diagnostic categories are seldom stable, neither as facts nor in practice, whereby the variability of diagnoses is shaped by the various perspectives in the clinic and beyond. As NETTLETON, KITZINGER & KITZINGER note, a “diagnostic illusory” captures “the ambiguities and nuanced complexities associated with the biomedical imperative to name and classify” (2014: 134). With the development of biomedicine and the growing blurring and convergence of disease and risk of disease (ARONOWITZ, 2009), diagnostic boundaries become increasingly more fluid and permeable. In this development, the power of diagnostic designation is promoted through ongoing efforts to classify increasingly minor and numerous bodily states as disease. At the same time, these efforts also ironically underscore the “diagnostic illusory”. The growing specificity also paradoxically introduces ambiguities and uncertainties into the clinical and practical settings where biomedical investigation takes place. On the one hand, this ambiguity seems to expand—scientifically and in particular clinical practices—while on the other hand, the stricter practice, management and bureaucratization of clinical investigations try to contain and limit its expansion. ROSENBERG (2006) eloquently asserts that even though the boundaries of disease expand they also remain contested and ambiguous. The growing specificity, despite its advantage of mapping disease and shaping a tool for management of disease, will remain reductionist and inconsistent with the cultural work of diagnosing.

Fluidity also denotes that diagnostic work is an on-going process of trial and error where knowledge and action are intertwined in practice and are not merely the enactment of a linear logic following from pre-set classifications or solutions (MOSER, 2010). From the above outline of nomenclature and the link between category and process, it is tempting to stay within a conventional notion of information processing that accentuates the idea of diagnosing as logical, mostly cognitive individual steps. An almost archetypical image of this is the medical anamnesis that is depicted as a unidirectional, one-person process of gathering information upon which to base a decision, a diagnosis, of the patient's problem. However, the chapters in this anthology move beyond this focus on skills, cognition and often context-free and temporally discrete views of diagnostic work. Rather, the authors recognize the complexity and ongoing dynamic of this work (Büscher, Goodwin & MESMAN, 2010; RISØR, 2017). They point to the many-layered negotiations in diagnostic work which expand the patient's story and examination results through multiple perspectives, including patients' and professionals' medical knowledge and experience, the range of health personnel involved, routine practices, available technology, and bureaucratic structures. These, in collaboration, bring a diagnosis into being. Laurence TESSIER (Chapter 4), attends particularly to how clinicians work with uncertainty and instability when diagnosing dementia. Drawing on fieldwork in a US Memory Clinic, she takes us through sequences of the medical team's interactions and conversations with a patient, her partner, and among themselves to show how a diagnosis is made, how evidence is created and how epistemic difficulties are dealt with. TESSIER asks how it is possible to reach a diagnosis based on very uncertain and even contradicting evidence and argues that "the burden of genetics" stands out as one criteria while the emotionally charged encounter between the clinic director and the patient provides another. In this encounter clues and signs of the person sustain a semiology that gives way to a "Gefühlsdiagnose" where feeling is an instrument and a mediator of diagnosis. Setting a diagnosis based on a mixture of interrelational work and a medical framework is also a theme in Mara BUCHBINDER's analysis (2011) of the explanatory models used in a pain clinic for children in the US. To legitimize the patient's suffering, the clinician uses neurobiological tropes to explain pain, but at the same time the clinician ties the patient's suffering to her/his personality. The patients are smart kids and smartness may make neurobiological circuits

go faster and cause pain. “Being smart” is then employed by the clinician to involve the patient as capable of learning to make the pain disappear, thus engaging moral judgments of being a virtuous and capable person. In other words, a personality is cast while enacting the explanation/diagnosis, and at the same time a personhood diagnostics and a therapeutic resource are mobilized (BUCHBINDER, 2015). Embodied and relational work of diagnostics is also at the core where the reading and vigilant sensing of an aesthetized patient is shown to be essential to the work of anesthetists (GOODWIN, 2010), as well as where the mutual configuration of patient-body and clinician comes forward in an analysis of physiotherapy work emerging from a specific diagnostic space (GARDNER & WILLIAMS, 2015).

Medical practices do not simply discover, define and interpret diagnostic issues. They instead act upon them and by enacting them they also process them into being, differently in different spaces and situations with an impact on how they become and what their consequences are (MOL, 2002; MOSER, 2010). As the above indicates, fluidity exists on several levels and becomes apparent in a number of ways. The mere involvement of people other than biomedical personnel in enacting diagnoses is one way of pointing to a re-understanding of the boundaries of a diagnosis. For example, parents, relatives, patient activists, and social networks are the main actors in all aspects of health where negotiations of diagnoses take place. Anna WITESKA-MŁYNARCZYK (Chapter 2) takes the example of ADHD (Attention Deficit Hyperactivity Disorder), a contested and ambiguous diagnosis that invokes moral values, and shows how this diagnosis is undertaken in the familial context of one child. Situated in a Polish context, the author scrutinizes the interactions between the different family members, and between family members, teachers and psychiatrists to show the stances and positions of each person and the collaborative but not always uniform process of doing an ADHD diagnosis.

Not only families engage as main protagonists in collaborative diagnostic work with relevant others. Health professionals too interact with a range of others within their professional contexts, as well as with the patient himself/herself or relatives in decisive ways. In addition, specific spaces and organizational contexts shape how doctors and nurses of different medical specialties arrive at a diagnosis, as explored by Torsten RISØR (Chapter 7), who examines the diagnostic reasoning of hospital staff surrounding a patient in need of emergency care. RISØR discusses the diagnostic work done by the intern, the attending nurses and

the patient as drawing on two different logics: the logic of pathology and an organizational logic. The latter is shown to overrule the former, and this observation provides not only a critical reflection on pathology as knowledge basis but also positions organizational logic as ubiquitous and necessary for diagnostic work.

Sylvie FORTIN, Annie GAUTHIER and Liliana GOMEZ CARDONA (Chapter 3) also evoke different spaces and pathways to diagnosis and care. The authors explore how medically uncertain and indeterminate symptoms are understood in both migrant and non-migrant families and within biomedical spaces. Through the examination of children's complaints of stomach pain and their care seeking (with their families), differences in explanatory models for stomach pain emerge. These direct the ways of handling children's complaints within the family as a space of care and in the clinical encounters. The authors argue for a need to improve the quality of the clinical encounter and to take into account culturally vested modes of expression. Both the organization in emergency units and the pediatric clinics are spaces ripe with normativity, moral issues, social habits and cultural imaginaries that drive and influence medical decisions and diagnostic work. These examples also foreground the social inherent in any diagnostic work which in turn highlights the importance of the clinical space and how spaces of diagnostic work extend beyond the clinic. The fluidity illustrated in these studies highlights that the order of things is not predetermined. It denotes change, points to flows and interactions between and across actors, bodies, technologies, knowledge and practices in the context of time and space. Fluidity also points to the collaborative nature of diagnosing. Any of these dimensions are socially dense and socially informed. Hence, the social processes inherent in diagnostic work underscore interaction, intersubjectivity and relations.

But what happens in these fluid practices and what are their consequences? Some contributors to this anthology specifically address how affect and/or emotion, used as analytic lenses to explore the fluidity associated with diagnostic processes, configure social relations and define diagnostic meaning-making. Previous anthropological work has been dedicated to the analysis of emotions, affect theory and possible differences between affect and emotion (BEATTY, 2014; LUTZ, 2017). One central strand in these discussions argues that emotions are "the very stuff of social relations" (LUTZ, 2017: 183). Emotions are not private property or individuated, nor are they states that pertain to the inside or

outside of the body (LUTZ, 2017; WHITE, 1994); rather, emotional life is social life consisting of emotional communication and exchange. In this way, emotions are conceptualized as capable of being makers of the world, a social power and a response that constitutes any action based on knowledge, experience and cultural preferences, including diagnostic situations. Emotional discourses organize the moralities and politics of everyday life (LUTZ, 2017), create social realities and direct social behavior. They carry moral implications in language and expression, and are thus more than merely culturally interpreted expressions. Particularly relevant for diagnostic work is the understanding that emotions are fundamentally relational and transpersonal. Emotions are embedded in interpersonal relations and actions and emerge in these, refer to them, and become meaningful in such relations while also having the power to constitute these relations qua emotional actions.

The implications of genetic testing and the estimation of genetic risk for diagnostic meaning-making are central to the contribution from Bernhard HADOLT (Chapter 5) in his analysis of a genetic counseling consultation. Drawing on recent work on affect and emotion in the humanities and social sciences, HADOLT explores whether affectivities are a generative force for creating socialities and meaningful diagnostics. He proposes that “affect and emotion happen relationally between people as an intrinsic part of the social”, and that affect constitutes an integral part of the counseling interaction. This affectivity is further understood as “affective coordination” that relies on the understanding that affect creates affordances and opportunities to react, and so underlines the reciprocal coordination of affective responses. This coordination, HADOLT suggests, guides and performs certain diagnostic practices, favored by specific affective styles, affordances and knowledge claims, whereby “...feelings of hope and fear, strain and relief are ‘built into’ genetic counselling as social practice and hold together its doings and sayings” (ibid.).

Marian KRAWCYK (Chapter 6) explores the diagnosis of total pain within palliative care and its impact on particular forms of care, while also addressing issues of emotion. Like HADOLT, KRAWCYK considers emotions to be intrinsic to social relations. In a detailed case study of a critically ill patient, total pain emerges as conducive to ordering both emotions and conduct towards a good death. At the same time, end of life management is often seen as “affective labor” through which patients and health carers collaboratively create and perform affective environments.

KRAWCZYK argues that despite tensions, resistance and ambivalences in the very process of diagnosing total pain, the affective practices for resolving pain help patients and their relatives to find meaning and achieve emotional closure.

In other words, diagnostic work, combined with affective labor or emotional work, creates realities and subjectivities. Processes of subjectivization are interwoven with the practices of doing diagnosis, with fluidity and permeability in the contexts of ambiguous scientific knowledge, enactments in clinical practice, and negotiations and enactments in everyday life.

Drawing on the above inspiring rich debates involving and surrounding diagnosis, the following chapters showcase new directions and open up innovative perspectives to further understand, analyze and conceptualize diagnosis. This includes a detailed focus on diagnostic work and processes; an emphasis on social interactions - between professionals, between patients/relatives and between patient and professionals; and the integration of affect and emotion as central to the topic of diagnosis. The emerging patterns and fluidity of processes and practices identified in the chapters brought together here evoke scenes of diagnosis as contested and in-the-making, as well as informed, shaped and manipulated by permeable classificatory categories, where subjectivity, intersubjectivity and emotional work become central to the configurations and power of diagnosis.

In the organization of the anthology, we have considered the spaces in which diagnostic work takes place. The chapters in *Part 1: Tensions in everyday diagnostic work* foreground the importance of domestic settings in individuals' and families' everyday diagnostic work, including the diverse sources of influence and information they draw on, and they interrogate the intersection of everyday diagnostic work with the diagnostic work dominant in the clinic. In doing so, the authors draw attention to the role of power and distributed knowledge. *Part 2: Diagnostic negotiations in the clinic* moves to diverse clinical settings. The chapters brought together here examine the ways in which diagnostic work is carried out and shaped in these different contexts, raising critical questions about the notion of evidence, the role of diagnostic technology, the significance of emotion and affect, and the implications of organizational structures to diagnostic processes. The chapters in *Part 3: The power of changing diagnostic categories* investigate nosological categories. By attending to the social

construction of diagnoses and the historical process of medicalization, these chapters highlight the existential meanings of diagnostic categories, and the significance of how nosology and its sociocultural sources have manifested across time and space. By making spatiality a guide to our reading of the chapters and other themes, we illustrate the decisive role of space, setting and knowledge context to making, performing, enacting, contesting, rejecting and living a diagnosis.

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PART 1
TENSIONS IN EVERYDAY DIAGNOSTIC WORK

A DEVIANT DIAGNOSIS? DOCTORS FACED
WITH A PATIENT'S DIAGNOSTIC WORK

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Abstract: Based on a case of a “lay” diagnosis that questions a treatment and leads the patient to decide to cease taking it, this paper examines the patient’s protracted journey, the conditions in which he made the diagnosis, the reasons for his decision and the doctors’ reactions to this. This case study allows us to investigate the patient’s relationship with medical authority and to reflect on fundamental issues such as pharmacovigilance, demedicalisation and patient agency.

Keywords: diagnosis, demedicalisation, medication, pharmacovigilance, patient agency, empowerment

¿Un diagnóstico puesto en duda? Los médicos frente a la diagnosis de un paciente

Resumen: A partir de un caso de diagnóstico ‘profano’ que pone en duda un tratamiento y lleva al paciente a decidir interrumpirlo, analizamos aquí sus andanzas, las condiciones de elaboración de su diagnóstico, los motivos de su decisión, y las reacciones de los médicos. Este caso plantea preguntas sobre la relación del paciente con respecto a la autoridad médica, y aborda cuestiones fundamentales como la farmacovigilancia, la desmedicalización, y la *patient agency*.

Palabras clave: diagnóstico, desmedicalización, medicamentos, farmacovigilancia, *patient agency*, empoderamiento

« Le propre du savoir n'est ni de voir ni de démontrer, mais d'interpréter »
("The peculiarity of knowledge is not to see nor to demonstrate, but to interpret"),

Michel FOUCAULT, *Les mots et les choses*, Gallimard, 1966 : 40.

In their endeavour to lay the groundwork for a sociology of diagnosis, NETTLETON and JUTEL, following Phil BROWN (1990) highlighted that diagnosis "forms the foundation of medical authority", while adding that "medical diagnoses are also contested, socially created, framed and/or enacted" (NETTLETON and JUTEL, 2011: 793). They noted that: "even in our contemporary era, where a greater emphasis is placed on the lay person to play a more active role, the diagnostician in the medical setting remains a key arbiter and thereby still holds significant jurisdictional authority" (NETTLETON and JUTEL, 2011: 796).

Though diagnosis usually forms the foundation of medical authority, it can challenge this authority when it is made by the patient against medical advice. While diagnostic activity is normally undertaken by health professionals, the task can also be assumed by patients, especially when the doctors have failed to find the cause of an ailment. In self-medication in particular, the patient makes a diagnosis as one of a series of stages: clinical self-examination, self-diagnosis, self-prescription and self-medication (FAINZANG, 2016). But this activity can also occur while receiving healthcare from a medical institution, in parallel to assessment, diagnosis and therapy proposed by a health professional.

The analysis undertaken here examines a case of a lay diagnosis and the therapeutic and social practices associated with it. I will examine the conditions in which the diagnosis was made, the role it played in the patient's life, the doctors' reactions to it and the solution proposed by the patient. Using this case, I will shed light on the social treatment of a diagnosis when it is made by a non-professional. I will show that patients can play a decisive role in forming a diagnosis, and yet demonstrate the limits of patient empowerment when they undertake diagnostic activity and examine how professionals receive such a "deviant" diagnosis.

Method

The data were collected during a research project financed by ANSM (The French National Agency for Medicinal and Health Products Safety) on lay management of medicinal risk, i.e. on the choices patients make to modify their treatment or the modalities of their medicine intake to manage the risks they associate with the drugs in question. This research was conducted using qualitative ethnographic research techniques. The bulk of the data was collected from users through interviews concerning, and observation of, their practices regarding drug risks. The material and observations presented here were gathered by spending time with the patients over a long period. Some were introduced to me by doctors, while others I met through the snowball method, whereby each informant would be asked to nominate one or more people they knew. As a contribution to research on pharmaceutical risk management, the questions at the centre of these interviews and observations looked at whether the treatment was, or was not, followed —i.e., practices where the prescribed medicines were modified, reduced, substituted or abandoned altogether— and the reasons for and mechanisms of these modifications. The research participants were invited to relate their health problems, the conditions under which they chose either to consult a doctor or to treat themselves, how their doctors had dealt with these problems, the medicines that had been prescribed to them, which of these they took or did not take or which medicines they modified the prescribed dosages, the resources they used to identify the problem and select the appropriate treatment, and the strategies adopted to ensure what they considered to be a satisfactory risk/benefit ratio. My presence at the homes of these respondents allowed me to see the medicines they had in their medicine cabinets and the ongoing drug treatments they stored in various places within the domestic space. I could also observe the place they assigned the drugs and drug information leaflets in their materiality and the uses made of them.

The account given here is the result of a meticulous reconstruction of the episodes of illness experienced by one patient, André. I describe the therapeutics he undertook to resolve a painful symptom and the actions and reactions of the different actors (the doctors consulted and himself). The events described here are based solely on the patient's accounts. It was very tempting to also ask the doctors for their accounts but I eventually decided against this out of respect for André (to not appear to be assessing his discourse with regard to what the doctors would say), and out of

consideration for the doctors who could perceive my questions as a criticism of their behaviour. I also wanted to avoid interfering with the doctor-patient relationship or modifying the situation being studied.

The fruitful nature of an analysis based on a case study has been comprehensively demonstrated. Gareth WILLIAMS (1984; 1993) showed that collecting illness narratives, and using *one* individual case study, allows us to see not only how people assess the origin of their illness, but also to analyse the wider social cultural values in which it is situated. The heuristic value of using one individual's story resides in the fact that the story itself contains a collection of information on the values, norms and models of the social world into which it fits. In this regard, M. BLAXTER (2004) also showed that the stories told by people are a demonstration of a broader cultural world within which their story takes place and, writing at an earlier date, that the narratives are as much accounts of a particular culture and period as of individuals (BLAXTER and CYSTER, 1984).

However, this article is not a study of a narrative. The case study is based on different pieces of information that the participant provided over the course of multiple interviews. It means that, on the one hand, the subject reconstructs his history (BOURDIEU, 1986). Bourdieu showed that, in creating a narrative, the subject relates lived events, but not necessarily in their chronological order. The subject chooses certain meaningful incidents and links them, in order to justify their coherence and assign them a meaning. This is what led Bourdieu to consider the life story to be a biographical illusion. But this means, on the other hand, that the subject's reconstruction is paralleled by that undertaken by the anthropologist to determine the chronological thread. At no point did André provide the entirety of the account as it is described here, and in this regard, my approach is distinct from that of C. RIESSMAN (1990; 1993), who, in her reflection on narrative analysis, explained that she was told lengthy narratives that she transcribed prior to textual analysis of biographical accounts of illness. My work of reconstruction did not consist of transcribing a long story, but of slowly and patiently building a story whose thread was reconstituted through numerous interviews. This prevented me from relating a continuous account in the first person and in quotation marks, but did nevertheless allow me to highlight the causal relationships established by the interviewee and the logics underpinning the social practices at work. It was thus a case of respecting, not the way in which the interviewee organised and constructed his account, but the way in which he attributed meaning to his experiences.

The Odyssey of a lay diagnosis

André, now 85 years old, experienced extreme pain in the stomach as a 14 year old when his parents were deported to Auschwitz. He attributes the emergence of his pain to his family history and associated distress and trauma. Doctors discovered he had a stomach ulcer for which he received medicinal treatment (a gastric bandage) for several years, but without significant effect. A few years later, after having suddenly lost 7 kg in weight, the doctors decided to operate. His duodenum was removed and the pain subsequently stopped. When he was 42 years old, André had a heart attack, and was then prescribed a number of drugs, including Kardegic® (a medicine based on aspirin used to thin the blood and thus prevent the formation of blood clots in the arteries). At the age of 74, André moved to another town and changed his GP. While consulting for stomach acid reflux, his new doctor decided to prescribe Omeprazole (an anti-ulcer agent in the protein pump inhibitor family), having learnt of André's gastric history. Regular intake of Kardegic® was likely to lead to stomach inflammation, and the Omeprazole prescription aimed to mitigate this risk. It was even more necessary in the doctor's opinion because André's medical history made him particularly vulnerable to stomach problems, and thus the prescription was regularly renewed.

A few years later, André began to experience increasingly severe stomach pains and pains in his pelvic bones. The pain was such that he couldn't sleep ("It was like lying on knife points!" he explained). His GP referred him for various tests (x-rays, MRI scans) and when he found nothing to explain such symptoms, sent him to see a rheumatologist, thinking he was probably suffering from arthritis. But the rheumatologist found nothing to explain such pain. André then consulted several more specialists. On the advice of his cardiologist, to whom he had spoken about the pain, André also consulted a gerontologist, who could not find the cause of the problem either, and referred him to another rheumatologist. André's pain continued for several years. André underwent various tests (blood tests, x-rays, pelvic scans, bone scans, MRI scan of the pelvis and hip, osteodensitometry, etc.). But all the results showed negative. The radiologist proposed a hypothesis of Paget's disease (a bone disease). But this was soon refuted by other doctors since the relevant tests did not confirm it. During this time, André's pain became more and more severe.

One day, his GP changed the wording of his prescription, writing Mopral® (the commercial name under which Omeprazole is sold on the French market) instead of the molecular name (the international non-proprietary name). When André noticed that it was not the usual packaging, he thought it must be a generic and decided to read the accompanying leaflet. There, he read that: “Longterm use of Omeprazole (for over a year), or other protein pump inhibitors, can lead to an increased risk of fractures of the hip, wrist and vertebrae”. The leaflet did not mention the potential for extreme pain, but said that the risk of fractures increased when the drug was taken for longer than one year. Intrigued by this information of a potential for the drug to have a negative effect on bones, he did some research on the Internet to find out more about the drug. His online wanderings took him to a forum where many people described the adverse effects they had suffered which they attributed to this molecule. Although no-one reported the same symptoms as André, the description of these numerous adverse side-effects led André to think that what he was experiencing was another side-effect of the drug. He found an account from a woman pointing to a government Canadian website describing the risks of osteoporosis from taking Omeprazole over long periods. This site, hosted by the Canadian Ministry of Health, published an Incident Report on 4th April 2013 entitled: “Protein pump inhibitors: bone fracture risk”. The report said:

Health Canada would like to inform Canadians and Canadian health professionals of the risk of bone fractures associated with the use of medicines known as proton-pump inhibitors (PPIs) [...] Health professionals should closely monitor patients with risk factors for osteoporosis who take PPIs, and must report any adverse effects to Health Canada [...] and they must prescribe PPIs at the lowest dosage and for the shortest possible time period in relation to the affliction being treated [<http://canadiensensante.gc.ca/recall-alert-rappel-avis/hc-sc/2013/26523a-fra.php>].

On reading what he called “the Canadians’ article”, to which he paid particular attention because it came from an official authority, André commented: “They say to take it for a maximum of one year, otherwise it attacks the pelvic bones! And that’s just it, I’ve had terrible pelvic pain for 4 years now! I’ve been taking it for 6 years!” Once he became aware of the risks of taking the medicine over the long term, he decided to discuss this with his GP, to whom he explained that he suspected Omeprazole was causing his severe hip pain. But the doctor replied: “No, there is no risk with that; this drug poses no risk at all.”

Nevertheless, the pain continued. So André decided, on his own initiative, to stop taking Omeprazole, “just to see what happens.” He told his cardiologist who he saw shortly after. As he explained, this revelation was easier to make since it was not this doctor who had prescribed the treatment. The cardiologist replied: “You did the right thing, we’ll see now what happens”. He did not however tell his GP. At their next consultation, he asked the doctor what he thought about stopping this treatment, without saying he had in fact already stopped, for fear of the doctor’s disapproval. The doctor replied: “It most certainly is not that! If you are taking Kardegic (the aspirin), you absolutely have to continue with the Omeprazole”.

André’s decision to stop the treatment was intended as an experiment. Two months in, he was feeling much better, and the pain lessened each day that passed. He had less and less bone pain, and no more heartburn. Four months later, he saw his GP again, and “confessed” that he had completely stopped taking Omeprazole. The doctor proved sceptical and warned him: “You are running the risk of having a hole in your stomach if you don’t take it!” raising the prospect of a recurrence of an ulcer. André then answered that he was willing to start taking Omeprazole again to see if the pain returned, but the doctor replied, “no, best not,” while nevertheless maintaining that this drug could not be causing the pain. As a precaution, he referred him for a gastroscopy to assess the state of his stomach, which showed no lesions.

Later, André consulted his rheumatologist, to whom he also revealed that he had stopped his Omeprazole treatment and that he had been feeling much better since. This doctor also appeared doubtful. He said to André: “No, there is no problem with this medicine. No, no, I would have heard about it!” Once again, André answered:

Doctor, four months after stopping the treatment, the pain has disappeared. It must be that, isn’t it? I don’t know. I am a philistine, I’m not a specialist, but there really must be some link! Isn’t it possible that my body has finally eliminated the Omeprazole?

In response to the doctor’s incredulous expression, he added: “I could start taking it again if you want, to see if it is that!” But again the rheumatologist responded: “Hmm, I would not advise that”. Later, André consulted his gerontologist, to whom he explained the situation, but once again, the specialist answered that it could not be that.

Today, the pain has completely disappeared. André says he is astonished both by the side-effect of the treatment and by the doctors' attitudes since all (generalist, gerontologist, rheumatologist) except the cardiologist refuted his hypothesis the origin of his pain was long-term intake of Omeprazole. His opinion of their reactions is:

They all say it isn't that, but when I say that the best way of knowing is to start taking it again, they don't want me to. I don't know, but if I heard a patient saying that, I'd look into it, I'd check it out. But maybe they are too scared that it will start again and that will prove me right! They don't want to learn anything from a neophyte!

None of this has eroded André's trust in doctors; nor has it led him to distrust biomedical or scientific expertise. He simply condemns the lack of regard given to his reasoning, which he says modestly, is the opinion of a non-expert, a neophyte - but nevertheless thinks he is right.

This case provides a particularly interesting exploration of the stakes and social implications of doctors' attitudes towards both the medicine and the diagnosis proposed by a patient. How can the disagreement between André and his doctors be understood and what conclusions can be drawn from it? What does it say about patient empowerment? What can we deduce from it about the process of medicalisation?

A "lay" diagnosis

Firstly, I will explain my use of the term "lay". The notion of "lay" knowledge, brought to prominence by FREIDSON (1984), has seen great popularity in the social sciences. Many studies have used it as distinct from scholarly knowledge, and have undertaken analysis of the relationship between expert categories (professional knowledge) and non-expert categories (BECK, GIDDENS, and LASH, 1994; MESNY, 1998; WYNNE, 1996). The category of "lay knowledge", referring to what patients know (McCLEAN and SHAW, 2005; BUREAU-POINT and HERMANN-MESFEN, 2015; BRITTEN and MAGUIRE, 2016), has nevertheless been disputed by some sociologists (e.g. EIDELIMAN, 2008) because it implies a reduction of the patients' point of view to a subjective one and thus disqualifies the non-medical point of view. But the notion of "lay" has also been criticised by anthropologists, who believe it involves seeing the patient through the doctor's eyes, which goes against the emic position required in the anthropological method. We

can add to these criticisms the fact that, considering that expert knowledge is frequently appropriated by lay knowledge, the result is no longer truly “lay”. Or again, the fact that the notion of expert-patient now in common usage (EPSTEIN, 1995; BOLAM, GLEESON, and MURPHY, 2003; FOX, WARD, and O’ROURKE, 2005) leads to a blurring of the distinction between lay and expert knowledge. The notion of expert-patient was dismissed by PRIOR (2003) who, in a more nuanced way, demonstrated the limits of lay expertise since lay people “are not (as lay people) skilled and practised in the diagnosis and management of illness” (PRIOR, 2003: 53).

However my intention is not to voice an opinion on the concept of a lay expert which, as COLLINS and EVANS (2002) pointed out and as PRIOR (2003) reiterated, sounds like an oxymoron. Instead, I intend, from an emic position, to consider André as lay in that he himself defines himself as such. Lay is the appropriate term here to account for the respective positions of André and his doctors, and to qualify the diagnostic work undertaken by this patient. Because his opinion is lay, the doctors object to the diagnosis. Moreover, he describes himself as a philistine, a neophyte and a non-specialist, in contrast to experts. Here, I will examine the social treatment of this lay diagnosis to explore the extent to which the patient’s discourse on his affliction is judged legitimate.

Agency and empowerment: the patient’s diagnostic work

Medicines can play a significant role in diagnosis, notably when practitioners identify an illness based on the patient’s response to treatment since the diagnosis is guided by the disappearance of a symptom (NICTER and VUCKOVIC, 1994). Drugs can also play this role in the patients’ eyes, when the person undertakes the treatment of the symptom him/herself (FAINZANG, 2016). Within this process, the disappearance of a symptom can lead the patient to conclude that the medicine was the right one and thus he/she can identify the problem or, on the contrary, the persistence of the symptom can lead him/her down another route. In both cases, the drug helps to form a diagnosis. In the case studied here, the appearance of a symptom followed by the discovery of the adverse side effects of a drug leads the patient to conclude that it is the drug causing the affliction. The response to the treatment is identified with the ailment itself and the iatrogenic effect is an integral part of the aetiology of the illness.

The patient's reasoning —based on his own bodily experience, on reading the information leaflet, and on information obtained through Internet research— is structured into two stages. André's hypothesis that there is a link between the risk of the drug weakening the bones and his own bone pain, which leads him to stop his treatment "to see what happens", is confirmed when the pains disappear. In this regard, he follows a line of reasoning that is similar to medical reasoning, since it takes into account the link between the body (appearance followed by disappearance of a symptom) and the presumed pathogenic agent, and is based on experience (ELSTEIN, SHULMAN and SPRAFKA, 2014). However, the diagnostic work always involves a degree of interpretation. Not only is it based on the concomitance of stopping a treatment and the disappearance of a symptom, but it also establishes a link between the risk of osteoporosis and bone pain, even though osteoporosis is not considered to be painful as long as no fracture occurs. In the manner of professionals resorting to semiology in order to convert signs and symptoms into diagnoses (NESSA, 1996), the patient formed a diagnosis as a result of the link he made between a risk and a pathology based on their connection with an ailment of the bones.

Here we can see the limits of the opposition between lay and expert knowledge, even if the two are evidently not equivalent. Besides, apart from the fact diagnostic activity is not a strictly individual act, in as much as the diagnostic process is always the product of multiple influences (discussion forums, personal accounts, information leaflets, official websites etc.), we can see that aligning the opposition between lay and expert knowledge with the distinction between objectivity and subjectivity is inadequate. On one hand, André's lay diagnosis is neither exclusively nor necessarily subjective since he borrows from objective medical reasoning. On the other, as we will see, the doctors' reactions to the patient's diagnosis are not exclusively objective.

When diagnosis challenges medicalisation

The issue of medicalisation has been the focus of a number of scholars, whether in support of the Foucauldian perspective where the problematisation of phenomena is thought to be based on medical knowledge and categories of thinking, or to criticise the expectations and implications of this idea (see BERLIVET's 2011 review on the subject).

But the medicalisation and the decoding of a symptom that precedes the diagnosis is not the exclusive preserve of healthcare professionals. In the context of self-medication in particular, forming a self-diagnosis consists, for the patient, of converting a symptom (or a pain) into a sign of a pathological state, leading to the need to medicalize the problem (FAINZANG, 2016). Moreover, once the patient makes his/her own diagnosis, notably when there is a disagreement between the doctor and the patient as to the cause of the affliction and the means of solving the problem, lay diagnosis can lead to recourse to a medication that goes against the doctor's advice and the patient him/herself can end up self-medicalising his/her case, potentially carrying political meaning (FAINZANG, 2013).

In view of the numerous works on what is commonly called compliance or adherence (an idea more in agreement with the concept of shared decision-making in medicine [BLACKWELL, 1976; DUNBAR and STUNKARD, 1979; SANDMAN, GRANGER, EKMAN *et alii*, 2011]), the case considered here invites us to reverse the perspective. Firstly, the diagnosis is proposed by the patient when no medical diagnosis has been made, and the disagreement on the patient's diagnosis comes from the doctor. Secondly, the decision to stop the treatment does not stem from non-compliance but rather from a decision in keeping with the diagnosis and critical examination of the effects of treatment, even though this treatment, and so medicalization, was preventative. Here, the patient's diagnosis gives rise to demedicalisation. The lay diagnosis brings the prescribed treatment into question, and this questioning challenges the doctors' knowledge. The patient responds to the doctor's preventative *medicalisation*, with a preventative *demedicalisation*.

While the diagnostic process is a central feature of debates on medicalisation (NETTLETON and JUTEL, 2011), it has not been explored in terms of its impact on demedicalisation. Yet, here, the diagnosis leads to the termination of a treatment. In this regard, in counterpoint to Nicolas

ROSE's claim that "diagnosis leads to treatment" (ROSE, 2006: 466), the diagnosis can have the opposite effect and lead to the withdrawal of a treatment. But the difficulty here is that the diagnosis was made by the patient and went against the doctors' opinions. At stake is not only what the diagnosis says and the etiology of the affliction in question, but also what the lay diagnosis tells us about patient agency and the power relations between patients, doctors and authoritative bodies.

It is often underlined in the literature that patients are social actors. The configurations described sometimes underline the patients' reluctance to accept a medical diagnosis. ROSE (2006) noted that patient responses to medicalisation are not necessarily passive. He shows moreover, with nuance, not only that patients may express resistance and tension linked to being labelled as ill but also that, in engaging with the images and narratives created by "Big Pharma," individuals play their own part in the medicalisation of problems of living. Other works highlight the complementarity of the patient's role with the doctor's one. A. MOL (2002) thus showed that patients not only experience bodily states or "have" a disease, but, like the physicians, they "do disease" since they undertake a series of practices, connected to physicalities, that influence the process: "The "disease" that ethnographers talk about (...) depends on everything and everyone that is active while it is being practised. The disease is *being done*" (MOL, 2002: 32). Equally, when JUTEL (2015) recognises the patient's role in diagnosis, this role is defined more precisely as pre-diagnostic work: "The lay person does pre-diagnostic work as he or she decides to seek medical attention for what ails him" (JUTEL, 2015: 847). The pre-diagnostic work is subject to the doctor's opinion and can sometimes form the first step in a medical diagnosis.

Yet, the case discussed here is different. There is neither resistance to nor complementarity with the doctor's diagnostic work. Consequently, the mechanism examined here is a double reversal of the situations described in the literature: on the one hand, the diagnosis is the patient's work; on the other, it is not the use of the drug that leads to a diagnosis but the identification of a risk linked to its use which forms a de facto challenge to the doctor's clinical, diagnostic and therapeutic practice. Although the diagnosis is deemed to be the foundation of medical authority (NETTLETON and JUTEL, 2011) and of the medicalisation it may entail, it can, paradoxically, be the foundation of a demedicalisation.

Risk management: half-hearted pharmacovigilance

Today, more than ever, pharmacovigilance is highly valued by the health authorities (WHO, 2008) and various measures have been taken to enable citizens to contribute. In France, while the 2011 law designed to strengthen health safety requirements for medicines and health products *oblige*s health professionals to report all serious or unexpected adverse effects not mentioned in the patient information leaflet, it also made it *possible* for *all* actors in the medicine chain to report any adverse effect suspected of being caused by medication. Users are also encouraged to contribute, either by informing their doctor or pharmacist (patient information leaflets are required to include the following: “If you notice any adverse effects not mentioned in this leaflet, please inform your doctor or your pharmacist.”), or by reporting directly to a pharmacovigilance centre, as they are invited to do by the ANSM [[http://ansm.sante.fr/Declarer-un-effet-indesirable/Pharmacovigilance/Centres-regionaux-de-pharmacovigilance/\(offset\)/4](http://ansm.sante.fr/Declarer-un-effet-indesirable/Pharmacovigilance/Centres-regionaux-de-pharmacovigilance/(offset)/4)].

Yet, although André made his doctors aware of the harmful effects that he believed to be caused by the drug, and even though they refused to let him take the drug again, these doctors did not report these side-effects —not mentioned in the leaflet— to a pharmacovigilance centre. The exception was the cardiologist, who was not the prescriber and who told André that he had communicated his problem to the pharmacovigilance service at the hospital, although André was never contacted by this service). The invitation made to patients and the obligation made to health professionals to report any unknown adverse side-effect does not seem to produce results as regards professional behaviour. No better results are achieved in encouraging patients to become actors in such reporting: when I asked him whether he himself had reported the effect on the ANSM website, André answered that he did not know about the site and he hoped the doctor or the pharmacist would do it. It should be noted here that, according to a study carried out over 8 years at a regional pharmacovigilance centre (GUÉDAT, GOURAUD and RAMIAH, 2012), under-reporting remains a significant obstacle to evaluation in pharmacovigilance. Pharmacists report very few adverse side-effects in France and very few of the reports made lead to a side-effect being validated by the CRPV (primarily because pharmacists believed there was no causal link between the adverse side-effect and intake of the medicine).

Should we see the doctors' denial of André's diagnosis as a tendency to reject any discourse that goes against expert knowledge, or as the result of doctors lacking information about pharmaceuticals and their tendency to be passive recipients of pharmaceutical laboratory information diffused by medical sales representatives (GREFFION, 2014; MINTZES, MANGIN, HAYESET *et alii*, 2013 [2009])? In support of the assumption that the pharmaceutical industry would organize an intense promotion of this drug to doctors because of the commercial interest of its sale, it should be noted that the anti-ulcer family of drugs, of which Omeprazole is a member, is one of the main expense items for health insurers and the second most sold family of medicines in France, with sales figures of 1 billion euros in 2006 (ROMAND, 2009).

The lost authority of the diagnostician?

Because diagnosis “forms the foundation of medical authority” (NETTLETON and JUTEL, 2011: 793), health professionals dismiss lay diagnosis. In taking hypotheses made by patients into consideration, doctors see a risk of the lay diagnosis being confirmed, and this would shake the foundations of their authority. André's diagnosis is rejected because it is at odds with expert knowledge. The patient information leaflets and the information diffused by medical sales representatives or through studies published in medical journals appear to be the only acceptable sources of information. However, not only do they refute the diagnosis of iatrogenesis proposed by the patient, they also paradoxically advise him not to start taking the incriminated medicine again. The doctors' simultaneous refusal of the patient's diagnosis and refusal to let him return to taking the drug he suspects is causing the pain renders the situation more complex and makes the status of patient empowerment uncertain. Although the doctors do not share André's point of view and reasoning, they take note of them, refuting and validating them at the same time. The health professionals accept the patient's diagnostic activity on a practical and empirical level, but reject it on a theoretical and cognitive level.

We should stop a moment on this paradox that while the doctors refute André's diagnosis, they validate his decision to not take the medicine again. The situation here results from a combination of denial of the patient's reasoning and fear that his symptoms may return. Thus,

beyond the iatrogenic risk, the doctors appear to want to avoid a social risk—the risk of losing face in front of the patient, whether by accepting his diagnosis or permitting him to take the medicine again. For the doctors, admitting that the diagnosis made by the patient is correct or relevant would challenge their own competence and amount to a recognition of their own fallibility (unfamiliarity with the contents of the information leaflet or the adverse side-effects of the drug, lack of awareness of the documents and recommendations discovered by the patient on the Internet, and persistence with the prescription). It is thus a matter of simultaneously managing two risks from two different registers: one physiological and one social.

This case study illuminates the limits of the role as an actor in diagnostic work granted to the patient. This role appears only admissible if it complements that of the doctor. Not only does the lay diagnosis challenge medicalisation since it gives rise to a demedicalisation, but it also tells us something about the power relations between patients and representatives of medical authority and about the social treatment of patient agency when medical knowledge is questioned. In response to the biopower held and embodied by the prescriber, the patient wields a counter power, the strength of which lies in his diagnostic reasoning. The lay diagnosis, by positing an iatrogenic effect denied by the doctors, undermines the very structure that dictates the positions and roles of the actors involved.

The subversive nature of a diagnosis

The notion of deviance, as devised by the second Chicago school (LEMERT, 1951), involves three elements: a norm, a transgression of this norm and a social reaction to the transgression of this norm (MUCCHIELLI, 2014). The contradictory elaboration of a diagnosis by André (and the challenge it implies to the prescribed treatment) is deviant in that it transgresses the positions assigned to doctors and patients, and the fact that the diagnostic activity is considered to normally come within the competence of the doctor alone, as the classification tool of medicine (GOLDSTEIN JUTEL and DEW, 2014).

On this subject, some authors (SOMMERHALDER, ABRAHAM, ZUFFEREY *et alii*, 2009; ROMIJN, 2016) record numerous patients not letting the doctor think that they have made their own diagnosis and not

communicating this diagnosis when they have made one, in order to avoid being in the position of competing with the doctor and not damage the doctor's authority.

Not only does André's diagnosis not conform with the doctors' diagnosis, he proposes an alternative explanation, challenging their ability to ascertain the cause of the affliction. Moreover, he questions the doctors' behaviour in not anticipating the termination of an iatrogenic treatment and in not validating his diagnostic hypothesis. The lay diagnosis thus becomes *subversive*, not only because it threatens the doctors' authority and knowledge, but also because it goes against the phenomenon described by EBELING (2011), where the marketing of self-diagnosis by drug companies aims to create well-educated consumers who demand medical diagnoses in line with a drug company's objective.

The doctors' reluctance to investigate the validity of the diagnosis proposed by André, and his disqualification from the start, are neither exclusively nor necessarily objective. These are expressions of their subjectivity, constructed by their socialisation in a world dominated by pharmaceuticalisation and the hegemonic discourse of the pharmaceutical industry. Lay appropriation of expert knowledge (BECK, GIDDENS and LASH, 1994) is verified by the type of diagnostic reasoning André undertakes, and is matched here with what we could call an expert expropriation of lay knowledge, in accordance with MESNY's (1998) observation that: "showing that lay people appropriate expert knowledge has often been a way to oppose the view that expertise "expropriates" lay people, by undermining their own "local" knowledge, and by depriving them of their capacity to deal with the problems that they encounter in everyday life" (MESNY 1998: 32).

The quest for a diagnosis is not considered to be something the patient should take on, despite increasing calls for ill people's voices to be heard (BRAY and CASAL, 2014). The idea remains that the doctor should know how to listen to the patient, his/her history, complaints, etc. to be able to form a diagnosis. But this listening rarely includes taking into account any diagnostic reflection. While it is now accepted that patients possess experiential knowledge (JOUET, FLORA and LAS VERGNAS, 2010), this leaves little space for a rational, analytical, even diagnostic, lay knowledge. Attributing an exclusively objective approach to the illness to the doctor and an exclusively subjective one to the patient contributes to constructing the basis for failure in pharmacovigilance. While the notion

of health democracy now seems to be accepted and validated, one of its forms—which could be called *pharmacovigilant democracy*—remains the object of great resistance, since it threatens the social role assigned to patients.

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ENACTING ADHD DIAGNOSIS
IN THE LANDSCAPE OF CARE IN POLAND¹

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Abstract: I present a case study of one boy's ADHD diagnosis understood as a collaborative, dispersed and asymmetrical social process marked by uncertainty and conflict. I explore the ways in which the psychiatric label is enacted in the everyday life of a middle-class family in a medium-sized Polish town. The paper adds to the literature on *contested illness* as well as foregrounding the significance of the *non-medical* in a diagnostic work.

Key words: ADHD, Poland, medical anthropology, psychiatric diagnosis, contested illness.

Realizar el diagnóstico del TDAH en el contexto de la sanidad en Polonia

Resumen: Presento el estudio de caso de un niño al cual diagnosticaron TDAH entendido como un proceso social colaborativo, disperso y asimétrico marcado por la incertidumbre y el conflicto. Analizo las maneras en que se pone esta etiqueta psiquiátrica en la vida cotidiana de una familia de clase media en una ciudad polaca de tamaño medio. Por un lado el artículo se inscribe en la literatura de las enfermedades cuestionadas; por el otro, destaca la importancia de los aspectos no médicos en el proceso de diagnóstico.

Palabras clave: TDAH, Polonia, antropología médica, diagnóstico psiquiátrico, enfermedad cuestionada

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The encounter between childhood and psychiatric knowledge and practice is rapidly expanding in the contemporary world (CONRAD, BERGEY, 2014). Among other things, advances in developmental science, neurobiology and pediatric psychiatry have resulted in a new way of becoming for contemporary children – ADHD, i.e. through the diagnosis of Attention Deficit Hyperactivity Disorder (CONRAD, 1976; ROSE, SINGH, 2009). This psychiatric diagnostic category involves symptoms of hyperactivity, inattention and impulsivity that are scrupulously described and quantified in the diagnostic manuals². The label, which itself has a long social and conceptual history (CONRAD 1976), has found a home in Poland³ where both the International Classification of Diseases (ICD) and the before Diagnostic Statistical Manual (DSM) are used in psychiatric practice; they also inform the bureaucratic and legal management of “special educational needs” of children in schools. The epidemiological data on ADHD prevalence in this country are limited. Medical experts claim that 3-5% of children in elementary schools in Poland “malfunction” due to the ADHD symptoms (see: KOŁAKOWSKI, WOLAŃCZYK, PISULA *et alii*, 2010: 30). According to the data from the National Health Protection Fund (Narodowy Fundusz Zdrowia, NFZ), in 2015 Polish doctors⁴ diagnosed hyperkinetic disorder⁵ in 13,827 children aged 6-13 (approximately 0.5% of the overall primary school population). The data also suggest that the number of children diagnosed is steadily increasing. Between the years 2009 and 2015, there was a 100% increase in diagnoses.

2 Both the Diagnostic and Statistical Manual of Mental Disorders (DSM) and the International Classification of Diseases (ICD) classify inattentive, hyperactive and impulsive behaviors in children respectively under the label of ADHD and the Hyperkinetic Disorder.

3 The Polish medical research has a modest history of applied research on hyperkinetic and inattentive behaviors in children (NARTOWSKA, 1972) dating to before the ADHD and hyperkinetic disorder nomenclature became settled.

4 The number is underestimated. It counts diagnoses made by child psychiatrists and neurologists who work in health centers contracted by the National Health Protection Fund. It does not include diagnoses made by doctors working in private practice or those by educational psychologists or therapists working in both private and public entities.

5 In Poland, the National Health Protection Fund (Narodowy Fundusz Zdrowia, NFZ) uses the International Classification of Diseases (ICD) nomenclature in the process of bureaucratic management of healthcare. This does not imply that psychiatrists do not use DSM in their diagnostic work.

ADHD – a contested diagnostic process

For social scientists, ADHD brings in an immediate association with the concept of *medicalization*, which challenges the growing extent to which medical knowledge and practice infiltrate the everyday lives of children. As described by David ARMSTRONG for Britain the twentieth century development of the child as an object of medical concern meant, among other things, establishing what could be referred to, in the language of developmental psychopathology, as “a normal child” (ARMSTRONG, 1983: 55-56). Mass and compulsory education resulted in the growing “visibility of childhood” as well as enabling the “gaze over the mind of the developing child” (59-60). American sociologist Peter CONRAD provided a critical reflection on such a process through which various deviant behaviors by children, including *hyperkinesis*, have come under medical jurisdiction in the United States of America. The ADHD diagnosis, in his view, has constituted a new form of social control. The medical discourse, tightly linked to the workings of state bureaucracies, provided a material from which the boundaries of pathology and norms in children’s bodies and behaviors have been drawn (CONRAD, 1976). From this critical perspective, the ADHD diagnosis medicalizes what is in fact normal childhood behavior, in boys in particular (CONRAD, 1976; CONRAD & POTTER, 2000).

Other sociological works on ADHD have traced the ways in which medical definitions of children’s deviant behaviors have advanced in non-medical spaces, such as educational and domestic spheres, changing both the environments and the interactions that unfold within them (MALACRIDA, 2004; ALLAN & HARWOOD, 2016; RAFALOVITCH, 2001). Recent neuropsychiatric findings and diagnoses, such as ADHD, transform the everyday lives of people involved in the diagnostic processes, molding their thoughts and ways of understanding children, directing their actions and feeding their anxieties. Sociologist Linda BLUM expresses her reservations about a strictly constructionist view of “invisible disabilities” such as ADHD, arguing that they are both real and embodied and should be understood as “cultural inventions specific to our time and place” (BLUM, 2015: 7). I share her conviction that what we research is a real lived experience anchored in the dialectics of biology and culture. The ethnographers’ analytical engagement with the interactions taking place between developmental psychopathology, family systems, communities and culture may prove very fertile (GUZDER & ROUSSEAU, 2010: 683).

A number of detailed ethnographic and sociological accounts present the voices of parents raising children with “invisible disabilities” (BLUM, 2015; FRANCIS, 2015; GARRO & YARRIS, 2009; MALACRIDA, 2001). These works shed light on the organizational routines and the sense-making activities undertaken around ADHD in the North American context. Writers using the feminist sociological lens gave us some careful insights into the struggles of variously positioned mothers, who navigate the lives of atypical children while facing the social stigma associated with the label (BLUM, 2015; MALACRIDA, 2001). These accounts allow us to listen to the voices of women who are the primary caregivers of “difficult” children, and whose care work is central to the local construction of normative femininity. These women carry an unusual burden of moving between and negotiating the complex medical and educational bureaucracies in the name of the wellbeing of their children (BLUM, 2015; MALACRIDA, 2001). When contextualized, their stories provide a critical commentary on life in the era of the neoliberal economy marked by the lack of public provisioning, changes in family structure and gender roles, and pharmaceutical innovations progressing along the logic of commercial interests (BLUM, 2007: 203). In this book chapter, I dialogue with the aforementioned works by paying close attention to the figure of a mother and the acts of care she performs. In the post-socialist context of Poland, the neoliberal values and the grammar of Western lifestyles clash with the traditional, conservative images of family life and gender roles, while the ideas of rights to proper child care in public institutions intermingle with new notions of individualized parental responsibility for a child’s success.

This analysis will treat the maternal voice as one of many that mold the ADHD experience. After Linda GARRO, I “broaden the analytic lens to explore health and well-being as ensconced in everyday family life and as bound up in relational connections with other family members” (GARRO, 2013: 193; GARRO & YARRIS, 2009). A family-level approach differs from an individual-level approach as it reveals the complexity of health and the diagnostic process. It makes it possible to focus on their embeddedness in everyday family life, as well as to flesh out the interactional aspect of “doing” (MOL 2002) or “undoing” the disease. As I will illustrate, much of the framing as well as contesting the illness label takes place outside the medical spaces.

Ethnographic accounts exploring the social life of ADHD as it unfolds in various localities constitute fascinating diagnostic stories⁶ due to the uncertainty and contestation of the label (TRUNDLE, SINGH & BRÖER, 2014). Such stories foreground multivocality, ambiguity, asymmetrical power relations and indeterminacy. The controversies surrounding the label are well-voiced in public debates. Joseph DUMIT (2006) pointed to five features of contested illnesses that partially fit the experience of ADHD diagnosis in Poland: they are often chronic, medics cannot easily determine their causes (their symptoms are “biomental”), their treatment includes a wide range of options including biomedical, complementary and alternative medicine, their boundaries are “fuzzy” (the symptoms can be attributed to other illnesses), and they are “legally explosive” (it is difficult for the sufferers to gain recognition) (DUMIT, 2006). Catherine TRUNDLE, Illina SINGH and Christina BRÖER, in their discussion on ADHD, suggest broadening DUMIT’s category of “contested diagnosis” “to incorporate all of the contests, challenges, and disagreements that occur during the diagnostic process” (166). I align with this broad definition which allows for bringing to the fore the ways in which the contest over medical meaning evolves in the territory of ordinary life.

ADHD is recognized as a *contested disorder*, among other things, because of the diagnostic ambiguity, the wide use of pharmacotherapy, and the reliance on historical and cultural norms set for childhood behaviors (TRUNDLE, SINGH & BRÖER, 2014: 176). For many, ADHD became almost synonymous with what PARENS (2014) calls “bad” medicalization, BREGGIN labels it as unnecessary pharmaceuticalization (2014) or what HORWITZ describes as a situation in which “non-disordered people are treated as if they are disordered, social behaviors are defined as individual pathologies” (2003: 20). While burgeoning diagnosis is worthy of critical attention (TRUNDLE, SINGH & BRÖER, 2014: 177), some scholars advocate

6 Peter CONRAD and Meredith BERGEY (2014) recognize the growing significance of the ADHD diagnosis outside the American context, calling for social research into the diversity of ADHD experience as it develops in different cultural landscapes. Existing research demonstrates that ADHD diagnosis can be differently enacted in various national and socio-economic contexts (TRUNDLE, SINGH, BRÖER, 2014: 176), including the cases that fall outside the English-speaking world (FILIPE, 2016; NAVARRO, VRECKO, 2017). This article expands the discussion by presenting a detailed ethnography of a Polish family and the ways in which it facilitates the process of applying a medical framework to a child’s behaviors in the context of transforming post-socialist society and its healthcare.

balancing the critical take on child psychiatry with careful ethnographic research concerned with the actual diagnostic process and what it does to children and their carers. They extend this call to include such questions as: what happens when the diagnosis is not given, when certain groups remain underdiagnosed and do not enter treatment? (SINGH & WESSELY, 2015).

The ADHD diagnostic process stretches over various medical and non-medical spaces. It involves numerous actors situated within the web of asymmetrical power relations. The children who are the central objects of the diagnosis are rarely involved themselves in discussions about the medical opinions, the prognosis, the treatment or the nature of illness (TRUNDLE, SINGH & BRÖER, 2014, WITESKA-MŁYNARCZYK, 2017). The diagnostic work can be viewed as a collaborative process of establishing an interpretation of the origins of the illness, defining the factors that are responsible and identifying appropriate interventions. At every step of this dispersed process “there is a space for contested meaning” (TRUNDLE, SINGH & BRÖER, 2014: 179). Both the increasingly active role taken by lay actors in diagnostic processes and the ambivalences embedded in psychiatric practice⁷ add more layers to the ADHD experience.

In this paper, I tell the story of a family whose child was diagnosed with ADHD in a medium-sized Polish town called Malden⁸. I chose to devote close attention to one case study because it makes it possible to follow the emergence of the meanings and uses of the psychiatric diagnostic category. Furthermore, it permits me to highlight how the diagnosis influences actual lives. How it is communicated and lived with are nevertheless indeterminate, socially negotiable and rooted in materiality and historical time. This chapter aims to examine *the status of the real* in order to foreground the processual, collaborative and dynamic nature of the diagnostic process (GARDNER *et alii*, 2011; GOODWIN & MCCONNEL, 2014; OLSON & ABEYSINGHE, 2014). In particular, I propose a careful analysis of everyday interactions generated around the behaviors

7 Psychiatry is recognized as “a second-class citizen” in medicine. Because it lacks the means to precisely identify disorders such as ADHD (ROSE, SINGH, 2009), it is said to be marked by a diagnostic uncertainty. Hence, what needs to be addressed in the actual ethnographic research on ADHD are the ways in which this vulnerable status of psychiatry influences the everyday lives of people who receive a psychiatric diagnosis. Another question to attend to is whether the new term “neuropsychiatry” fulfills its promise of a novel explanatory framework and diagnostic reliability (ABI-RACKED, ROSE, 2013) or, more precisely, how it actually impacts upon the acts of diagnosis and care.

8 Malden is a pseudonym.

of one child in one family with whom I spent time during 2015-2016. This interactional focus allows me to show a diagnosis of a *contested disorder* as a dynamic and fluid process that exceeds what happens in the medical spaces (JUTEL & DEW, 2014). I will explore various social forces, organizational routines and social agents whose interactions lead to a particular framing of ADHD and produce an elusive outcome of this diagnosis.

The chapter is based on my recent fieldwork⁹ designed as a multi-sited ethnography (MARCUS, 1995), in which I examine various enactments of ADHD in one locality. Telling one story, I will comment on how ADHD came to be pronounced as a diagnostic category and was later tinkered with by multiple actors to coproduce the ADHD experience. I will draw the contours of particular cultural understandings and social circumstances in which decisions were made, actions were taken and affects arose. Finally, I will look at the diagnostic work taking place in both the clinical and non-clinical spaces, imagining it as a production of social order through the interactional acts building upon each other over time. Particularly in the case of ADHD, much of the diagnosing and healing takes place in non-medical contexts. Collaboration between lay-diagnosing and clinical pronouncements may be intentional and non-intentional. It may take place in proximity and at a distance. Families and doctors may experience stages of certainty and uncertainty (OLSON & ABEYSINGHE, 2015). The pace and the movements become apparent when we carefully follow one story. The story gains depth when we place it in larger contexts.

9 Between 2015 and 2017, I followed the practices evolving around ADHD through different field sites in Malden. I gathered the material around a few focal children (with different levels of intensity, I gathered the material about the experiences of 11 boys). I conducted ethnographic work in familial, educational, medical or counseling spaces used by these boys on a regular basis. I used mixed methodology depending on what was possible in each case. I conducted ethnographic interviews with the carers: the family members, the teachers, the school directors, the psychologists, the psychiatrists. In a few cases, I regularly visited children's homes. In five cases I did participant observation in schools and in two cases I conducted research in focus groups with the focal child and his/her classmates. With one teacher and one mother, I worked using autoethnographic diaries. Over the course of six months, I participated in a therapeutic group for ADHD children run in a public psychological center. In this very center, I participated in educational meetings organized for parents and teachers. Where possible, I participated in diagnostic, therapeutic meetings or consultations with parents and/or children. I traced the academic research conducted in this town on ADHD when it spilled over into the educational spaces. I interviewed the few child psychiatrists working in this town. Finally, but no less significantly, I worked with the diagnosed children using participatory methodology derived from the new childhood studies.

The macro landscape of care

MILLIGAN and WILES suggest that engagement with landscapes of care as an analytical framework requires “an understanding of macro-level governance or social arrangements that can operate at either (or both) the national or international scales as well as the interpersonal” (2010: 738). The landscape I will describe here has its peculiarities. Since the collapse of the socialist regime, like other countries in the region, Poland has undergone rapid transformations in the areas of economy, lifestyles, values, social norms and care. Poles have been building a multifaceted relationship with Western medical cultures, their own socialist past and the heritage that reaches beyond that period. Among other things, the consumption of pharmaceuticals in Poland has grown rapidly since the 1990s. The country is recognized as a part of a “pharmerging group,”¹⁰ which in 2016 reached 30% of global spending on medicines, compared to 14% in 2006 (Medicines Outlook Through 2016 Report). Along with the striking increase in the consumption of pharmaceuticals came the advance of “a new awareness”, i.e. the growing engagement with the ecological movement or a dialogue with a critical view of ‘technochemical’ medicine (PIĄTKOWSKI, 2012: 21).

Since the 1990s, among other things, the cultures of therapy came to play a more significant role in the lives of the people in the region. Psychological discourse about the *self* filled conversations and internal dialogues of Poles, who now could easily access self-help manuals and other forms of psychological and psychiatric knowledge present on the Internet and in parenting guides, lifestyle magazines or other media. This discourse valorizing self-responsibility, autonomy and prudentialism (RAIKHEL & BEMME, 2016) infiltrated contemporary Polish families and influenced how proper parental care, gender roles, the normal child, the good family life, proper parental intervention, and desirable education started to be imagined. The expansion of biological psychiatry found fertile ground in the field of poorly developed child psychiatry, as much as cognitive-

10 Pharmerging countries are defined as those with >\$1Bn absolute spending growth over the period 2012-16 and which have GDP per capita of less than \$25,000 at purchasing power parity (PPP). Pharmerging markets include China, Brazil, India, Russia, Mexico, Turkey, Poland, Venezuela, Argentina, Indonesia, South Africa, Thailand, Romania, Egypt, Ukraine, Pakistan and Vietnam (Medicines Outlook Through 2016 Report: 5).

behavioral models were eagerly applied in the fields of psychology, child therapy and parenting. The post-socialist landscape of mental healthcare in Poland is characterized by its rapid privatization, a growing plurality of state-financed and private services and entities available on the market to the patient-client, who is solely responsible for choosing the right option. Notable is the emergence of spaces devoted exclusively to diagnosing and treating the mental health of children, bringing together experts who are trained to help families design the proper child-centered interventions. Psychiatric and psychological care is currently in high demand.

Yet, being exposed to the new models does not imply an easy realization of these ideals or an absence of critical commentaries stemming from the previous cultural formations. Poland retains its distinctiveness, among other things, through “the persistent influence of religion on social life, the importance of the Church in public life, the size and importance of the peasant class, or the deepening social differences” (PIĄTKOWSKI, 2012). Old and conservative structures of family and gender relations, traditional schooling, rigid patient-doctor relations, to name a few, are changing more slowly than individual desires. As Piotr SZTOMPKA (2003) puts it, Poland is characterized by progressive “cultural disorientation”—as new ways of living and thinking need to be measured against traditional structures and values negotiated in everyday life. This tension is apparent in the lives of families whose children are diagnosed with ADHD.

The micro-landscape of care

I met Leo’s family through a pediatric psychiatrist who consults families and children in a number of medical spaces in the city – both private, such as a psychological centre, and public, such as a psychiatric hospital. The Catholic, female doctor, in her seventies, with an eccentric outfit and decisive and authoritative way of talking to people, introduced me to an energetic and sociable mother in her early thirties and an eight-year-old boy, who seemed very shy and was completely silent. The mother, Agda, was very eager to learn about my research. She invited me home for an interview. Soon, I got to know other family members —the father, Bart, and a younger brother, Michael. I started to make regular visits to their temporary apartment and, later, their newly built home— a small house with a garden —a middle-class dream taken from a prospectus with

trendy modern designs. Over time, I attended Leo's classes at school and met his classmates and teachers. I joined Agda and Leo at some of the psychiatric consultations. I maintained regular contact with both parents, although mainly with Agda, who frequently called me to talk about the current state of Leo's affairs, and to share what worried her¹¹. Throughout our consecutive meetings, Agda appeared to me as a patient/consumer, who holds not only biomedical knowledge but also a knowledge of the healthcare system and how to navigate within it.

Both Agda and Bart hold university degrees. Agda is a pharmacist and Bart works as a sales representative in a large company manufacturing food products. They can afford to run two cars, have a newly built house, go for holidays twice a year and arrange their children to enroll in private extracurricular activities. Bart's work requires him to travel frequently. He stays away from home a few days a week. After Leo was born, Agda stayed home with the baby for a few months and then returned to her full-time job in a pharmacy. It was important for her to be professionally active. When Agda was at work, Bart's mother took care of Leo. Tensions arose between the women with regard to their visions of proper childcare and upbringing. At the same time, Leo's grandmother was considered a natural replacement for his mother and the couple did not consider seriously other care solutions. After becoming pregnant with their second child, Agda decided to leave her demanding job in a pharmacy and stay home to care for her newborn son, Michael. This dual-income family transformed into a single-earner family because of the moral imperative Agda generated while going through the diagnostic process with Leo. In Agda's retrospective narrative, some blame for Leo's ADHD problems is ascribed to the mother-in-law and what Agda considered her incorrect care practices, while other factors include her own absence from home which precluded her from noticing when things started to go wrong. She did not want to repeat the same mistake with Michael. Moreover, her work

¹¹ I visited Leo's home a number of times over a period of two years (the visits resulted in 485 minutes of audio recordings and one notebook of field notes). I played with him and did some schoolwork, I talked to the family members, I walked him to school, I maintained regular contact with his mother, I used visual assignments for the boy and his family (131 minutes), and I had access to his medical and educational records. I participated at psychological consultations twice and at a psychiatric office three times. I also undertook observations at school and I conducted seven focus groups with children from his class. I interviewed the school director and four of Leo's teachers.

in the pharmacy was not fulfilling. She felt rather exhausted by working late hours and she complained about being forced to talk people into buying certain drugs that she considered somewhat ineffective.

Looking at the story of this young married couple and their children, I am interested in what MILLIGAN & WILES (2010: 739) call a micro-landscape of care. In their understanding, a micro-landscape of care could include “the reorganization of specific rooms, social arrangements and work practices within and beyond the home to accommodate the performance and paraphernalia of care as well as shifting power relations they imply” (MILLIGAN & WILES, 2010: 793). In everyday settings, policies and values constructed on a scale beyond home influence how the micro-landscape of care is produced. With such a focus, ambivalences become more visible and a researcher can turn his/her attention to the clashes of values and meanings that are enacted in a domestic space. In this micro-landscape, care has been constructed in reference to a socially contested medical framing which became available for interpreting and negotiating the meaning of atypical child behaviors.

The story of this family uncovers innumerable details of this landscape of care. Here, women are more likely to take a greater caring role (Agda often underlined how she took on all the care work, including concerning building the new house). Yet, the father also aspires to greater involvement: Bart stressed how important it was for him to spend weekends at home and involve himself in leisure activities with the children. The traditional family-based system of care-giving is still the norm with which people interact, and both Bart and Agda were unwilling to engage paid child care. The care of a child and his/her wellbeing is perceived as “a private activity built around values of familial obligation” (ibid: 749). This care rests on an individualized responsibility for decisions taken mostly by mothers, as exemplified by the number of extracurricular activities arranged for Leo by Agda. Yet, at the same time, the people involved in this care network interact with more “progressive” images of family life and of care practices. In particular, Agda interacted with an image of a “progressive”, working and educated mother. In this case, opposing social norms and discourses have shaped family and personal decisions about the provision of care and brought tensions into the household. This ambivalent landscape was perforated by concrete interventions related to ADHD, and the continuously unfolding acts of care in which the positions of the actors and their voices become clarified, empowered, weakened or reformulated.

The road towards the diagnosis: dispersed enactments emergent in a field of sociality and materiality

The diagnostic moment is not as discrete as it would appear (GOODWIN & MCCONNEL 2014). It stretches over a number of spaces, people and ideas interacting in time. Stories about difficulties with a hyperactive child usually take a more decisive shape when a child starts to attend an educational institution. Within institutional walls, the picture of abnormalities emerges more clearly. This is how Agda recalled Leo's initial years in the kindergarten: «And during the first year in the kindergarten the problems started. He began to disturb other kids, push them, hit them, he was so naughty. He did not want to sit. He rejected paperwork. He drew sloppily. He drew outside the lines. We did not know what was going on with him». The disclosure of diagnosis “doesn't come in a discrete moment but is a part of series of interactions and encounters with a variety of health care personnel” (JUTEL & NETTLETON, 2011: 796). It requires pre-diagnostic work. For Leo, a number of acts of pre-diagnostic labeling took place between his years in the kindergarten and his first two years in school. These pre-diagnostic actions, well evidenced in the medical and educational records I looked through, were performed in a spatially dispersed cooperation between the mother, the educational staff, the various psychologists and, later, the psychiatrists. Agda brought into our conversation the idea of her being the first who thought of this particular diagnosis: “[...] and he in the kindergarten, he was like this, and we, I asked that psychologist to talk to him, perhaps he has, maybe there is something pointing towards ADHD”. Yet, she needed much collaborative work for the idea to become materialized.

The *diagnostic preliminary* (DEW & JUTEL 2014) is a period in which a shared and negotiable nature of diagnosis becomes evident. We have the non-medical context of a kindergarten in which adults elaborate on the behavioral and emotional problems of a child. Organizational routine guided this collaborative process. The immediate elaboration was possible because Leo attended a private kindergarten with an inclusive approach to various kinds of disabilities. The staff members tried to solve problems *in situ* instead of referring the parents to another building and to experts who were not participants in the everyday life of the institution, as often happens in public kindergartens with no psychologist physically present in the building. Since kindergarten, Leo's difference was tacitly underlined

through corridor conversations between the mother and the educator and during parents' meetings with the psychologist. The adults looked at the behaviors, tried to find a name for them and then tried to manage the apparent difference. Leo's transgressive behaviors and frequent visits to the psychologist's office at the kindergarten implicitly pointed to him as a person "at risk of illness" (JUTEL & NETTLETON, 2011: 795). At the same time, the period between kindergarten, where Leo did not receive any clear label, and the moment he entered school should be recognized as liminal. The female psychologist in the kindergarten did not clearly endorse the ADHD idea suggested by the mother. She preferred to use the safer label of "emotional immaturity" and to mark Leo as in need of observation. The ADHD diagnosis was not pronounced at that point. This liminality generated uncertainty and anxiety instead of hope. Agda was influenced by an image of Leo as at risk of disorder. She talked to me about the time in the kindergarten as being full of worries about the failure of her child (imagining Leo as a drug addict or a failure at school). These worries led her to strengthen practices around Leo and his behaviors and to look for available expert knowledge that might have helped manage his unruliness through specific care techniques.

When Leo entered school these worries intensified.

Agda: And I started the search. I got interested that something wrong was going on, because doing the homework, I am saying, doing one single homework assignment took over two hours. [...] When he was to write something, he took and he was writing and he was staring wherever, somewhere else. I am saying: Leo, write. – What? He started to lag behind in writing the things down from the blackboard.

School means more elaborate administrative procedures. There are specific rules for evaluating children, for seeking support for a child who is atypical, for stating his/her needs. In addition, the practical difficulties of daily life with a child who attends school increase.

Agda: And I am saying, I also started, I started to search. I was coming back, how did it all start? Because I became more nervous. I started to disintegrate [...]. Because non-stop I heard that he does not want to learn, that he does not work properly, he does not want to do things. In the classroom kids were also complaining about him... and he was also more nervous. And I went to Dr Glusek, to Morwin.

I: What kind of specialist is she?

Agda: She is a psychiatrist [...] I trust her. So, I went there firstly alone. In two weeks again. And she said – “Come with Leo”. She started to talk to him, look at him, observe him and, it was still in the previous year in June, and now somehow, at the end of August, I went there again, for a check-up and I reported to her about the problems with Leo [...] she said – “Well, Leo is hyperactive, it is easy to notice, but Leo, Leo has serious attention deficits. She started to do some tests with him, worked, asked questions and she told me it was noticeable that there was something. And she suggested I went to Dr Markowicz.

Framing Leo’s unruly behaviors as a neurodevelopmental disorder should be considered an action taken jointly by Agda, the private disability-friendly kindergarten, the schooling system, the easily accessible popular psychological knowledge filling the bookshelves in Agda’s house, everything that enabled Agda’s mobility and, eventually, a psychiatrist whom Agda consulted initially because of PTSD following her involvement in a car accident. Yet, such a framing was enabled by the existing biomedical practice and the infrastructure of psychiatric care. In this framework, the young child was placed at the center of psychiatric testing and interventions. He was separated from his family and from his mother in order to be understood as an autonomous subject/object inside of which certain biological processes took place, producing unruly effects that could nevertheless be managed if a proper therapy was applied.

Dr Gluska works in a private clinic located in a villa with a garden in a small town outside Malden. Together with her husband, a professor of psychiatry, she created a kind of private asylum for people seeking psychiatric and psychological support. Dr Gluska, having listened to Agda’s reports about Leo, subtly and temporarily included the child in a therapeutic process of the mother in order to quickly detach him and navigate his autonomous diagnostic track. She made a pre-diagnostic pronouncement and defined another point of the psychiatric infrastructure, where Leo’s deficits might have been explored with greater confidence. A few months later, Leo was diagnosed with ADHD by the recommended child and youth psychiatrist. Because no pediatric psychiatrist was employed at Dr Gluska’s private asylum, in order to have Leo’s pre-diagnosis confirmed Agda needed to find a specialist in Malden¹². Dr Gluska gave her the name

12 In fact, in Malden, there are not many doctors with these qualifications. To my knowledge there are a dozen.

of the recommended doctor, and she had to decide where she wanted to benefit from this psychiatric care. Her financial status enabled her to make a choice. The psychiatric hospital in Malden has a counseling centre and is located a short distance from Agda's home. It is a public institution. It turned out Agda would have to wait two months for a visit. She decided to make an appointment at a private psychiatric healthcare center where, nonetheless, corridors become overcrowded with parents and children from all walks of life and from both rural and urban areas.

*Multivocality, hierarchy and dissolved authorship:
the social life of health records*

Agda, coordinating Leo's dispersed diagnostic process, was looking for ways of establishing a legitimate explanation for the difficulties they were experiencing. She moved between spaces like a patient between wards, trying to collect and then hand in notes by various authors to different figures who would undertake some interpretational work. She registered her son for a visit to the recommended Dr Markowicz. She asked the psychological and pedagogical counseling center to test her child's emotions, competencies and abilities, as well as to issue an official psychological opinion for Leo —the only one acknowledged by the public schooling system. She also took a written opinion about Leo from Madame Alice, Leo's teacher, who served as an intermediary between the psychiatrist and the teacher. Madame Alice generated more diagnostic evidence. For example, Agda arrived at the psychiatric office with a notebook for communication with the parents filled out by Madame Alice, and presented it to the doctor. She traced a number of sad faces attached with glue and read through the phrases written by Leo: "I ran to the toilet and yelled", "I must work on complying with the discipline". These words and graphic signs were interpreted as proof of ADHD symptoms¹³. Such reported voices were relied upon by the psychiatrist in the process of a diagnosis. Concurrently, the health and educational records became an attribute of Agda's competence, a tangible sign of good care. During a few consultations I attended with Agda, she always appeared prepared.

13 However, as I observed while spending time with Leo's class, in a classroom context, they did not differentiate Leo from most of the other boys.

This is what is expected from her. She knows that, in the encounter with a psychologist or a psychiatrist, a good mother is a mother who is prepared, who knows, who is able to quickly locate a document for the specialist. After a number of medical examinations, the results of which were presented during the second visit (EEG, blood tests, blood pressure tests), the psychiatrist determined that Leo was suffering from ADHD. She gave Agda a small piece of paper on which was written the child's name, his address, and the name of a disease—in this case, a *Hyperkinetic Disorder*.

Agda brought this small piece of paper to the psychological and pedagogical counseling center, whose staff knew that Leo was being examined by the psychiatrist. They would want to issue an official document stating their opinion about Leo's functioning only after Agda had brought in the document with the psychiatric diagnosis. As one of the psychologists working in the public psychological center explained to me, the professionals working in such spaces do not feel competent to diagnose this disorder as it is perceived more as a neurobiological one than a psychological one. This is the case mainly because they do not have access to the diagnostic tools (the psychologist mentioned the Conners rating scales¹⁴) and to the norms valid for this age group. They also consider themselves insufficiently trained. This lack of tools is explained by the financial shortages suffered by the public institutions. In this city, only one public psychological center structurally tied to the education system is equipped to diagnose and issue an ADHD diagnosis. Otherwise, a child may be diagnosed only by a psychiatrist (often), by a neurologist (rarely), or by a pediatrician (almost never). The psychiatrist's paper is most authoritative as it has the power to pronounce the final diagnostic category. From the moment Agda brought the diagnostic pronouncement written in the psychiatrist's hand to the psychological centre, this category started to exist outside the psychiatric office as a name. The people from the counseling center took this document, read it, and interwove its meaning into their own text without acknowledging a psychiatric authorship. The final opinion given by the psychological and pedagogical counseling center to the parents, under the rubric the position on the matter, says: "After conducted examinations, mixed Hyperkinetic Disorder with deep attention deficits as well as developmental deficits pointing to the risk of dyslexia was found".

14 Conners Comprehensive Behavior Rating Scale, Conners CBRS, is a protocol used by psychologists for assessing ADHD.

This diagnostic story demonstrates the power of the psychiatrist's voice. From what I understood from Agda's account, this diagnosis was taken by default by the psychologists working in a small building remote both from the school and from the private psychiatric practice. During initial consultation, these same experts had expressed doubts about whether there was a reason to talk about ADHD in Leo's case. A certain hierarchical order is evident here. These variously situated voices eventually fused and became indistinguishable. A focus on the circulation of diagnostic papers reveals the relevance of the form of the historically emergent infrastructure of psychological and psychiatric help for the micro-landscapes of ADHD. The well-established diagnostic and consulting formats, the physical disconnection of psychiatrists, educational psychologist and therapists, the economy of diagnostic tools and knowledge, and the historically delimited lines of professional competences give shape to individual experience. The diagnostic documents eventually merged into a final format legally demanded and recognized by the schooling system.

The pronouncement and its contested life

Agda: You did not know, you did not pay attention to his [AWM – Leo's] behaviors, you thought it was laziness¹⁵. That sometimes you shouted at him, well, you shouted at him all the time, because, you demanded something from him and he, as if, did not react, as if he did not feel like. And it turns out that it was not it. It is simply something different. And now when we really know it is necessary to learn to live with it somewhat differently.

These are the words through which Agda describes a diagnosis as a turning point in her care practices. A diagnosis understood as a pronouncement can serve as "a starting point, a foundation from which sense-making and experience are crafted" (JUTEL & NETTLETON, 2011: 794). In Agda's narrative, the ADHD diagnosis constitutes a turning point, a moment which legitimates a switch from a moral to a medical framework of interpretation of Leo's behaviors. Yet, the diagnostic label can also become an actant in the affective performance of familial relationships. It should

¹⁵ Agda's utterances are characterized by indirection. She repetitively used a personal pronoun "you" instead of "I". This linguistic strategy shows her desire to distance herself from the image of the mother who interprets ADHD symptoms as laziness (compare WITESKA-Młynarczyk 2017).

be perceived as an element reconfiguring larger networks of care that surround Leo in terms of the ways in which actions are directed, the kind of frameworks used and the emotions felt. The opinion will become a resource in the mother's fight for the improvement of Leo's learning conditions. Yet, this psychiatric technology will also turn into a resource through which the power positions, hierarchies, responsibilities and blame will be negotiated within the family. The main tensions appear here on the mother-father line of interaction, as the child is left out as a "non-person" (GOFFMAN, 1958)¹⁶.

Bart: We had a difficult situation, because Agda later got pregnant [after she gave birth to Leo – AWM], she miscarried, and later she had such problems that she herself needed help and I think that Leo felt very lost, because, well, he wanted to be with his mother, and the mother, she rejected him because she was unable to help herself, so she rejected him and he was very lost. It was a very difficult period for him.

As exemplified by the above, Bart frequently talked about Leo and his problems in relation to Agda's transgressions of the mother-child relationship. During the research, I could see how, in Leo's family, two divergent explanatory stories emerged. In reply to the diagnostic practices initiated by Agda, there grew an oppositional version worked out by Bart and his family. In this version, the child was demedicalized and described as normal, while the mother was seen as in need of medicalization and labeled as abnormal, more specifically as a borderline personality¹⁷. Bart's family considered Agda's moves towards diagnosing Leo as an unnecessary folly. They also thought Agda herself should seek professional help. Both parents struggled to negotiate their own and Leo's positions – trying to locate and name the problem. Bart, influenced by his mother and sister, as well as by an anti-pharma episteme and discourse on attachment

16 His role during such conversations resembles what Goffman called a position of "non-person". "Those who play this role are present during the interaction but do not, in a sense, take the role either of performer or of audience, nor do they pretend to be what they are not" (GOFFMAN, 1958: 95). I write more about the position of a child in this family in an article entitled "Competences as a form of situated practice. Ethnographic reflection on enacting ADHD in Poland" (WITESKA-MŁYNARZYK, 2017).

17 Agda often referred to a day when Bart's mother gave him a book about life with a person who has a borderline personality diagnosis. She explained to me that this was a hint about her. Bart did not reject this statement.

parenting, argued that Agda created artificial problems. Yet, Agda did not want to align with this explanation. She wanted to regain lost status as a competent mother. Bart, on the other hand, did not participate in the diagnostic work.

I: Did you decide together about consulting a psychiatrist with Leo?

Bart: You know what, well, no, no [...] at the beginning of the year, Leo went back to school and he could not, I do not know, find his place and at that point all that action with the counseling centers started. But I also was not convinced that all these come from this ADHD or, or from a sort of, or, whether this is connected to, is it more about rebelling, so as to show that, because this little Michael was already there, so I will, at least, bring their attention to myself in this way. I am not completely sure, so that, all, all of that therapy, giving these medicines, whether it is necessary. Agda was going to all those doctors alone.

Bart hinted at the big life event as a possible explanation for Leo's problems. Again, reading between the lines, there is a *mother-blame-narrative* (see: BLUM, 2015; SINGH, 2004), in which Agda favored the new baby and again did not give enough time and love to Leo. Bart distanced himself from the diagnosing process, introducing it as Agda's business in which no one else had ever participated. Meanwhile, Bart did not seem interested in taking control of medical care – he never attended psychiatric consultations, yet at the same time he was tacitly complicit in giving Leo psychostimulant drugs when Agda was away from home. Apart from his family, Bart gained one more ally strengthening his not very well-articulated oppositional voice —Madame Alice, Leo's teacher. One day, Bart recalled in front of Agda and me the conversation they had with the teacher concerning Leo and his readiness to pass on to another grade:

Bart: She even said something like, that we should also be careful with these opinions from these kinds of psychological centers, because the child can be stressed out [...]. Or that someone is giving a medicine, she also said this, that someone is prescribing a pill for a child, even when he does not know the child and after one or two meetings, so that we should be careful. [...] That this opinion may be unreliable.

School and less palpable ways of elaborating the diagnosis

Varied opinions may surround uncertain diagnostic categories, and conflicts over meaning may arise in various phases of the diagnostic work. Landscapes of care in which children with ADHD diagnoses dwell are quite complex. In the case of ADHD, school is a crucial element of the landscape of care. It is a space in which the agency of the diagnostic category is further elaborated. Most of the children in Leo's class did not know what ADHD meant. Those who knew said that ADHD was "a disease, when someone does not know how to control himself", was "when someone gets crazy", "when someone cannot sit in one place"¹⁸. One girl explained to me:

Busia: I know what ADHD is. It is when kids get crazy. I watched one movie. It was that children were fighting, kicking and talking to themselves and crying. They behaved in a weird way.

Me: Did you watch this film alone?

Busia: No, with my mother. And they did not want to eat something.

Me: Was it explained why they behaved this way?

Busia: No. I do not know. But it was said that these children had ADHD.

Me: How would you know it was ADHD?

Busia: Because it was written: "Children with ADHD".

Those children who knew the abbreviation associated it with something that they could have used as an insult or with something that could have made them laugh or with something weird. Some of them eagerly imitated behaviors produced by ADHD and used it as a resource for playing out. Yet, they did not know the causes of this "weird" condition. Importantly, those children in Leo's class with some knowledge of ADHD, had no idea of Leo's diagnosis and would not have pointed to Leo as an ADHD child. As noticed by his teachers, Leo did not stand out in the class in terms of everyday behaviors. My observations conducted in school confirmed that he did not break up the normative order in any unusual way. His disability did not manifest in a way that could be perceived by his peers. Nor did Leo use the label in interactions with his classmates because he lacked precise knowledge of the connection between the abbreviation and himself. He learned about it indirectly only during encounters with a psychiatrist,

¹⁸ The citations come from the research I conducted with Leo's classmates in the form of focus groups composed of 2-3 children.

overhearing his parents talking to each other, or listening to them talk to other adults. He also figured out his difference through regular everyday practices mediated by medical technologies such as pill taking, measuring his blood pressure, and tapping his feet on a scale. He made attempts to take the ADHD name into his possession by confronting his parents. Yet, the mother clearly denied the relevance of the concept. She reported: “Maybe he heard somewhere because one day he told me something... not that he had ADHD, but he asked what ADHD was. No, no, Leo, this is just an abbreviation, not important, yeah? I passed it over.” In another conversation with me she confessed: “We do not tell him he has ADHD because we are afraid that, if he knew, he would have abused it —I will not do something because I have ADHD”. Leo’s father also reported situations in which Leo visibly struggled with his difference and implored the adult carer to help him work out what was going on. «He asks me sometimes: —Am I sick? Because when he, for example, does something wrong: —I am a psycho! —he yells, I am stupid!»

In a classroom, it was possible to keep the name away from Leo because Leo’s biology did not manifest itself in any overt fashion and because he obeyed the social norms. Another crucial element in this landscape was the position taken by the principal teacher. Madame Alice perceived Leo as a normal child and she did not distinguish him from other children on an everyday basis in the classroom. Other teachers had a similar approach, such as a football instructor, who came up to me in school to ask about my research: “Look [showing Leo and other boys from his class sitting in a gym], they all sit calmly – does anyone there have ADHD? ... I do not see. A normal kid [talking about Leo]”. Similarly, an English teacher, while talking to me about Leo, recalled the first months when Leo started to take psychostimulants —“He was like frozen”. He thus voiced his criticism of the medicalizing of children.

The legal discourse dictates that the school must accept the opinion issued by the psychological center allocated to the school. The teachers must treat Leo as a child with special educational needs. If such an opinion is issued, the teachers must adjust their work according to the recommendations. In the case of ADHD, such recommendations written on a piece of paper by an employee of a psychological center include the following: the pupil should sit in the front row and be allowed to move frequently, e.g. go to moisten the board eraser, the teacher should check whether the pupil has noted down a homework assignment, and tap the

pupil's arm to refocus his attention. Madame Alice did all this in a subtle way, but not because she had received a piece of paper from a psychological center. From what I observed, she did this with every child she recognized as being in need of repetition, attention or movement.

The psychiatrist's office

The literature on diagnosis explains that the nature of the medical encounter is dialogical. The process of “organizing illness” depends on the ways in which the attention is directed, the symptoms are talked about or the evidence is displayed (OLSON & ABEYSINGHE 2014). In the case of Leo, it was Agda and the psychiatrist who, on a regular basis, negotiated the meaning around ADHD.

During visits to the child psychiatrist's office, the mother and the female psychiatrist acted in ways that confirmed the diagnosis and the chosen treatment. During the interaction, Agda performed her role of a competent mother. From my conversations with the psychiatrist and observations made over three visits, I saw clearly that the medics' motive was to provide Agda with some support, confirm that her efforts were taking the proper direction, and acted as a backing for “the overtired mothers”. The visit and the social acts performed can be read as an expression of solidarity between the mother and the medical authority. This medical figure strengthened the mother's position in the given constellation. The dynamics are visible in the following passages uttered during the visit.

Agda opened the meeting by expressing her satisfaction with the pharmacotherapy: “When he does not get the pill he is, evidently, a kind... even my mother noticed [...] [when he takes the pill] he calms down, even Madame Alice said, he could concentrate OK. He works with Miss Martha [a tutor who comes to their home once a week] —very nicely”. She also talked about her efforts to support Leo: “I do not hide, the physical stuff he has provided – the skiing, the football, we skate [...]. I even introduced a plan of a day, there is for each day a plan, it hangs on the wall. For each day separately, it is written down – what he will do, how many hours”. During this meeting, Agda repeatedly showed her engagement and competence. She had hired a private teacher, Miss Martha, who visited their home to work with Leo on his deficits. With this move she gained much favor from the doctor who made a few positive comments on her report.

As I understood from my conversation with her, the psychiatrist felt that Leo was in good hands and that his mother, who she saw as an exemplary caring mother, was performing the required technical tasks well. She weighed Leo, she took his blood pressure every day, and she experimented with the quantity and frequency of medication. Her education as a pharmacist helped her perform the medical tasks that were expected to be carried out by a mother. Agda was very eager to take them up. She left the psychiatrist's office with a sense that an authoritative voice spoke for her. Listening to her reporting about the consultations, I interpreted her experience of these interactions as generative of good feelings—that she was performing well as a mother, for which she was valued.

While the ADHD label was attached to Leo through indirect communication, leaving him no space to fully interact with it, his mother was empowered by the diagnostic category both in educational and domestic spaces. Yet, by taking it up, she also entered an emotionally unstable, socially contested territory. As I learned from my observations in the home and from conversations with Bart, he saw no benefit in holding to this diagnosis. To the contrary, he felt it would have been beneficial for his child to oppose it. At the same time, however, he lacked the power to turn it into an invalid pronouncement or a sham. Instead, he played with the meaning of the diagnosis through indirect everyday communication, such as when he criticized Agda for giving little Michael a tranquillizer when he had trouble falling asleep. His anti-pharma episteme pronounced in this specific situation was just a tiny example of an extension of the criticism directed at Agda's engagement with the psychiatric treatment of Leo's behaviors.

In this chapter, I have provided an ethnographic description of an instance of ADHD diagnosis enacted in a medium-sized town in contemporary Poland. I looked at the practices that are persistently uncertain, loaded with affect and co-produced by differently positioned actors and resources. I chose the story of Leo to talk about caring practices involving a contemporary Polish family in the context of reforming and increasingly privatized mental healthcare, where psychological discourses permeate intimate lives and shape people's fantasies of a good family and what a properly behaving child should be. It is a landscape of a constantly reforming conservative schooling system, where psychiatric labels have become a legally binding resource, although the people who make up the

everyday life of an institution do not necessarily enter into an extensive dialogue with the label. Eventually, it is a landscape in which traditional gender roles continue to shape family life, where the figure of a mother is particularly loaded with expectations. This landscape of care, as noted by MILLIGAN & WILES (2010: 740), comes as “a complex embodied and organizational spatiality that emerges from and through the relationships of care” (2010: 740).

I offer this story as a critical reflection on the new medical developments (e.g. neuroscience, pharmaceuticalization in pediatric psychiatry, expansion of diagnostic practices into schools) that affect lives of children in the formerly socialist countries of East Central Europe. I bear in mind that Leo's story is just one possible configuration of how ADHD is enacted in Malden. It seems to me that in this landscape of care the local solutions to specific problems of unruly children have not yet been stabilized. The neurobiological framework is available as a resource and comes in as an actant, yet ADHD remains a controversial label which, once received, opens up a way for various socially situated enactments. Surprisingly seldom do we raise questions about the consequences of such contested diagnostic processes for the children themselves.

Coda

My last visit to Leo's house took place when Leo was at school. Agda, Bart and Michael received me with a cup of tea. Unexpectedly, the micro-landscape of care gained another dimension. When I asked about Agda's pharmacotherapy (she visits a psychiatrist regularly and takes antidepressants with various effects), she laughed and exclaimed that she had a new form of therapy. She called her husband, who was sitting in another room: «Honey, is it true that I have a new sort of therapy?» When Bart came over to the kitchen table, Agda took out a little booklet and started to explain what had replaced her psychiatrist and at the same time helped her to finally accept that she has «such a child». Now, the story had turned into a tale of becoming a part of a religious movement within a catholic church that enabled “the renewal” of the entire family. I found it captivating that this new extension was so neatly interwoven by Agda and Bart into the practices of caring for and about an ADHD child. Agda now argued that her fate as an ADHD mother was chosen

by God, and her most burning task was to face it and care for Leo just the way he was —hyperactive, inattentive and impulsive. For Bart, God and religion were always dear, just not practiced, and they helped him to grasp his love for Leo. The new religious component did not eradicate the pharmaceutical agent that helped Leo perform at school, but it allowed the family to embrace the conflicting narratives and understand that the ways in which each family member struggled with Leo's difficult behaviors had a meaning and made sense. Hence, whatever they had lived through thus far was meant to be.

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DIAGNOSTIC UNCERTAINTY AND PATHWAYS
TO CARE FOR MIGRANT AND NON-MIGRANT FAMILIES
AND THEIR CHILDREN

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Abstract: Stemming from a study with families of migrant & non-migrant backgrounds in Montréal on children's stomach pains, this paper questions how ways of dealing with medical uncertainty has bearing on pathways to care. These pathways are enacted within and beyond the family space as well as in medical settings. While acknowledging that group practices call for nuance, non-migrant children lead a greater quest for legitimacy of their pain while most migrant families place stomach aches in the range of normality.

Keywords: uncertainty, pain, care pathways, migrant & non-migrant children, agency

Diagnóstico incierto e itinerarios terapéuticos de niños de familias inmigrantes y no inmigrantes

Resumen: Tras estudiar la percepción y tratamiento de dolores estomacales de niños de familias nativas y migrantes en Montréal, indagamos la respuesta a la incertidumbre médica y cómo afecta los itinerarios terapéuticos. Aunque cada grupo es diverso, las familias nativas tienden a dudar

de la veracidad de la queja de los niños mientras las migrantes ven sus dolores dentro de lo normal. Nos cuestionamos si todas son escuchadas en la clínica y cómo esto altera los itinerarios terapéuticos.

Palabras clave: incertidumbre, dolor, itinerario terapéutico, niños de familias inmigrantes y no-inmigrantes, agencia



“Ouye, it hurts”, Simon, 10 yrs, FQ

“It’s like swelling up and exploding” (Armanda, 10 yrs, LA)

“I don’t know how to explain it. In my head, I want to, but I can’t put it into words. There are no limits! It’s like being stabbed” (Valérie, 16 yrs, FC)

“It’s like being hit by a ton of bricks” (Simon, 10 yrs, FC)

“It’s as if someone was hitting me with a stick, eating me from inside” (Florence, 12 yrs, H)

The nature, causes and treatment of functional gastrointestinal disorders and related symptoms (FGDs) are unclear and place “stomach pains” in a wider area of medically unexplained symptoms. These disorders are medically defined as recurrent gastrointestinal dysfunctions with no apparent physiological lesions, organ deficiency or pathological findings of the digestive tract, and are often referred to as “stomach-aches”, “abdominal pain”, “stomach gas” or “heart burn” (DROSSMAN, 2006).¹ As with chronic

¹ The generally accepted hypothesis to explain the pain is that there is a combination of sensory and motor activity along the brain–gut axis. It appears that the information we get from the outside through our senses and perceptions (emotions, thoughts, smells, sights), by the nature of the neural connections in the higher centers, can affect gastrointestinal sensations (FORTIN, GOMEZ and GAUTHIER 2013). In other words, stressful situations or

pain, FGDs are widely associated with persistent sensations that cannot be related to tissue damage (JACKSON, 2005), and still little is known about the factors involved in the onset and evolution of FGDs (WALKER and JONES, 2005; ROSH, 2010). From an anthropological perspective, FGDs are not solely confined to the abdominal region. They embrace personal experience, life trajectories and social relationships in diverse settings, including the clinical space and broader healthcare environments beyond the material body. In turn, these dimensions colour the interpretation of FGD symptoms, their meanings and the actions undertaken to alleviate suffering, that give way to an array of healthcare pathways.

Montreal is a cosmopolitan city that welcomes between 40,000 and 50,000 migrants each year from over 100 different countries. Even though 31% of the population is born abroad, only a small percentage (9%) of patients of a paediatric gastroenterology hospital clinic seeking consultations for symptoms associated with FGDs are migrants (CAPLAN, WALKER and RASQUIN, 2005). The prevalence rates of FGDs are 13–20% in the general Canadian population, 10–15% in the global population, and approximately 10% in the paediatric population (FORTIN, GOMEZ and GAUTHIER, 2013). So... if both migrant and non-migrant children can experience FGDs, and mostly non-migrant children attend a specialized hospital clinic for this pain, what do migrant children do when experiencing “severe” stomach pain and where do they go?

Stemming from a study on how children’s stomach pains are understood and treated, in this chapter we focus on paths to care of migrant and non-migrant children and their families, with particular attention to biomedical spaces. We examine the interpretative and pragmatic aspects of migrant and non-migrant patient and family life with FGDs and discuss how symptoms, meanings and actions taken to relieve them are shaped by a diversity of relations, within and outside the family. Non-migrant children seem to encounter more difficulties when seeking parental recognition of their pain at home, while most migrant families talk with what we perceived as greater “acceptance” of their child’s stomach-aches. We find that non-migrant families are more likely to

sensory stimuli may affect hormonal secretions, degree of inflammation, and gastrointestinal sensitivity and motility. These internal phenomena combine with individual characteristics (e.g., clinical history, distress) and group characteristics (e.g., societal norms, culture), to influence the behaviour of sufferers (YAMADA 2005).

consult “formal” health professionals while migrant families more readily rely upon home remedies and family support. In conclusion, the medical encounter is reaffirmed as a space permeated by relational uncertainty, reflecting the different registers of expression inherent to cosmopolitan milieus. Narrative practices are an essential dynamic of this encounter, and we question whether migrant and non-migrant families’ voices are equally heard in these clinical spaces and how this impacts diagnosis (as an intersubjective process) and care. But first, a few words on the study that fostered these ideas; we follow this by a rapid overview of diagnostic uncertainty and help seeking patterns.

The study

This study was supported by a Québec funding agency (FRSQ, 2008-2011) and carried out with fellow anthropologists and medical colleagues.² We met with 43 children (8-16 years of age) and 38 families of migrant (16/38) and non-migrant background (22/38) (Haiti [H], North Africa [NA], Latin America [LA], Eastern Europe [EE] and French speaking Québécois [FQ]) (total : 81 interviews).³ All children had experienced severe abdominal pain over the last two months. Nine families were recruited in a paediatric gastroenterology clinic and the 29 others, in the community. The main themes documented were the development, perception and expression of the children’s abdominal pain; explanations and meanings attributed to the symptoms; actions⁴ undertaken to relieve the pain, and families’

2 Gilles Bibeau, Andrée Rasquin, Christophe Faure and Sylvie Fortin (principal investigator) with strong support of research assistants Annie Gauthier and Liliana Gomez Cardona.

3 The study was approved by the ethics research committee of both the paediatric hospital where some of the families were recruited and the principal investigator’s university ethics board. Consent was obtained by every member of the family taking part in the family interview including the child or children experiencing stomach pains. Drawings as well as verbal exchanges (verbatim) were an integral part of the interviews with the later.

4 The signs, meanings and actions model (CORIN *et alii* 1992) was used for the analysis, in order to better understand the health care pathways of our participants. The semiologic variables (signs) are the symptoms characterising the child’s experience of FGDs. The interpretation variables (meanings) are the patients’ and families’ own representations of the onset and evolution of the symptoms. The pragmatic variables (actions) are the many different methods used to relieve the child’s symptoms, whether home or medical treatments or paramedical services. In short, how one identifies different manifestations of “stomach aches”, as well as their meaning(s) and takes action to relieve the pain are socially, culturally,

relationships with medical services. The collected narratives were analysed thematically, with data compared on three levels: between respondents in the same family, between families of the same ethnic group (and in a more inclusive way between migrants and non-migrants) and between families who consulted the paediatric gastroenterology clinic and those who did not. In this chapter, we focus on paths to care.

The complexities of uncertainty... and diagnosis

In 1988, Renée Fox confirmed what other researchers had found previously: despite formidable scientific progress, the practice of medicine was permeated with insoluble uncertainty. She distinguished two types of uncertainty. The first results from the impossibility of being familiar with all medical knowledge and techniques. The second arises from the inherent limitations of medical science and the fact that there are questions about the human body that no doctor, however qualified, can solve. When she revisited her work in 2003, the literature revealed signs of deep uncertainty that went to the very foundations of medical thought. She wrote about the insistent questioning of the links between the scientific and non-scientific aspects of the practice of medicine; between theory and its applications; and between knowledge, perceptions and beliefs.

These thoughts have been furthered by many, as medical uncertainty gives rise to a rich body of literature (JUTEL 2011, 2010). For BABROW and KLINE (2000), the desire to eliminate uncertainty is rooted in a belief system that holds medicine as an objective practice where causal determinism can be elucidated with certainty, and the possibility of developing definitive tests for specific diseases (the key to diagnosis and treatment). On the contrary KIRMAYER, GROLEAU, LOPER *et alii* (2004: 664) remind us that as medical knowledge and technology evolves, diagnosis uncertainty may diminish but that “fundamental epistemological constraints on what can be know in the clinical context will persist.” Diagnostic systems are rooted in ideal types that can be very different from individual illness experiences, while clinical medicine applies general knowledge to specific patients.

an often politically based. Also, this analytical model does not necessarily infer a linear model of explanation or action but suggests, rather, that all three dimensions must be examined in order to better grasp the trajectories at hand as well as the variations within each facet (BIBEAU and CORIN, 1995).

While both doctors and people who suffer from FGDs share the hope that symptoms can be explained and treated, many clinicians define FGDs from a variety of points of view, often presuming that the pain is imagined (SCHURMAN, HEATHER and CRAIG, 2010). Given the typical absence of apparent organic lesions, functional gastrointestinal disorders are conceptualized and studied largely from a biopsychosocial perspective (DROSSMAN, CREED, OLDEN *et alii*, 1999). As in the wider area of the medically unexplained symptoms (MUS),⁵ clinicians, patients and researchers remain uncertain about the nature, causes and treatment of FGDs (ROSH, 2010; CASIDAY, HUNGIN, CORNFORD *et alii*, 2008; WALKER and JONES, 2005). The Rome Foundation, an international non-governmental organization that provides assistance for the diagnosis and treatment of FGDs, has identified four sources of uncertainty: (1) the absence of biological markers to define the pathology; (2) dissatisfaction with treatment; (3) not knowing what triggers the pain or whether it is serious, and (4) inability to control the pain (DROSSMAN, 2007). And as in MUS, lack of diagnosis, prognosis or treatment give way to “embodied doubt and uncertainty” (NETTLETON, 2006:1167).

Many studies also underline how diagnostic uncertainty generates clinical uncertainty (TALLEY, 2004; CASH, SCHOENFELD and CHEY, 2002). As well, diagnostic uncertainty can make parents anxious, especially if they feel that doctors may be missing a serious illness causing their child’s symptoms or if the doctor suggests that the symptoms are emotional and psychological. According to Boyle (1996), this climate of anxiety triggers or reinforces the child’s pain, while denying the social recognition of their suffering (DUMIT, 2006). It may also be a site of tension among caregiver, sufferer and other family members.

Help seeking

Beyond diagnostic uncertainty though, what do we know of help seeking behaviours in relation to FGDs? Medical consultations are thought to vary with the severity, frequency, duration and repercussions of the “disorder” on children’s everyday activities (HYAMS, BURKE, DAVIS *et alii*, 1996); other

⁵ According to KIRMAYER, GROLEAU, LOPER *et alii* (2004), patients with MUS in Denmark, UK and Canada account for 15% to 30% of all primary care consultations.

studies show that the decision to seek or not to seek medical attention is embedded in the mother's perception. If she believes that her child displays psychological distress (LEVY, WHITEHEAD, WALKER *et alii*, 2004), perceives that her child's symptoms are severe (LANE, WEIDLER, CZYZEWSKI *et alii*, 2009), or that the stomach aches will persist and disrupt her child's everyday activities (VENEPALLI, NAN TILBURG and WHITEHEAD, 2006) she is likely seek medical advice. On the other hand, mothers who consider their child's stomach aches as normal or believe that the symptoms will disappear may not seek medical attention (VENEPALLI, NAN TILBURG and WHITEHEAD, 2006). In line with Bluebond-Langner (1996) for whom family dynamics and care paths are interwoven, the perceived intensity of symptoms is stronger in families who are more likely to attribute the symptoms to a biological cause as well as with families who experience conflicting relationships. In turn, in a diversity of national contexts, clashing family relationships are associated with more severe gastrointestinal symptoms while supportive family relationships are associated with less severe symptom manifestation (GERSON, GERSON, AWAD *et alii*, 2006).

The quality of a family's past biomedical encounters may also have a bearing on the child or family's pathways to care. In cosmopolitan contexts, differences in interpretation and narrative practices can result in communication difficulties within clinical encounters (GAUTHIER, BIBEAU and ALVAREZ, 2008; FORTIN, 2008) leading to inequalities in the evaluation of the condition and treatments offered (CROWLEY-MATOKA, SOMNATH, DOBSCHA *et alii*, 2009). Beyond communication issues, pathways to care, therapeutic itineraries and choices can resonate with multiple rationales that stem from structural issues (healthcare systems, medical traditions, social status) and other circumstances (financial issues, social networks and familial contexts). As well, former encounters with illness and how it is perceived in prior homelands may come into play. What do our stories reveal? Were the children listened to? How did the families respond? And the clinic? Were all voices heard?

Pathways to care

Two main therapeutic spaces emerged from the parent's and children's narratives of FGDs: home remedies and care and biomedical treatments (see table 1). Many families (29 out of 38) regardless of background or place of recruitment turned to biomedical health services (paediatricians

and general practitioners, hospital emergencies, as well as paediatric or paediatric gastroenterology clinics) at least once for their child’s stomach-aches episodes. However, fewer migrant families (2/11) than non-immigrant families (9/11) were referred to a specialized paediatric gastroenterology clinic.⁶ As we discuss further, non-migrant children lead a greater quest for legitimacy of their pain at home; doubts as to the authenticity of “real pain” are only mentioned by parents of non-migrant background. In contrast, most migrant families place stomach aches in the range of normality and come up with all sorts of tentative explanations, namely food and stress, always framed with uncertainty.⁷

Table 1. Actions and Spaces of care

Home-family space	Biomedical space	Alternative space
<i>Rest</i> GETTING CLOSER TO OTHER FAMILY MEMBERS (MOSTLY MOTHER) – OR - ISOLATION FROM FAMILY MEMBERS Changing eating habits <i>Getting warm (ex : warm on stomach, hot showers)</i> <i>“Over the counter” medication</i> <i>Tea, herbal tea</i> Belly massages <i>Going to the toilet</i> TRYING TO THINK OF OTHER THINGS	GPs or community paediatrician Hospital emergencies and «open clinic» emergency services Gastroenterologist Psychologist	Prayers Acupuncture, reflexology, massages and chiropractic Yoga and meditation

Terms in **bold** letters were mostly mentioned by parents.

Terms in CAPITAL letters were mostly mentioned by children.

Italic terms were put forth by both children and their parents.

Top terms were mentioned more frequently.

6 In Québec, in order to access third line health care (specialized medicine such as gastroenterology), one must first see a GP or an emergency physician and then be directed to a “specialist”.

7 Food, for example, is often questioned, but no consensus is achieved as to what is “good food”. For some, the good is “traditional” and the bad, “local”. For others, good or bad food practices may be features of the same food, within a given family.

In addition to providing home remedies, one third of the families (all backgrounds) also sought help from non-medical resources (meditation, acupuncture, prayer, massages). These therapies were perceived as partial, offering temporary relief in comparison to a more formal, curative biomedical approach. Religion (and the church as a gateway for community life and social solidarity, as well as a place of healing and hope) is an exception for Haitian families, for whom prayers are intricately woven into treatment. “When we’re sick, before going to the doctor, we pray to God. I think God is the only one who can cure me and then the doctor with his medication can help” (Mother, H).



“Sometimes, I feel really really bad and sometimes it hurts so much I cry”,
Grace, 9 yrs, H

Relieving pain in the family space

All families use some form of home treatment, such as rest, dietary changes, herbal tea, or warmth on the child’s abdomen. “As did my parents and my grandparents, when someone has a belly ache, we give him tea, we brew orange leafs” (Mother, H). For many, these treatments and the recognition of pain, bring comfort. In some ways, this pain is “normal”. Yet there is a limit to the normality of this pain: “For some people, the stomach pain never stops, it goes on and on. Then we must go to the doctor and see what is happening. We must have an ultrasound to see what is happening.”

(Mother, H). A Haitian mother refers to tea leaves she imports (through family and friends) from her homeland. This home remedy for stomach pains has been in her family for generations. She also mentions lying down with her 10 year old daughter, massaging her belly until she feels better. As another Haitian mother says: “Often, when the girls don’t feel well, they get close to me. I want to sooth the pain. It helps when they find affection, it sooths the pain” (Mother H). Other ways of dealing with FGDs create tension within the family or lead a child to go off by himself: When I have a stomach-ache, I don’t want anyone to talk to me” (David, 15 yrs, FQ). His parents are often mad at him for missing school (due to stomach pain). He talks of shame, being ashamed of missing school because of stomach pains: “ I make up more manly reasons for my friends because I don’t want to say I was in my bed, not that I was crying, but really not feeling well.”



David, 15 yrs, FQ, entitled his drawing “shame”

DAVID’S STORY: David loves to play hockey. He has a girl friend with whom he shares “almost everything” and an older sister he says to be “the brain of the family”. Their mother, a primary school teacher, recalls David being a “late talker”. He was three years of age when he started to talk. “He did not make the effort,” she says. When David refers of his stomach pain he mentions “burns” and “stabbing pains”. His first memory of such pain was prior to a hockey game when he was 9 years of age. His father had then suggested he take “Tylenol”. David was later hospitalized with severe pain,

“difficult to cope with”. He is “ashamed” of not being able to tolerate such pain (whether in this specific circumstance or in general). David’s father (also a primary school teacher) affirms he must keep an eye on David who misses too much school: “I want to see his books, I want to see him work. It is very difficult to get him to work”. The father says his wife is too lenient with David, and she agrees, saying she does not punish David enough. This said, mother and daughter share the idea that punishing David will get him nowhere. When he is punished, he develops a stomach-ache and when he is in pain, he misses school. David prefers to be alone when in pain, without witnesses. He watches TV to “make noise around me”, reads something “that is so interesting that it will keep my mind busy”, “crying and falling asleep”. He sometimes shares the pain episodes with his parents, with some girl friends, but never with his teachers and never with boys. At one time David’s gastroenterologist suggested psychological therapy, to which he complied reluctantly: “I did not want to do it but the doctor wanted me to, so I did it, it looked better”. Commenting on this, David’s father recalls how his son was not taking the therapy seriously: “He did not do the work that was asked, he did not write down what he was as asked to, he does not write well”.

David has no formal diagnosis. His sister associates his stomach pain to stress while he does not share this point of view. David thinks it is linked to some kind of depression. His mother associates her son’s pain episodes to family arguments. He acknowledges this pattern but says it is not unique. She also wonders if he does not have an undiagnosed cancer (having had one herself a few years back). From a GP to an emergency ward and later to a specialized gastroenterology clinic, David’s father claims, “they don’t know, he goes from protocol to protocol (for the last three years now)”. “They (the specialists)” must find a cause. There must be a cause. David hopes someone will “heal him”.

Yet, for pain to be addressed, it first has to be acknowledged as “real” pain. In our study 8/38 families shared doubts on the authenticity of their child’s complaints: “the child is faking, trying to get attention, being oversensitive or trying to get special treatment”. In a family interview, Louis’ mother (9 yrs old boy, FQ), asks him “to tell the truth about his stomach-ache, or else he will be punished”. Marc’s (9 yrs, FQ) parents say they don’t always take

his complaints seriously. According to Marc's father, Marc often says he feels sick to his stomach, that he is worried and afraid of vomiting, when in fact he never vomits. Jeanne's (10 yrs, FQ) mother asks her daughter if "it is always really, really, really true" when she says she has a stomach-ache, or whether sometimes it is because she has not done her homework and doesn't want to go to school. In some ways, Jeanne shares this disbelief and acknowledges only partially her stomach pains: "You know my stomach hurts and then in my head everything becomes confused. Like lets say I have homework and then my stomach hurts. I become anguished, I'm not able (to do it) or something like that". Another mother also seems somewhat doubtful of her daughter Nadia's (10 yrs, FQ) complaints: "I wasn't really worried because I thought she was just being manipulative, because she always wants to stay home with us. So it was an excuse". In short, parents may think the child is faking, trying to get attention, being oversensitive or trying to get special treatment.

Seven out of these eight families were non-migrants (FQ), many of whom attended the paediatric gastroenterology clinic. One could ask if these doubts are generated by the clinic and the diagnostic process itself, as medically unexplained symptoms are known to generate uncertainty amongst clinicians and can sometimes be dismissed by them as "emotional" or "psychological" problems.

Turning to the biomedical healthcare services

Many families (29 out of 38) regardless of background (migrant or non migrant) turned to biomedical health services (paediatricians and general practitioners, hospital emergencies, as well as paediatric or paediatric gastroenterology clinics) at least once for their child's stomach-ache episodes. While some families may be referred to specialized clinics, others never go beyond the general practitioner (GP). In our study fewer migrant families (2/11) than non-migrant families (9/11) were referred to a specialized paediatric gastroenterology clinic.

For the families (18/38) who, at one time or another, consulted a GP for their child's abdominal pain, the outcome was not always sufficiently informative. These parents were dissatisfied with the prescribed medications and medical advice, as there was no long-term pain relief for their child. In fact, seeing a doctor (GP or specialist) rarely eliminates this diagnostic uncertainty, even when medical tests are done or medical advice

is given. Half of these families (9/18) from all backgrounds (migrant and non-migrant) recalled being told that either there was “nothing wrong” with their child, or that it was a “mild case of reflux, a stomach bug or anxiety”. This situation puzzles parents, as shows Victoires’ (13 yrs, H) mother: “They told me they couldn’t find anything, that everything was all right, but she still has stomach pain”.

The narratives reveal two contrasting strategies in dealing with this uncertainty. The first is to doubt the need to seek further medical help. Victoire (13 yrs, H) relates how she ended up lowering her expectations: “They never found out what was wrong or why I had it, so, no, I don’t think they’re going to find out what I’ve got”. Jessica’s (8 yrs, FQ) mother shares similar feelings: “They say, it’s all right, there’s nothing. Maybe it’s because she’s constipated? But she’s never been constipated. Never! That’s not it” (Mother, FQ). She feels helpless dealing with her daughter’s pain. She doesn’t know “what to do about it”. Feeling powerless, she says pain is “part of life” and simply has to be endured. In Nadia’s case (10 yrs), her pain is left unbelievably and unrelieved: “Everytime she cries, she screams, I don’t go to her. ‘Listen, you have nothing’” (Mother, FQ).

The second strategy, in contrast, consists of persevering in the search for medical expertise. Faced with his son’s repeated complaints and the lack of satisfactory answers from their family physician, Marc’s (9 yrs) father thinks it is time to turn to specialists: “We need to consult other people, to find out, as they say, why it hurts” (Father, FQ). This being said, the decision to seek health-care advice (in a specialized hospital clinic) is always made when parents are at a loss of what to do, after many consultations amongst general physicians or paediatricians: “Sometimes, the more we look for answers, the less we find them. It’s like with our daughter, we don’t want to lose her. Sometimes life brings you cancer or other problems you know? So when something happens, whooooo - what does she have? It makes us worry” (Father of Loïse, 9 yrs, FQ). Geneviève’s [13 yrs] mother (FQ) shares Loïse’s father perspective “When are they going to find out what he has? It makes me mad. It can be anything, but *find* it”.

The Issues

Attempting to understand why some parents of children with FGDs seek medical attention while others do not, we must recall the social nature of all medical encounters, where children, parents and medical professionals

engage and negotiate different illness experiences and explanatory models. These encounters are shaped by the opportunities afforded to children and their parents to discuss their problems in ways that both clinicians and families can understand, respective to their individual backgrounds (FORTIN, RIETMANN AND DUCLOS, 2011).

From this point of view, an important issue emerged from both children's and parent's narratives--the need for a therapeutic space that is receptive to the authenticity of a child's complaints for gastrointestinal disorders. Perhaps non-migrant FQ families find this receptiveness more easily within the clinical encounter (with gastroenterologists and general practitioners) and are therefore more comfortable seeking biomedical advice.

In general, migrant families welcomed that their children sought care and attention from their parents. This attitude is fostered by relationships within the nuclear family, community networks (churches, friends) and/or the extended family. In our data, this form of receptiveness means allowing children to describe complaints in their own words, acknowledging their pain, diligently caring for them in a healthy (rather than tense) emotional atmosphere, and allowing these children to temporarily withdraw from other social obligations (such as attendance at school).⁸

To enable children to express their pain and intensity requires a complex intersubjective process involving the co-construction of a shared representation of pain. Receptiveness within the family as well as in the clinical encounter accommodates the child's experience without immediately labelling it as false or abnormal. Furthermore, being attentive to narratives in the clinical encounter allows patients to become partners in care (GOOD & GOOD, 2003), acknowledging diversity in the individual and collective resources that children and families draw upon in their environments in coping with FGDs. Yet, if "feelings imbue subjectivity with a character reflective of our embodied being in the world" (CROMBY, 2007: 234), David's story, as many collected in this study, talks of pain in multiple ways.

8 This may appear as parental indulgence that goes both ways: it could aggravate the condition by giving it undue importance or rewarding it (WALKER AND JONES, 2006).

Concluding remarks

If we were to try answering our initial questions of what migrant children do when experiencing severe stomach pain and where they go, our study shows that migrant children share with their family who seem to be generally more receptive to their stories of pain and attempt to find answers in diverse ways. The specialized biomedical path is less likely to be theirs. In contrast, non-migrant families seem more reluctant to believe the child or any diagnosis that involves non-organic causes but seem to access more easily specialised care. They are perhaps more permeable to care providers uncertainties in regards to the pain and its meanings.

Diagnostic uncertainty is a space into which migrant and non-migrant parents and children can project their fears, anxieties and desires. Whether they accept or doubt their child's complaints, whether they insist on trying to find out the cause, whether they rely more on inner resources, extended family, friends, the community, or experts, both parents and children take variable positions towards uncertainty.

For pathways to care, family network support, one's capacity to negotiate uncertainty and, in some ways, trust in the child's expression of distress seem key features in the necessity felt by parents and children to reach certainty, while everyone wishes to alleviate pain. Nevertheless, we question the quality of the encounters with healthcare providers, as most families did seek medical advice at one or another time. All narratives reveal uncertainty *a propos* the medical advice they received. We did not document these encounters directly (no observations were done in the clinic). But as wider literature supports, narrative practices in the clinic are an essential part of the medical encounter (GOOD & GOOD, 2000). This said, Kleinman (2012, 2013) questions contemporary medicine's ability to listen (and more broadly "care"). The ever-increasing expertise (inherent in the evolution of medicine) separates, perhaps definitely, treatment from care (FORTIN, forthcoming). This knowledge remains disease focused rather than illness (and person) focused. In a way, the families more closely attuned to biomedicine seemed to share this same paradigm.

It is not only a question of sharing the family's and children's concerns but also how this sharing is done, that make sense for patients and clinicians, given their respective backgrounds (FORTIN, RIETMANN AND DUCLOS, 2011). Families may not have equal voice as they may not express themselves in the appropriate manner in the medical milieu. Uncertainty,

then, is associated with medical practice, symptoms, diagnosis, prognosis and treatment. It can also be relational and here, migrant families may be at a disadvantage given culturally invested modes of expression and the symbolic resources they may or may not have.⁹

Lastly, in documenting the disparities between migrant and non-migrant families in a hospital clinic, the different pathways to care help us grasp, in part, these patient's social world, while shedding light on the intricate relationships between values and social milieux, between culture, practice and the logics that guide individuals to act.

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⁹ By symbolic resources, we intend social recognition attributed to the individual, based on his or her social position and the value attributed to this position within a given context.

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PART 2
DIAGNOSTIC NEGOTIATIONS IN THE CLINIC

FROM EVIDENCE TO EXPERIENCE:
THE DIAGNOSIS OF DEMENTIA IN A US CLINIC

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Abstract: The diagnosis of neurodegenerative diseases is characterized by a persistent degree of uncertainty and instability. Based on fieldwork conducted at the Memory clinic, a world-famous US clinic for the diagnosis of dementia, this paper aims to understand the work of clinicians given and despite uncertainty through the unfolding of one case-study. Particular attention is given to the gradual production of evidence, to the epistemic indecisions that appear at different moments and to the way clinicians actively work with —rather than work around— uncertainties.

Key words: Alzheimer's disease; neurosciences; medical knowledge; experience; feelings.

De la evidencia a la experiencia: el diagnóstico de la demencia en una clínica de los Estados Unidos

Resumen: El diagnóstico de enfermedades degenerativas se caracteriza por un grado de incertidumbre. Basado en una etnografía en la *Memory clinic*, el objetivo de este estudio es entender el trabajo de los médicos cuando su juicio no está completamente avalado en herramientas tecnológicas y en evidencia médica. Para eso, recurro al desarrollo del estudio de un caso y se da particular atención a la producción gradual de evidencia, a las indecisiones epistémicas que aparecen en diferentes momentos y la manera en que los médicos trabajan activamente alrededor de la incertidumbre.

Palabras clave: enfermedad de Alzheimer, neurociencias, conocimiento médico, experiencia, sentimientos

A doctor consulted in a case like this must be more than just well versed. In the face of symptoms which may be those of three or four different illnesses, the thing that enables him to decide which of them he is most likely to be dealing with, behind appearances which are very similar, is ultimately his flair, the sharpness of his eye. This mysterious gift implies no superiority in other aspects of the mind, and may be found even in a person of the utmost vulgarity, someone who is devoid of intellectual curiosity and who enjoys the most dreadful painting or music.

Marcel PROUST, *In the Shadow of Young Girls in Flower*.

The Memory clinic, where I did fieldwork, is a world-famous US centre specialized in the diagnosis of dementia. Patients travel to this clinic from all over the country because “it’s the best”. They come because they, their spouses or their doctors are worried that they might have this widespread disease —according to the Alzheimer’s Association, it is an “epidemic” — called Alzheimer’s disease (AD). Neurologists at the Memory clinic diagnose not only Alzheimer’s but also all sorts of neurodegenerative diseases (dementia with Lewy Bodies, semantic dementia, Amyotrophic Lateral Sclerosis), and have actually built their international expertise on the diagnosis of frontotemporal dementia (FTD)¹. These diseases all cause “dementia” but present at first with different symptoms, hit different parts of the brain, and are suspected to be caused by the anomalies of different cerebral proteins. To make a diagnosis, neurologists use several technological means in addition to the history of the patient’s symptoms: a score on a standardized psychological test, measurement of specific biomarkers in the cerebrospinal fluid of the patient (LOCK 2007, MOREIRA *et alii* 2009), genetic testing (LOCK 2011) and the assessment of cerebral atrophy with various techniques of brain imaging (MRI, PET and PiB imaging). Despite these tools, the diagnosis of neurodegenerative

1 Frontotemporal dementia is a neurodegenerative disease characterized by a predominant neuronal loss in the frontal and the temporal part of the brain (whereas Alzheimer’s is characterized by neuronal loss in the back of the brain). Described by the Czech neurologist and psychiatrist, Arnold PRICK, in 1892, it was first called PRICK’s disease. While Alzheimer’s disease is primarily characterized by disorientation and memory loss, memory is at first preserved in FTD. What characterizes FTD (at least its most frequent form) are changes in social behavior and conduct, with apathy, loss of social awareness, lack of empathy and poor impulse control. FTD is the second most common form of dementia after Alzheimer’s. Like Alzheimer’s disease, its cause is unknown and it is incurable.

diseases remains rather uncertain. In *The Alzheimer Conundrum*, LOCK (2013) illustrates how conceptual problems and uncertainties endure in the “Alzheimer’s world” (and this is also true of other neurodegenerative diseases which are not of the “Alzheimer’s type”): from the difficult concept of “normal aging” to the still unknown causes for these diseases and the impossibility of establishing a diagnosis other than retroactively, by post mortem autopsy of the brain. In addition, the diagnosis of these brain affections cannot be put to the test by a medication —unlike other uncertain diagnoses, like depression for instance (EHRENBERG 2009)—since Alzheimer’s disease, frontotemporal dementia and other types of dementia cannot be treated today by medicine as curable illnesses. To diagnose dementia, neurologists therefore rely on a *probabilistic* reasoning, based on the results of various tests (brain scan, neuropsychological test, lumbar puncture, etc.) combined with the assessment of clinical signs.

In my 16 months of fieldwork at the Memory clinic, one particular question stood out in LOCK’s account of this prevailing uncertainty: how is medical work actually possible when doctors are not supported by a standard body of knowledge? For, uncertainty notwithstanding, doctors ultimately need to take a decision. What do they use as a guide or as evidence in order to make a diagnosis, if their medical judgment is not fully sustained by technological tools and evidence-based medicine? What do we learn about the type of knowledge that constitutes medical expertise, that is, about the ability (or the talent) of the clinician to respond to new situations?

To answer these questions, I draw on observations of team meetings, clinical consultations and patient interviews at the Memory clinic, and on the development and unfolding of a case study. From 2010 to 2013, I observed about 150 patient consultations with the neurology fellow, the neuropsychologist or the nurse, and attended their “case-conferences”, during which the team discussed their cases. I progressively shared a form of life with this American team: I tried to be up to date about what was going on in the clinic, I took notes, I asked questions, I asked for explanations, I was surprised and sometimes this led to comments, and I learned about the way of making a diagnosis. After the first six months of fieldwork, the director, Dr. Daniel, granted me a moment alone to talk to the patient and his or her family. The case study that I describe and analyze opens with a sketch of the patient and of her husband —reconstituted from small hints dropped here and there when I personally met with

them— and then follows with the staging of the medical team during its discussion of the patient's case. To keep the "spectacle of the clinic" (FEATHERSTONE *et alii* 2005) alive, with its theatrical arrangement and dramatic effects, I present this "clinical case" as a scene² divided into different sequences. Each sequence describes the medical team's context of interaction and consists of conversations as well as silences, attitudes and nonverbal communication. Through three sequences I study the role of the "informant", a member of the patient's family, in diagnostic work; the importance, in clinical medicine, of analogical reasoning between the case of one patient and another; and the clinicians' judgements based on their emotional proximity with the patient. The analysis of the sequences that follows their description pays particular attention to the epistemic difficulties that arise at different points of the diagnostic work, and to how clinicians experience, deal with and interpret these difficulties. I detail how, in the process of the making of a diagnosis, clinicians use contemporary instruments of objectification and standardized concepts³ (the MRI, the neuropsychological test, genetics), along with more elusive impressions. Through the description of the case, I will endeavor to understand how these impressions arise from the "affordances"⁴ (GIBSON 1979) provided by the empirical context. The work of the expert will be understood as an assemblage, or a composition (DODIER 1993), between

2 I have transcribed the dialogues for this article in several ways: in direct speech as well as in indirect speech (both free and normal). Nevertheless, most dialogues in direct speech between clinicians are modeled on the structure of theater scenes: they are presented as typically done in a play (no introductory verb —such as "he said"— and dashes replace inverted comas). Indications about the context of interaction such as the place of action, character's mood, affects and gestures are written in italics.

3 In saying that these instruments allow for "objectification", I follow BESSY and CHATEAURAYNAUD (1995: 307): I do not mean that these instruments are not "constructed" or "performed" in certain ways (see MOL 2002, for an example of the study of the construction of atherosclerosis), but that they *preexist* the work of the expert, under the form of codified methods, spaces of calculus and specialized processes.

4 Affordance is a word made up by GIBSON from the verb to afford. It refers to the information that arises from the environment when an agent (or an animal) engages in an action; it lies neither in the animal nor in the environment, but between them, within the perception by the animal of its environment. GIBSON introduces the word "affordance" in the following way: "I mean by it something that refers both to the environment and the animal in a way that no existing term does. It implies the complementarity of the animal and the environment" (1979: 127).

pre-existing standards of qualification and a process of adjustment to the environment, here constituted by the specific encounter and by the concrete relationships between one medical team and a particular patient (and her husband).

Because this chapter aims to understand the work of medical experts given (and despite) uncertainty, it dwells on the interactional dynamics of the medical team in situations in which opacity reigns. I here follow the lead of pragmatic approaches (BOLTANSKI 2009, DODIER 2005, RABINOW and STAVRIANAKIS 2016, REMY 2009) that place the notion of “test” (“épreuve”) at the centre of their analysis. Studying the ways in which people dynamically respond to situations marked by uncertainty and tension, and where moral dilemmas are often present, has indeed been fruitful in documenting modalities of learning, knowledge and expertise (BESSY and CHATEAURAYNAUD 1995, HENNION 2015). Following the work of STRONG (1979), HEATH (1986), CICOUREL (1985, 1987), MOL (2002), and JUTEL and NETTLETON (2011), which share an approach to medical diagnosis as a “process” with movement and temporality, I emphasize the processual dimension of diagnostic practices. Particular attention is hence given to the gradual production of evidence, its unfolding over time, the epistemic indecisions that appear at different moments, and the way clinicians actively work with —rather than around— uncertainties (CAREY 2012). Nevertheless, the uncertainty of the diagnosis itself will be left untouched at the end of this story. I will not provide supplementary information regarding the veracity of the diagnosis relative to the incomplete set of evidences produced by this medical team. I will rather focus on understanding the solidity, or the fragility, of the ways in which forms of certainty and uncertainty are made visible.

Sequence 1. “I feel strange”

When I enter her hospital room, Cheryl Joe is sitting on her bed, a foot on the floor, the other swinging. I ask her how she is. “I feel strange” she answers. She feels spacy all the time. It’s a sort of lightness in the brain, she says, while brushing the back of her head: “it’s like being cooped up.” “It means, tight, in a small space: like a chicken” her husband, sitting on a chair next to her, explains to me.

Cheryl Joe is a slim and tall woman who does not talk much. When she does talk, she measures her speech and her gestures so as to give herself time to voice her thoughts. Neurologists say that she is slow. Her answers to their questions are brief, precise and sometimes curt. Her dry humor, condensed in a short line and spoken with a thin voice, strikes all the doctors of the clinic who examine her. Mr. Joe remembers that ever since he has known his wife, her humor has surprised many. Some do not understand it. Mr. Joe smiles: “The doctors of the Memory clinic might impute this to her disease!” He himself enjoys his wife’s jokes and welcomes them with a hearty laugh that resonates in the hospital room.

They met forty-five years ago at a football game in college. He fell in love with her right away. This morning when John, the neurology fellow⁵, asked Mrs. Joe what she still enjoys doing today, she answered: walking, swimming, being in love with my husband. Mr. Joe too, from the way he listens to his wife, appears to still love her. This visit to the Memory clinic is their last attempt, he says, “to understand why a high functioning person suddenly crashed in the space of one month.” “But, let’s not get depressed!” adds Mrs. Joe stoically.

Sequence 2. The Informant.

Patients like Mrs. Joe, who stay a few days and nights at the hospital, take part in a research program of the Memory clinic. All the tests, the imaging, and their stay at the hospital are financed by this research program. The team conference for these patients —supposed to be more complex cases than others— is often run by Dr. Daniel, the chief of the Memory clinic. Later in the afternoon, in the room without windows on the eighth floor of the hospital, we are all waiting for Dr. Daniel, the director of the Memory clinic. Bruno, a medical student, is connecting the computer to the screen to have the MRI of Mrs. Joe’s brain projected on the wall. John, the neurology fellow, is laying out his notes. Olivia, the neuropsychologist, finishes grading a pile of tests. The nurse Beth is not there but she has given her report to Bruno. Two other individuals with pens and notebooks are also waiting around the table: Leticia, a resident in neurology, and me,

5 A neurology fellow is in a period of medical training in neurology after having completed his or her residency.

the anthropologist. Some medical school students and monthly visitors to the clinic are seated behind the table, on chairs and filing cabinets. “We expect to be a full house”, someone comments.

Dr. Daniel comes in, smartly dressed with a white shirt and a grey linen jacket. He closes the door.

Daniel. — What have we got?

Bruno [the medical student]. — Ah! Very tough case.

John. — Yeah, she is puzzling... Bruno might have something...

Daniel (*to Bruno*). — You think you’ve got the diagnosis?

Bruno (*serious*). — I have my hypothesis.

Daniel (*kindly smiling*). — All right.

John (*to Daniel*). — I think... well, we’ll see what you think, but certain things make her hardly fit in anything in particular... actually one question is whether this is neurodegenerative...

John turns to the sheets of paper laid out in front of him.

John (*reading his notes*). — So, this is Mrs. Joe, a 63 year-old woman who is here for a two-year history of memory loss and functional decline. These changes were initially associated with anxiety and panic attacks, although over the past year the anxiety totally resolved... (*After a pause.*) According to her husband...

Daniel (*to John*). — Trusting?

John. — Um... hard to say... I would say yes but... there’re reasons to feel that her husband might not be particularly perceptive.

Daniel (*impassive*). — Have we ever had a perceptive husband?

John (*laughing*). — I’ve seen more or less... But just from gestalt: she’s described as being the normal one ... and she’s not normal.

Bruno [the medical student]. — He is definitely an odd informant. When I was talking to them, first, I thought he was the patient!

Someone laughs in the back of the room.

One crucial step in the making of a diagnosis of dementia is the assessment of clinical signs, symptomatic of these cerebral afflictions, and their unfolding over time. These signs, which are most often trivial events, are not always clearly identifiable as dementia symptoms. Losses (of keys, glasses, some words, somebody’s name), small changes in character, sadness, anxiety, excessive purchases, an incongruous remark: are these the germs of an imminent metamorphosis due to a neurodegenerative process, are they symptoms, or are they mere difficulties, effects of a “midlife crisis” or of “normal aging”? To decide, the neurologist needs to turn back to

the entire life of a patient in order to ask if these small changes in habits and tastes are in conflict with “who” the person is. At the Memory clinic, this historical work mainly proceeds from the accounts of the patient’s family. In this US center, as in other dementia diagnostic centers (see BROSSARD 2013 for a French example), patients’ voices have no authority; even though they speak, their words are not taken at their face value. Why, one may ask, would patients be deprived of the capacity to give an account on their disease? First, as a result of their possible cognitive disorders, what these patients say might not reflect reality. Second, it would be in the nature of neurodegenerative diseases to cause “anosognosia” [*a-* “without”, *nosos* “disease”, *gnōsis* “knowledge”]: denial of the disease is one of the symptoms of the disease itself. Progressing brain diseases would deprive persons from their ability to know in general, but also from the possibility of knowing how the disease affects them in their own flesh and blood. As patients are *a priori* regarded as unable to narrate who they are, it is their “loved ones” accompanying them at the consultation who recount; at the Memory clinic, the identity of the patient and its possible metamorphosis are always uttered by the other⁶.

6 That the patient is considered as unable to speak for herself is contested by studies (GRAHAM and BASSETT 2006, SABAT 1998) that have been preoccupied with giving a voice to the person with Alzheimer’s —as opposed to giving only voice to his or her caregiver— and which describe how persons affected by Alzheimer’s disease do express insight despite decline. From the practices that I document, the neuroscientists at the Memory clinic do not share this view —nor do the neurologists from a French diagnostic center (BROSSARD 2013). What may remain surprising to us is the fact that the patient is considered to not have insight *prior* to the actual making of a diagnosis. This might be especially surprising if we know that many patients who make an appointment with the expert diagnosticians of the clinic do not actually seem sick. At the Memory clinic, I rarely met patients who could be said to be those “dead without cadaver” like Lula, the wife of Serge Rezvani, whose “neuronal soul” had inexorably been destroyed by the cerebral disease (REZVANI, 2007). Most patients I encountered at the Memory clinic, seemed to live a fairly normal life and generally struck me as being the people HERSKOVITS speculates about, “afraid, sometimes terrified, of losing their minds as they grow old” (1995: 153). The suspicion of “anosognosia” that explains why patients’ voices are not attended to, could be a first manifestation of the “social death” of dementia sufferers described by Annette LEIBING (2006) and Janelle TAYLOR (2008). This term was initially used by David SUDNOW (1967) to define the threshold from which someone, before being physically dead, is no longer considered as a “person”. In the dementia world, this threshold would be overstepped at the very moment someone worried of having Alzheimer’s, crosses the doorstep of a memory clinic.

The person who recounts the habits, preferences and dispositions of the patient and who portrays the metamorphosis of her or his character is defined at the Memory clinic by the somewhat special status of “the informant” (also sometimes called “the historian”). This status is nevertheless quite ambivalent, as the clinicians of the Memory clinic clearly acknowledge. On the one hand, the informant is considered to be a diagnostic tool like any other (the MRI, the neuropsychological test) and is assumed to skillfully allow the clinician to objectify a disorder. On the other hand, the role of the informant is occupied by someone who has affective relationships with the patient: the ones who *know* the patient, also *exist* through the relationships they have with him or her. As a result, the informant can be affected, and even suffering in this relationship. This raises (as raised by Dr. Daniel in Scene 1) the question of trust that can be granted to the informants’ accounts. And to be sure, every now and then this team of clinicians believes that their informants are unable to tell what “really” happened: because they seem to be myopically in love or, to the contrary, indifferent to their spouse; because they somehow give the impression of being “bad informants”; or because they appear “not deeply psychological”, “anti-western medicine”, “prickly”, “odd” or “weird”. Sometimes like Mrs. Joe’s husband, they even look as if they could be the patient. In these cases, the team implements what PERÄKYLÄ (1989) and DODIER (1994) have called a “psychological framing” (in their ethnographies this framing is done on patients, not on their informants): clinicians scrutinize the informants’ psychology and attribute to them a psychiatric label (based on a quite vague symptomatology). The one who is usually seen as a key *means* for the diagnosis is thus exposed as a *subject* of a diagnosis.

My inquiry, situated in a dementia clinic, is not the first to describe how the loved ones, who accompany the patient to the medical consultation, may fall under the medical gaze. Ethnographies that broaden the analysis of medical interactions to the triadic (patient-doctor-family circle) relationship, do describe how parents are suspected of being affected, like their children, by “pervasive development disorders” (BUCHBINDER 2012: 116) or chromosomal deletion syndromes (DIMOND 2014). The parent plays a crucial role in the diagnoses of psychiatric or dysmorphology syndromes of their child, not only as a narrator of the child’s story but also as a “quasi-patient” (DIMOND 2014: 11). At the Memory clinic, the informant may become a full-blown patient and would be better

described as a “co-patient” than as a “quasi-patient”. In this example, especially, Mr. Joe is so “odd” that he could be the patient: according to Bruno, the informant might be the demented one. For Daniel, who raises the question of trust, Mr. Joe’s “perceptiveness” is at stake: because he is a “husband” (a man? a man in love?), Mr. Joe seems as “anosognosic” as his wife. These impressions (“odd”, “unperceptive”) that John “felt” (thanks to his “gestalt”), are adjustments that go against a preestablished plan, according to which the informant is meant to help the medical team in the making of the diagnosis. In Mr. Joe’s case, the “affordances” selected by the medical team during its encounter with the couple, disqualify him from his role as informant. As we will see in sequence 4, such disqualification will actually be put into action since some of Mr. Joe’s remarks will not be taken into account for the elaboration of the diagnosis.

Sequence 3. The Doppelgänger.

John proceeds with the presentation of the case.

John (*monotonous voice*). — Panic attacks started two years ago when her ophthalmologist diagnosed her with a corneal disease⁷; at least this is how they [Mrs. and Mr. Joe] think about this... They feel that the eye problem triggered anxiety, which seemed to set everything off. It’s sort of curious, because her father had ALS [Amyotrophic Lateral Sclerosis⁸] and his case also seemed to be precipitated by some emotional stressors...

Daniel looks at Bruno who is silently smiling.

Daniel (*to Bruno*). — I know what you think, it is...

Bruno and Daniel are silently thinking that there is a gene in this family which predisposes Mrs. Joe to a neurodegenerative disease.

7 This disease is called FUCHS: it causes a slow progressive visual loss, which in the end usually results in the need for corneal transplant.

8 Amyotrophic lateral sclerosis (ALS) or Lou Gehrig disease (or *Maladie de Charcot*), is a progressive neurodegenerative disease that affects motor neurons, which reach from the brain to the spinal cord and from the spinal cord to the muscles throughout the body. The brain’s ability to initiate and control muscle movements is lost: in the later stages the person becomes fully paralyzed. ALS eventually leads to death. ALS is a disease that is traditionally diagnosed on exclusive motor symptoms. Since 2011 however, a unique gene (C9ORF72) is considered as causing both ALS and FTD. It is possible for someone to be sick with FTD and ALS, to the point that at the Memory clinic, some clinicians wonder if it is not the same disease.

Anxiety would be the first symptom of the cerebral disease and would not be related to Mrs. Joe's eye problem or another kind of "emotional stressors". One gene (called the C9) predisposes both to ALS (Mrs. Joe's father disease) and to frontotemporal dementia [FTD]⁹.

John continues. Today, Mrs. Joe's anxiety has eased, but her life has changed¹⁰. She stopped working, she stopped driving because she cannot remember where she parked the car, and she stopped going to her exercise class because she no longer understands the instructions. Yet, she does one new thing: she plays Sudoku, a lot.

Daniel. — Is that a compulsion? [compulsion is a symptom of FTD]

John. — She says she feels that's calming... So one interesting thing is that she says she can still cook but she has to do it all from recipe; she can't do it from memory. But she'll work out equations: if you have a recipe that feeds eight and you've got five people, she'll work out for each ingredient how much to put in.

Daniel. — A little compulsive. Is this new?

John. — I don't get the sense...

Daniel (*doubtful*). — Maths and cooking... that's unusual.

Bruno decides to intervene.

Bruno. — Can I say my thought?

We are all looking at Bruno.

Bruno. — She is the identical doppelgänger of another patient: Lea Strong... (*Showing Beth's report.*) Comparing this nursing report to the one of Lea Strong, you could transplant them.

Daniel (*to Bruno*). — What does Beth say in the report?

From the discussion Beth had with Mr. Joe, the nurse reports that Mrs. Joe "compulsively plays Sudoku"; is "apathetic regarding the household"; she does "some cooking but is very methodical about it: crossing each step while it is completed"; and she is "methodically taking her eyes drops every day". Nevertheless, Mr. Joe said that his wife "cares much about her family but has much less initiative". "So more apathetic", Bruno concludes.

⁹ C9, or C9ORF72, is a gene discovered by a U.S. team of researchers (some of which work at the Memory clinic). It predisposes a person to a range of diseases: FTD, ALS, FTD combined with ALS, and Parkinson's disease. Its penetrance is not full, which means that carrying this gene does not necessarily cause (any of) these diseases. See DEJESUS-HERNANDEZ (2011).

¹⁰ Mrs. Joe was first treated (one year ago) with antidepressants for her anxiety attacks, but they had no effect on her anxiety. Today she is not taking any psychiatric medication.

“Apathetic”, “compulsive”, “methodical” are adjectives chosen by Beth (and Bruno) to characterize Mrs. Joe’s attitude from Mr. Joe’s account of her everyday life. The nurse’s report, thanks to its command of a specific language, makes some FTD symptoms appear clearly now, whereas previously they were veiled by John’s hesitant report (“I don’t get the sense”).

Daniel summarizes: these “symptoms” suggest “possible” FTD: “We have apathy, we have compulsive repetitive motor [Sudoku, crossing while cooking, taking eye drops]”. Some symptoms are lacking though: “We don’t have loss of sympathy and empathy for people”.¹¹

Daniel (*after thinking*). — But she is atypical. I cannot say that the genetics have not totally influenced the way I heard the story. (*Pensive.*) I keep trying to suppress it, but in my heart to heart I believe this is going to be that chromosome 9 gene, which our patient Lea carries. I think the gene carriers are not so typical of FTD, but... you know... it’s a stretch.

A silence.

John (*with animation*). — One thing that struck me is that she has a very quick kind of wicked sense of humor.

Daniel (*intrigued*). — Give me some examples.

John. — So one example was that her husband said that they went for a tour in France and she said: “We must have walked by some mad cows!” (*Laughing.*) Or when I asked her to give me her thumb for the exam, she said: “It is attached”.

Daniel. — So she plays with words a little bit...

Leticia [the resident in neurology] (*to Daniel*). — This is not very FTD...

Daniel (*to Leticia*). — I mean... Sometimes people in the humor area are over-represented in FTD... and especially right side cases [the lesion is on the right side of the brain] do a lot of punning and playing with words ... but it’s not quite that...

Bruno. — I have seen a few FTDese in the research program who had a solid ironic sense of humor, including Lea.

11 Daniel bases his assessment of FTD symptoms on the revised diagnostic criteria for frontotemporal dementia described by Rascovsky *et alii* (2011). Here, Mrs. Joe symptoms *could* meet the criteria for the “possible behavioural variant FTD” (the earliest, and thus most uncertain, stage of FTD).

Daniel. — Yeah, so Lea had a real love for horror, she'd just watch horror movies all day long, and her dad died of something, probably ALS, and she had that kind of dark ironic humor, and she went very slowly and a lot of people didn't think she had FTD. I did. Anyway, she's got this chromosome 9 gene... (*To Bruno.*) And she reminds you most of this...

Bruno (*with great authority*). — Doppelgänger.

What Daniel “knew”, that Bruno had known since the beginning, was that Mrs. Joe could be affected by FTD caused by a gene. It would be the same gene, the C9, that Lea Strong was recently found to be carrying. The team at the Memory clinic often compares one patient to another one. Beth, the Memory clinic nurse, once explained to me that neurodegenerative diseases “give a coloration to the personality”: a disease gives to its bearers a sort of family resemblance —an air that the neurologist and even the novice might intuitively perceive —provided that he or she has seen similarly behaving patients already. The search for a family resemblance does not bear on any kind of formal recognition nor any meticulous description; it reminds us of what WITTGENSTEIN (1973) calls “the grip of an expression”, that can apply to concepts, face recognition, or the identification of a work of art. The analogy draws mainly on the observer's impression of the patient, and the resemblance, which strikes Bruno, has not really been explained, except for the dark humor of both women. Mrs. Joe has a resemblance with Lea Strong, whose case is sometimes related to an audience of medical students listening, fascinated, to the account of her “weird” symptoms (in particular her love for “horror”)¹². Lea Strong and Cheryl Joe are seen by the clinical team to be “doppelgängers” (from the German: double goers) —not only “twin” but also “evil twin”, emphasizing the curious, even unsettling, aspect of the comparison. This term, which is underpinned by a logic of assemblage between patients, can be compared

¹² When Lea Strong came for the first time to the Memory Clinic, she was 48. She first saw Dr Blake, who diagnosed her with bipolar disorder. Six months later she met Dr Daniel, who diagnosed her with FTD. But the years went by: Lea was coming back to the Memory Clinic every year to do the same tests, to answer the same questions, and she was getting better. Another surprising thing about Lea is that she was using a ‘check-list’, a sort of aide-mémoire of commandments. She always had the list on her and referred to it to know what she absolutely shouldn't say or do. For a patient diagnosed with FTD, her wish to self-monitor was atypical. Therefore, for five years the FTD diagnosis was challenged. A month ago it was finally discovered that she was carrying the C9 gene which predisposes to FTD and to ALS.

to the Morellian method described by GINZBURG (1992: 96-97). In order to distinguish original paintings from copies, Giovanni Morelli—a doctor and an art historian (1816-1891)—examines the most trivial details (such as the shape of the ears in Botticelli’s figures) in paintings. By gathering these details (as opposed to the attention to the most obvious characteristics), it becomes possible to isolate some standards proper to an artist and to identify the original from its copies. The theory of twinship used by Bruno and Daniel rests on the same logic: from the collection of these “weird” symptoms (as opposed to symptoms described in the DSM, for instance), the clinician aims to identify the particular “coloration” that a disease gives to a personality.

The family resemblances between the patients of the Memory clinic’s “curiosity shop” powerfully support Daniel’s certitude that Mrs. Joe’s symptoms are those of FTD, against evidence provided both by the neuropsychological test and by the MRI. The neuropsychological test dispensed by Emily does not concord with the diagnosis of FTD. Emily, first, warns us that she had the impression that Mrs. Joe has Alzheimer’s disease (AD): “Interpersonally... I thought she was odd, with a strong AD flavor... but it’s me, I could just have missed her”. Second, Mrs. Joe’s test scores show a memory deficit: “So the main thing I really saw was memory”, concludes Emily. The MRI of Mrs. Joe’s brain is concordant with the neuropsychological test: it shows atrophy in the back of the brain and in the temporal part of the brain. Seeing the image of Mrs. Joe’s brain powerfully challenges Daniel’s conviction that Mrs. Joe had FTD. After a silence, Daniel concludes: “It looks more like AD than FTD”. But after thinking he reasserts: “I still think she is a gene carrier... I mean: the gene carriers are a little funny... They sort of are not the classic FTD phenotype... Which is interesting.”

Bruno’s assessment of Lea Strong and Cheryl Joe as “doppelgangers” does not only lead to a diagnosis, FTD, but moreover to what might cause it: a gene.¹³ A genetic cause would justify the “atypical” presentation of the disease. Mrs. Joe does not present the classic range of FTD symptoms: she “cares”, she is “empathic”, her humor appears strange (as her husband

13 At this point of the discussion, the team does not have the gene testing’s result, but blood has been drawn and the test will be done. Yet, the Memory clinic’s ethics board does not allow Daniel to release the results to the patient and to her family (nor to me) since this test is in its experimental stage.

predicted) but “it is not quite that”. Mrs. Joe is “atypical” just as Lea Strong is “atypical”. While Daniel tells us that his knowledge of Mrs. Joe’s father’s disease made him stray from clinical reasoning (“I cannot say that the genetics have not totally influenced the way I heard the story”), this theory of twinship helps rationalize —with “atypia” conceived here as a symptom— what Daniel’s “heart” believes to be true: that Mrs. Joe, like Lea Strong, carries a gene, one that Mrs. Joe’s father most likely carried, a gene that predisposes to FTD and ALS. This impression will have to be confronted to the test of the encounter with the patient and her husband.

Sequence 4. Judgment of normality and emotive proximity

Daniel stands up, introduces himself and shakes Mr. and Mrs. Joe’s hands.

Daniel (*charming*). — Nice to meet you.

Daniel offers Mrs. Joe the seat next to his own. Mr. Joe sits down on a chair next to his wife. Everybody is looking at them.

Daniel (*to Mrs. Joe*). — So I would like you to tell me a little bit about your past...

The team’s excitement, fueled by the search for a diagnosis, fades slowly with the long quiet pauses and the sparse answers of Mrs. Joe. Her responses, disappointingly concise, force Daniel to constantly revive the conversation with a question that finally finds an answer in two words uttered in a low and smooth tone. Mr. Joe is more talkative: he describes his wife as “very bright, reserved, not a big talker... She likes to make jokes, and always has!” During the interview, Mrs. Joe makes some jokes. Her humor creates a diversion, as if she was trying to avoid the path marked out by Daniel’s questions. Daniel ignores them or meets them with a dismayed “Mmm”. After Daniel completes his examination, he recapitulates for the couple.

Daniel (*to the couple*). — So I think the illness is unusual... The family history of ALS worries me a little bit... But I wouldn’t call the motor problems bad enough to be ALS and I wouldn’t call the behavior bad enough to be frontotemporal dementia. The image doesn’t show a lot of frontal problem either, so it is not classical... although it does worry me. What I’ve heard is maybe a little bit of apathy and compulsive playing of Sudoku and these sorts of things...?

Mr. Joe (*vigorously*). — Oh yeah! She graduated at UCLA School of Business, she worked in my office doing all the accounting... (*Bitterly*.) And now she won't even write a check at home!

Mrs. Joe (*joking*). — But I'll write one right here!

No one laughs.

Daniel (*to Mr. Joe*). — So a lot of apathy.

Mr. Joe (*doubtfully*). — If that's apathy... When you ask her, she'll say that she is unsure of herself: that's what you call apathy? The cognitive slowing is called apathy?

Daniel. — No. I think there is a little cognitive slowing but boy! (*to Mrs. Joe*) You are quick with your wit, that hasn't slowed at all! But I think the lack of interest in things sounds like a change. (*To Mr. Joe.*) That, I call apathy. (*to Mrs. Joe.*) Do you agree?

Mrs. Joe. — With your definition? Yeah, I agree.

Daniel. — Do you think you are apathetic?

Mrs. Joe (*to Daniel*). — About some things... (*Laughing lightly.*) About the things that may be of interest to you...

Daniel (*serious*). — OK... Do you think you've become less interested in a broad range of things?

Mrs. Joe. — No.

Mr. Joe. — She has, I mean, she was very interested in politics... and now, not at all. She was a devout catholic, and now she doesn't go to church.

Daniel (*to Mrs. Joe*). — Lost interest in church?

Mrs. Joe (*discouraged*). — Well... joining... the car...

Daniel. — If there were a car to drive you there, would you go?

Mrs. Joe. — Sure.

Silence.

Daniel (*moving on*). — Any question for me?

Mr. Joe. — I have a couple.

Mrs. Joe (*teasing, to her husband*). — About the apathy?

Mr. Joe (*laughing*). — Ah-Ah! ... (*Serious again, to Daniel.*) So apathy is the cognitive slowing and the memory status is...?

Daniel. — We think it is poor.

Mr. Joe. — You think it's really poor?

Daniel. — Not really poor but...

Mrs. Joe (*calmly, to her husband*). — Poor.

Daniel. — Fair to poor: not terrible. (*To Mrs. Joe.*) I mean, it's not like your memory is wiped out. But you've got some...

Mrs. Joe. — ...deficits.

Daniel. — Yeah, some deficits.

A silence.

Daniel. — I am going to give you my card, email me whenever you have a question.

Mr. Joe. — Thank you for your interest. (*Bitter again.*) Where she went to school and where she is now... so rapidly...

Daniel. — I know. It's pretty rapid isn't it? (*to Mrs. Joe.*) What was the hardest test you went through?

Mrs. Joe (*after a silence*). — They were all hard.

Mr. Joe (*anxious*). — She gets her spinal tap [lumbar puncture] tomorrow¹⁴...

Daniel (*comforting*). — Often it's not too hard: a little freezing and ... (*to Mrs. Joe*) Easy for me to say, uh?

Mrs. Joe (*to Daniel*). — Well, it is reassuring to hear.

They stand up, everyone says good-bye and they leave the room.

John leaves with the couple, the rest of us stay around the table, in silence. Leticia, the resident in neurology, speaks first.

Leticia (*proudly*). — Nothing frontotemporal dementia in my opinion.

Daniel. — Oh really?

Leticia (*shaken*). — No! Why? I think she performed well with you, she is very appropriate, after one year of history! She doesn't have any symptoms of frontotemporal dementia!

Several persons talk at the same time.

Daniel (*amused*). — Even the image [the MRI] isn't good for frontotemporal dementia. (*To a resident in neurology.*) What do you think it is?

The resident in neurology (*impassive*). — I think it is FTD.

Daniel (*determined*). — I think it is frontotemporal dementia with ALS.

14 Spinal tap (or lumbar puncture) aims to collect the cerebral spinal fluid in the patient's marrow. The cerebrospinal fluid (CSF) analysis will assess the levels of two biomarkers: amyloid-beta and tau proteins. A low level (lower than the "norm") for the a-beta, combined with a high level (higher than the "norm") for tau, is statistically correlated with Alzheimer's disease (AD). Such result means that the bearer is *at risk* to having AD, yet this result cannot be conclusive (only the post mortem autopsy of the brain can). The lack of standardization of the test (see LOCK 2013: 114) and the number of false positive (30%) are among the criticisms voiced against CSF analysis for AD diagnosis.

A second resident in neurology (*smiling*). — I am changing my position: I think the interview...

Daniel (*to the second resident*). — That too. Yeah...

Both residents nod.

Leticia (*disturbed*). — But why doctor Daniel? Why?

Daniel (*after a silence*). — Here is why: mostly because of her father. Also, I think she has a very odd personality. She is pathologically cold, she doesn't care about this disease: she sits around playing Sudoku, she doesn't ask about the effect on the children. She isn't concerned about anything; she isn't concerned about her LP [lumbar puncture]... I think she is really emotionally blunt. And then, the punning, the joking... (*Annoyed*.) I mean she was more interested in thinking of making a joke than anything I said: that's what her whole thought process was during all this. So I went from like pretty sure she was FTD-ALS on its way, to really sure. That's me...

Leticia (*fiery, to Daniel*). — How can you explain the memory deficit and the atrophy that we see on the MRI? She has temporal posterior atrophy on the left. How can you explain this if we think it is frontotemporal dementia?

Daniel (*energetic*). — This is the gene! It gets a lot of posterior atrophy!

Me (*to Daniel*). — But then... what is the essence of FTD?

Daniel (*smiling*). — I know... I know... (*Confident*.) She is FTD.

Laughs.

Daniel. — The essence is there: the odd personality with all the jokes. I bet in six months she will be FTD-ALS and everyone will agree.

John (*pensive*). — I was struck by the anxiety that sort of resolved by itself. I guess if she is a gene carrier... because she got very anxious, that was her first symptom...

Daniel (*casual*). — Oh, yeah...? I don't see it now. She is flat like a pancake. (*Joyfully*.) OK! Good case! Thanks.

Everyone starts to disperse.

How can a diagnosis in neurology be in contradiction with what the image of the brain shows? Leticia, and I, wondered about this incongruity: how is it possible to make a diagnosis of frontotemporal dementia, a disease that hits principally the frontal and the anterior part of the temporal lobes, on a patient whose MRI does not show such geographical atrophy and —quite the opposite— whose posterior brain mainly is atrophic? Daniel's answer —with the gene everything is possible— flouts the presupposition that

frames his discipline: the causal relation between, on the one hand cerebral anatomy, and on the other, cognitive capacities and mental symptoms. Challenging Joe DUMITT's account (2004) of the centrality of brain scans in shaping our identities, the expert neurologist ignores the significance of the MRI. Moreover, he turns around the image of the patient's brain: with the gene everything is possible, it is *even* possible to observe an inverted image of the disease. The neuropsychological test and the informant's speech—which has not been attended to (“she likes to make jokes and always has”)—suffer the same fate as the MRI. The three principal types of evidence which are typically used to diagnose dementia are therefore ruled out. How then is the director of the Memory clinic, Dr. Daniel, able to display such messianism: in six months everything will be clearer (“she will be FTD”), trust me (“I bet”) and you will see (“everyone will agree”)?

Two criteria stand out: first the burden of genetics, second the emotionally charged encounter between Daniel and Mrs. Joe. The burden of genetics, supported by epidemiological methods, statistics and Mendelian calculus, pertains to the realm of what is called evidence-based medicine. Although genetics are clearly the bedrock of Daniel's diagnosis, it is not genetics that allowed Daniel to answer my question (“what is the essence of FTD then?”) with this quite imprecise redefinition of the disease: “an odd personality and a taste for jokes”. This redefinition is based on a symptomatology that seems to go without saying, elaborated during Daniel's encounter with the patient. During this encounter, the clinician made himself receptive to quite imperceptible clues—at least for Leticia and me—which allowed him to consider Mrs. Joe as “very odd”, “emotionally blunt”, “cold”, “flat like a pancake”. Historian Carlo GINZBURG would put Daniel's attitude within “the evidential paradigm”—common to medicine, connoisseurship, detective work, divination, the art of forecasting rain and hunting—for which the analysis of specific cases “can be reconstructed only through traces, symptoms and clues” (1992: 104). At the Memory clinic, these clues are however not “infinitesimal” like the “footprints and cigarettes ashes” (1992: 98), “excrements, hairs, feathers” (1992: 103), examined by the detective or the hunter. “Taste for jokes”, “to not ask questions”, “a lack of care”, are not “imperceptible” symptoms, but appear rather as a hazy semiology supported by a rough, rather unscientific and pop psychology kind of language—the same kind of semiology that allowed Mr. Joe to be judged “not perceptive” and “odd”.

These judgements, which seem to elude critique and justification, can be understood only from the specific encounter of one reality (the doctor's) with another one (a particular patient); an encounter which, as GINZBURG has emphasized, engages an emotive proximity between observer and observed (1992: 112). This emotive proximity seems to lie at the source of Daniel's annoyance over Mrs. Joe's jokes ("more interested in making jokes than in anything I said") and his decision to make the "taste for jokes" a symptom. These judgments, based on what Daniel felt, are shared with two residents in neurology (they nod), but not with Leticia. Leticia, a young neurologist, bases her judgment on diagnostic rules (the MRI, the neuropsychological test), while Daniel's judgment, like that of other scientists' (see DASTON 1995:4), is imbued with emotions in a way that evokes what the psychiatrist Binswanger (trans. MINKOWSKI 2002) wrote in 1924 about the "*Gefühlsdiagnose*" ("diagnosis by feeling"). Binswanger criticizes natural sciences' method for the diagnosis of schizophrenia, arguing that it is often not practicable to enumerate and classify symptoms because, most of the time, the "striking symptoms" are not obvious (MINKOWSKI 2002: 96). Nevertheless, we might experience "the certitude that we are in front of schizophrenia". How? "We will talk of a *Gefühlsdiagnose*" (2002: 96). Binswanger explains that his certainty is anchored in the perception of a "lack of affective contact" or in the "distinctive expression of her [the person's] gaze" that will "strike" him each time he meets that person, in a way that will cause him to be gripped by "a movement of interior retreat" (2002: 97). This is a withdrawal that should not be confused with a banal feeling of antipathy that anyone can experience towards anyone else. Even though the *Gefühlsdiagnose* does not call for reasoning, it is nevertheless the diagnosis of an expert psychiatrist (Binswanger says that it requires a lengthy apprenticeship). But unlike medical reasoning that comes from the exterior (taught in medical school), this "infallible instrument [is] in us. It is our own affectivity, our own personality", as MINKOWSKI states (2002: 93). Feeling then, is an "instrument", and the goal is to objectify a trouble. Calling it schizophrenia is already an objectification, but feeling mediates the diagnosis by "penetrating" (2002: 98) a patient's personality, not by "analyzing" it. "Diagnosis by feeling", as MINKOWSKI insists, is not reducible to an "impression" (2002: 95); rather, it appeals to an effort to establish contact between the psychiatrist and the patient.

This effort, which has here been studied through three mediums: the informant, the doppelgänger and the emotive proximity with the

patient, emphasizes the fluidity and unruliness of diagnostic processes. I have documented the ways in which diagnostic work is characterized by the assemblage and the reciprocal interplay between stabilized concepts given a priori (here genetics) and a concrete and affective relationship to the empirical context. The presence of this effort takes into account what GIBSON (1979) calls the “affordances” —the ensemble of signals present in the immediate environment of his or her interlocutors— and shows how, despite being driven by neuroscientific concepts, medical expertise is still bound to a sensible experience of the world that is never given *a priori*. In the scientific endeavor, the *effort* is a force that resists, and at the same time overtakes, the tendency to mechanize the living. It resists a conception of the human being that, as CANGUILHEM (1965) repeatedly underscored, may be necessary to treat diseases but is insufficient for understanding them.

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A DESIRE FOR KNOWING: ONTOLOGICAL UNCERTAINTY,
DIAGNOSTIC EVIDENCE AND GENERATIVE AFFECTIVITY
IN PRE-SYMPTOMATIC GENETIC COUNSELLING

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Abstract: Using pre-symptomatic genetic testing in Austria as an ethnographic case and drawing on recent work in the study of emotions, which tries to foster understanding of affect as an intrinsic part of the social, I focus on the entanglement of ontological uncertainty, the use of diagnostic evidence and the generative affectivities that are “built into” pre-symptomatic counselling. I argue that genetic counselling is organised by an affective style that stresses rationality and autonomous decision-making and is motivated by affectivities revolving around the desire for knowing about individual affectedness.

Keywords: genetic testing, genetic counselling, diagnosis, prognosis, affect, social practice, Austria

Ansias de saber: incertidumbre ontológica, evidencia diagnóstica y afectividad generativa en el asesoramiento genético presintomático

Resumen: A través de la utilización de pruebas genéticas presintomáticas en Austria como caso etnográfico y sobre la base de trabajos recientes en el campo de las emociones, cuya intención es facilitar la comprensión del afecto como parte intrínseca de lo social, me concentro en la interacción que se establece entre la incertidumbre ontológica, el uso de la evidencia diagnóstica y la afectividad generativa que forma parte del asesoramiento presintomático. Defiendo que el asesoramiento genético es organizado por un estilo afectivo que acentúa la racionalidad y una toma de decisiones autónoma y es motivado por una afectividad que gira alrededor de las ansias de saber si se está afectado.

Palabras clave: pruebas genéticas, asesoramiento genético, diagnóstico, pronóstico, afecto, práctica social, Austria.

The striking rise of molecular genetic diagnostics since the 1990s has fostered novel forms of medical knowledge and a new kind of biological information by means of which a predisposition to future ailments has become diagnosable long in advance of any symptoms. Such ‘predictive’ or “pre-symptomatic” tests promise great advances in controlling diseases, but also entail new uncertainties, problematic futures and unwanted affective states in the present for those affected. Genetic counselling, which in many countries is mandatory before undergoing genetic testing, is intended to mitigate such problems.

In this chapter I deal with some of the implications that genetic testing and the estimation of genetic risk can have for diagnostic meaning-making and for knowing the future as they are played out in biomedical consultations and ramify in the lives of those undergoing genetic testing, using pre-symptomatic genetic testing in Austria as an ethnographic case. I explore what can be learned about genetic counselling as diagnostic practice when approached via an understanding of affectivities as a generative force that co-constitutes socialities, as suggested by recent work on affect and emotion in the humanities and social sciences (MASSUMI 2002, AHMED 2004, CLOUGH and HALLEY 2007, SVAŠEK and SKRBIŠ 2007, SEIGWORTH and GREGG 2010, DURHAM 2011, NAVARO-YASHIN 2012, WETHERELL 2012, BEATTY 2013, RECKWITZ 2016). Rather than conceptualising emotions in the usual ways as private mental or somatic states of the individual, this body of work maintains that affect and emotion happen relationally *between* people as an intrinsic part of the social. For doctor–patient interaction, this means that the central task is not to search for the presence (or absence) of certain emotions (hope, fear, anger, despair, etc.) and to ask how such emotions influence the interactive pattern. Rather, the challenge is to understand the interaction itself as intrinsically affective. Taking affectivities seriously in doctor–patient interactions, thus, is not about adding a level of psychosocial ‘texture’ to such interaction. More fundamentally, it is about recognising the generative role that affect and emotions play for such interactions.

In the following I focus on the entanglement of ontological uncertainty, the use of diagnostic evidence and the generative affectivities that are “built into” pre-symptomatic counselling and which organise it. In preference to the term “emotion”, I use the notion of “affect” here in a way that is inspired by DELEUZE and GUATTARI’S (1987) usage of the term, broadly conceived as the bodily capacity to affect and be affected

and the continuous experiential flow of somatic agitation, or as “embodied meaning-making”, as WETHERELL (2012: 4) delineates affect. From a practice theory position I argue that genetic counselling is organised by an affective style that stresses rationality, client-centredness, autonomous decision-making and professional compassion, and is motivated by affectivities revolving around the desire for knowledge about individual affectedness.

The empirical material stems from extensive fieldwork that Monika LENGAUER and I did in five Austrian counselling centres between March 2006 and June 2007 (HADOLT and LENGAUER 2009, HADOLT 2011). Apart from analysing relevant documents (legal texts, national and international guidelines, etc.), we conducted 21 expert interviews (mostly with the heads of clinical organisations engaged in genetic testing and genetic counselling) and collected 37 genetic counselling cases related both to late onset hereditary diseases and carrier status. Concerning these cases, we conducted participant observation during counselling sessions and carried out interviews both before and after counselling sessions with both counselees and counsellors, at times also with family members.

Although insights from other counselling sessions also inform my analysis in this paper, I only discuss three exemplary scenes from one of these counselling sessions. Due to space restrictions and for the purpose of giving the level of detail necessary for descriptions of the micro-perceptions, actions and shifts in the atmosphere involved in genetic counselling to be accessible I leave out any differentiations in terms of counselling styles, or the genetic conditions or demographic characteristics of counselees. By looking in detail at the affective movements of a counselling session, I also seek to contribute to the meanwhile extensive body of social science literature on genetic counselling (e.g. SARANGI 2003, KOCH and SVENDSEN 2005, KOLLEK and LEMKE 2008, KONRAD 2005, SVENDSEN 2006, PRIOR 2007, SUI 2009, GIBBON 2013, TIMMERMANS and SHOSTAK 2016). Although questions of affect and emotions have also been taken up in this vibrant field of study, they have been mainly approached at the discursive level, by focussing either on the verbal exchange between counsellor and counselees during counselling session or on ex post accounts of counselees in interviews. Nonverbal aspects of social exchange and experiences as they are perceived and felt have been largely ignored. Let us first look at some important features of pre-symptomatic genetic testing.

Genetic testing and genetic counselling

Genetic tests have become available in increasing numbers since the 1990s. They have not merely altered medical diagnostics by adding an additional layer of focal points to the canon of diagnostic techniques. More importantly, these new techniques allow the future medical histories of “not-yet patients” to be envisioned in novel ways as they can be used to make a prognosis about a person’s future diseases in the absence of present symptoms (including late onset diseases such as Huntington’s and Alzheimer’s, certain cancers, as well as a growing number of common diseases associated with a genetic factor, such as diabetes).

With some rare exceptions (Huntington’s disease is the paradigmatic example), though, such a prognosis is not definitive, but rather is cast in terms of a probability statement. Despite the confirmed existence of a genetic indicator in the present, the prognosis remains a matter of probabilistic estimation concerning exactly when or whether the disease will manifest in the future, and how severe it will be if it does. As in the case of genetic counselling before the arrival of genetic testing, risk assessment is therefore absolutely central, but now is based on new grounds. Whereas genetic risk assessment before genetic testing had to be done on the basis of manifest diseases of a client’s parents, it now takes the diagnosable genetic status of the client itself as its reference point of biological certainty. Thus, when not-yet patients are informed about their “genetic risk” for a disease, they are not only confronted with general statistical calculations, which they have to translate for their individual situations, but they also learn that they are actually genetically “predisposed” to developing the disease in question. This turns them into “presymptomatic persons” (KONRAD 2005), the not-yet ill who have to integrate their genetic status and the ontological uncertainty which goes with it into their everyday lives, their social relations with relatives, and their future life plans. What makes this more difficult is that for most diseases that can be genetically tested, there is no treatment or cure; prominent exceptions to this are certain hereditary cancers including hereditary breast cancer and some forms of bowel cancer. In addition, due to the inheritability of such diseases (“classical” genetic diseases which are passed on according to the principles of Mendelian inheritance, but increasingly also multifactorial diseases with a comparatively minor “genetic factor”) such diagnostic evidence not only relates to the individual tested but may concern their

blood relatives, who might also carry the mutation and pass it on to their children, thus establishing a “ommunal body” (SVENDSEN 2006), a common unity defined by biogenetic relationships.

Genetic information, thus, is regarded as highly problematic, not least due to the finality of the result of a genetic test: such genetic information cannot be “taken back”. Related concerns include maintaining the privacy of genetic data and protection against genetic discrimination – issues that are particularly sensitive in light of the atrocities of eugenic programmes in countries such as the USA, Sweden, Australia, Japan, Nazi Germany and Austria since the beginning of the twentieth century (KOLLEK and LEMKE 2008).

As a measure to safeguard patients and their families from unwanted outcomes of genetic testing many countries have put regulations in place that prescribe obligatory genetic counselling before undergoing genetic testing (BOURRET *et alii* 1998). In Austria, the Gene Technology Law (*Gentechnikgesetz*) and professional guidelines prescribe that genetic counselling is mandatory before and after predictive genetic testing, that counselling must be non-directive, and that patients not only have the right to know but also the right not to know. In addition, the right to work as a genetic counsellor is restricted to specialised medical doctors, either medical geneticists or other medical specialists (such as gynaecologist, paediatricians, surgeons, oncologists, dermatologists and neurologists) provided the respective genetic condition falls within his/her field of speciality.

In consequence, depending on the particular disciplinary orientation and genetic expertise, genetic counsellors usually put forward one of two main understandings of clinical genetics, which can be called “autonomous clinical genetics” and “additive clinical genetics” (HADOLT 2011). Concerning the former, doctors with a specialisation in medical genetics stress the importance of their broad expertise in human genetics that crosscuts all other medical areas for diagnosis making and their sensitivity to the peculiarities of genetic counselling for the counselling process itself. As for “additive clinical genetics”, doctors from other medical specialities understand genetics as part of their main speciality that they only need to take into account selectively; they claim to be the best equipped to handle genetic issues related to their main medical field. This perspective is particularly prominent in cancer genetics, where the main aim is not merely to provide good counselling but also to enrol patients in

treatment programmes. This is not to say, though, that all cases of cancer genetics necessarily are handled in the institutional context of “additive clinical genetics” (as the case shows that I discuss below). In Austria, most pre-symptomatic genetic counselling is provided by counselling centres located within medical university hospitals or other major general hospitals that have their own laboratory facilities for genetic testing (as described in HADOLT AND LENGAUER, 2009 and HADOLT, 2011).

Genetic counselling as social practice

In our study we found a considerable variety of counselling styles and “logics” in how genetic counselling is organised as social practice (HADOLT and LENGAUER 2009). Among other things, these depended on the professional background of the counsellor (if he/she is a medical geneticist or e.g. a gynaecologist) and the routines of the counselling centre (some centres schedule regular dedicated clinics on particular days, while others allow counselees to make appointments with their counsellor on a more ad hoc basis). In addition, counselling sessions are governed by the disease concerned (if medical treatment is available or not, if it is a well-known disease with clear heredity or a rare and ill-defined condition), and by the case itself (what is already known about the family medical history, whether the counselling is taking place before or after the genetic test, etc.). Notwithstanding such different “logics”, most counselling sessions include a minimal set of phases that must be completed: the opening of the session and “setting the stage”; the counsellor’s opening question (“Why have you come?/What can I do for you?”); the counselee’s account of the problem; the counsellor’s account of what they know so far and how they see the case; taking the family medical history; outlining the basics of human genetics; (preliminarily) clarifying the genetic status and prognosis and communicating them to the counselee; explaining relevant clinical findings and what tests are available; explaining and discussing the treatment options (or that there are none); discussing and agreeing on the next steps for clarifying the genetic status (if still unclear) or dealing with the situation (collecting more clinical family data, doing sound literature research, waiting for test results, making appointments for future medical consultations, etc.); taking the blood sample needed for the genetic test; and closing the counselling session. These basic phases are at times

complemented by offers and discussions of psychosocial support and—in the case of hereditary cancers— getting a place in a screening programme, and counselling about various non-medical issues (implications for the job situation and health/life insurance, reproductive decisions, if and how to tell relatives, joining a support group), etc.

Counselling sessions, therefore, have a complex structure and involve a multitude of tasks. Many counsellors explained to us that genetic counselling is cognitively and emotionally demanding (for both counsellor and counselee) due to the complexity of human genetics and of statistical risk estimations, the scarcity of existing medical knowledge about many conditions and/or the respective case, and long waiting times for test results (often a matter of months and sometimes even years). In addition, genetic counselling is challenging in terms of grasping the present and future implications for one's own and one's family's health and life in general and dealing with strong feelings of loss, worry, fear, uncertainty, hope and relief. Furthermore, each session involves a considerable amount of preparation for both counsellor and counselee, including reading the case-related medical literature, reviewing the available medical findings, and asking family members about medical information concerning things that may have happened long ago. The session itself usually takes between an hour and more than two hours. Certain phases of a counselling session have a more general character: explaining the basics of human genetics, for example, for which every counsellor has a prepared lecture of about 10–15 minutes which he/she delivers to the counselee in more or less the same way, with the counsellor doing most of the talking, always using the same metaphors and props to explain difficult matters (e.g. referring to chromosomes as a “library” and to genes as “books”, and showing pictures of chromosomes and drawings of Mendelian heredity). Other phases, such as the counselee's account of the problem, are more directly related to the medical case concerned and grant the counselee a more active part in terms of explaining, asking questions and making decisions.

In all cases we witnessed, the counsellor initiated the transition between phases, defined their course and direction, and led the whole counselling process. The counselee answered questions and talked when he/she was encouraged to do so (by the counsellor, who paused to wait for a response or after his/her direct prompt). The counsellor (and the whole setting of the counselling room, which is often the counsellor's office in a hospital) defined the situation; the counselee followed. In any case, there

was no doubt that the counselling situation is a medical setting and not to be mistaken for psychological or religious counselling, or counselling by a life coach or friend. We did not witness a single counselling session during which something so unexpected happened that it re-defined the situation in a radically different way. The overall biomedical framing—in all its modalities— always remains intact. As I propose in the next section, this is so not in the least because counsellor and counselee do not simply play out their roles as doctors and patients, but because they interact affectively.

Genetic counselling as affective coordination

Counsellor and counselee relate to each other not only cognitively, engaging in a discourse based on the exchange of rational arguments and pieces of information. More fundamentally, they connect and resonate with each other as experiencing and receptive bodies (which, of course, also includes the cognitive and discursive level). They are tuned in to each other and engage in a communal process of co-action which philosopher Paul DUMOUCHEL (2015) calls “affective coordination”.

DUMOUCHEL starts with James GIBSON’s (1986) suggestion that, based on the idea that perception and action are inseparable, what we perceive in the world are not things, but “affordances”, that is possibilities for actively relating to things in ways that are afforded by them. Dependent on our bodily capacities and our positioning in a particular environment, affordances are “opportunities to act”. For example, for somebody who is tired after having walked for many hours in the woods, a log lying on the ground affords the opportunity to sit—one that may be taken advantage of or not. With affects it is similar: they create affordances, opportunities to act. DUMOUCHEL refers to this modality of affordance as “strategic affordances”, since they involve the joint achievement of at least two individuals who actively relate to each other in strategic ways: “It is not enough for me to respond to some feature of the world, a “strategic” affordance also requires for my social partner play his role. Among us, human beings, affect, I submit, plays a central role in bringing about this result” (DUMOUCHEL 2015: 7f). By means of the dynamic exchange of their affective expression (facial expressions, body posture, words, etc.) participants in a social encounter perceive opportunities for action, rather than simply emotions, and coordinate their attitudes and actions towards

each other accordingly. With such affective coordination we reciprocally and complementarily modulate our affective responses and grasp (or not) opportunities for action that arise in the flow of the exchange.

Let us consider the example of a counselling encounter that stems from the 45-minute *Erstberatung* (an *opening counselling* session in which counsees come to the counsellor for the first time). It takes place at a counselling centre that is located within a major general hospital and provides both counselling and testing services for a broad range of genetic conditions, thus falling in the category of “autonomous clinical genetics”. The counslee, Mr Richter, is a 45-year-old craftsman living in rural Austria who is married and the father of a 7-year-old son; the counsellor is a medical geneticist greatly experienced with various kinds of genetic conditions. Mr Richter had undergone bowel cancer surgery a few months before in another hospital in the area, and although the surgery was successful, a doctor there had recommended he go for counselling, because an investigation of the cancerous tissue indicated that “it could be genetic”.

Part of most *Erstberatungen* is to take the family medical history and to draw the medical pedigree in order to get hints regarding a possible hereditary factor and to identify other family members who might be affected. For some counsees this specific counselling part is confusing because they have no prior experience of similar medical encounters and sometimes do not understand the underlying medical rationale. Accordingly, many counsees at first do not quite know what is expected of them and thus react in the ‘wrong’ way.

The session proceeds as follows. While drawing the family tree, the counsellor asks medical questions about the patient’s kin: their age, where exactly they come from, how many children they have, whether they are still alive and/or had any serious illnesses or operations, whether there were any signs of cancer, what the cause of their death was. Starting with Mr Richter’s siblings and going up and down three generations, the counsellor gradually lays out the family tree on a big sheet of paper in front of the counslee, noting down every node in the network, each family member’s age, marital status, number of children, suspicious diseases and operations. He also makes notes in cases where there exists additional, potentially useful clinical information to be collected in the future. Some 15 minutes of talking and drawing result in a kind of preliminary genetic family disease map (similar to those kinship maps anthropology

students learn to draw in introductory courses on kinship). It not only charts all family members and their genetic links to each other, detailing certain kinds of medically relevant information, but also visualises further diagnostic steps with the aim of supplementing relevant medical information and ultimately coming up with a definite conclusion about the genetic status in the future.

At the beginning of this phase the counsellor creates a relaxed and casual atmosphere. He does so by repeatedly leaning back in his chair in between his brief drawings on the chart, as well as by talking more in the local dialect (which contrasts with the *Hochdeutsch* he predominantly used in the previous phase in which he lectured about genetics and probability estimations), and by phrasing his questions in a humorous way (asking impishly: “You do know your brother’s age, don’t you?”). He makes it easy for Mr Richter to give the “right” answer, but also shows his compassionate interest in Mr Richter as a person and his life circumstances. Mr Richter is relaxed, smiles at the jokes, also leans back in his chair and is confident in giving correct answers.

Soon, the counsellor initiates a change of atmosphere to focus on medical issues. Similar to other counselling sessions we witnessed, the exchange between the counsellor and counselee falters as Mr Richter answers the counsellor’s question not quite in the way he wants him to. The answers are now too elaborate, with Mr Richter giving not only medical details but also information about the life circumstances of the person in question as he tries to convey small details of his relatives’ life narratives. The counsellor does not interrupt Mr Richter, but nevertheless makes it clear that this is not exactly what he wants to know. He stops writing and waits with an indifferent facial expression, he looks silently at his first drawings, comments with a short uninterested ‘aha’, repeats his medically focused question or comments that such issues will be discussed later in the session. An uneasy atmosphere immediately arises and Mr Richter seems puzzled and nervous. Whenever he gives the “right” kind of information, however, the counsellor becomes more active, giving encouraging nods and reassuring “aha’s” and writes things down. Mr Richter soon learns to get to the expected point quickly and the question–answer game continues as a smooth exchange of short questions and short answers. While the matter-of-fact statements of “nothing special”, “still alive” and “already dead” may seem strange and even macabre to an outsider, Mr Richter once again partakes in the exchange eagerly.

This rhythm is interrupted when Mr Richter mentions that his father, who died from lung cancer, might also have suffered from breast cancer. The counsellor switches out of the mode of routine asking, adjusts his position in his chair, straightens up and displays a keenly alert facial expression. In reaction Mr Richter also straightens up and becomes more alert. As they collaborate in searching for and compiling medical facts, both counsellor and counselee engage in a more explorative questioning-answering in which Mr Richter also asks questions. Although Mr Richter is unable to give many details about his father's medical history, the communicative atmosphere is attentive and focused and the flow continues without awkward ruptures.¹ They agree that Mr Richter will try to gather more information about his father by the next counselling meeting, and they then switch back to the previous rhythm as they continue charting the genetic family disease map. Later, when we talk with Mr Richter about the consultation, he wonders why the counsellor had been so interested in his father's possible breast cancer, rather than the lung cancer; and, in general, he praises the counsellor's professionalism, interest and clarity in his statements and questions.

What the counsellor makes clear when he expresses his "strategic affectivities" of professional indifference, pedagogic patience and cautious disapproval on the one hand and of encouraging nods, interested "aha's" etc. on the other, is that this is a medical setting and that medical matters are of prime concern. Notwithstanding the manifold uncertainties involved in establishing medical facts, he also underlines the rational and intellectual nature of the encounter, without, however, abandoning a compassionate attitude towards the counselee and his accounts of his life. In turn, by acting on the affordances that the counsellor opens up the counselee tries to follow his lead and play along with the game. Nevertheless, because of the novelty of the situation he at first fails to give "correct" answers and —guided by the affordances of the counsellor— only hits the right tone and level of discussion after some trial and error. He too expresses his affectivities "strategically" (in the sense of being co-dependent on the actions of his social counterpart) —smiling at the counsellor's jokes, confidently leaning back in his chair, displaying facial expressions

1 As also found in other studies (HARTOG 1996), it is worth noting here that female counselees could usually provide much more elaborate and precise information on such "family knowledge" than male counselees.

of uncertainty and puzzlement, eagerly partaking in the matter-of-fact exchange of questions and answers. These affectivities guide the counsellor's affective responses as they afford the conveying of the extent to which the counsellee follows the counsellor's lead. Eventually, when in this dynamic exchange of affective expressions the encounter turns into a smooth intellectual exchange of case-related medical facts, in which the counsellee settles into the role as a provider of medical information about his family and the counsellor confirms his role as medical expert and genetic diagnostician, the affective coordination comes to what DUMOUCHEL (2015: 9) refers to as temporary "coordination equilibrium", situations in which each participant has found his role and is clear about the other participant's reciprocal role. As affective coordination converging towards equilibrium is a process that takes certain turns but misses others—that is, it is selective—it maintains and guides our (bodily) attention towards certain trajectories (cf. also RECKWITZ 2016). In the above counselling encounter affective coordination helps to organise genetic counselling as social practice and carry out certain diagnostic procedures, but at the same time it also emphasises the overall biomedical framing of the situation.

What is at stake in genetic counselling

In genetic counselling, the counsellor's affectivities are most powerful (or have the most "affective value", cf. AHMED 2004) because they guide through the counselling session, whereas Mr Richter's affectivities signpost his wholehearted participation and his current position as he tries to follow the counsellor's lead. Mr Richter does so not only because this is what the patient role requires, but also because he has a particular interest in finding out if "it is genetic" and learning more about the associated consequences.

When we meet Mr Richter for the first time right before the counselling session starts, he explains how "all this" came about: he was working "full power" and had never really been sick; the diagnosis of the tumour in his bowels therefore was "a shock"; but the subsequent surgery went very well and as "they got it early", he thought that was the end of it. However, when the call came from the hospital that there was a reasonable suspicion that it "is genetic", once again it was "a shock". The doctors told him that he

could get “it” (the cancer) again, and now it also concerns his family; they also told him that it is not inevitable that he will get cancer again, even in the event that he “has the gene”. This gives him a great deal of hope, and now he is here to find out more, which is what is now most important for him. Not knowing what to expect Mr Richter is tense, impatient and nervous as we wait for the counselling to start.

After the initial phases of Mr Richter’s *Erstberatung* (the opening of the session, the counsellor’s opening question, the counselee’s initial account) the counsellor explains how he sees the case, based on the available information. The atmosphere of the encounter is openly friendly, but also tense and observant on the part of Mr Richter. As the counsellor explains the particular diagnostic technique that had been used to investigate the cancerous tissue after Mr Richter’s surgery he also mentions the possibility of carrying out a genetic test as the next diagnostic step. After a second he adds: “If you want to do this”. Mr Richter nods with an approving facial expression, but probes by saying that he had not prepared for genetic counselling and does not really understand the “heredity component” and what it would mean if he “has the gene”. The counsellor replies that the genetic test would be interesting, because in the event of a positive result it would allow them to start taking preventive measures, in particular regular colonoscopies; nothing can be done about the “heredity component” in therapeutic terms, but regular check-ups would identify a tumour early. Mr Richter asks warily at what age check-ups should start. The counsellor answers: usually around the age of 30. Mr Richter again: “No sooner?” As the counsellor confirms his previous answer, Mr Richter exhales, relaxes the tension in his muscles and swings his upper body back in his chair. When we later talk to Mr Richter, he emphasises again and again the relief he felt at this point, as in the following:

What obviously reassures me tremendously is the statement that check-ups need not start earlier than at the age of 30, or, if you are being cautious, at 25. Because, I am really worried for my son especially, but of course also for my nieces and nephews. Do we have to do anything now, at the age of 7? And obviously you get plain scared when one has to say: well, the small one could already have it too, right? When you are 30, well, then you can handle it, or handle it more easily. But explaining something like this to a boy or a girl at the age of 7? But, yes, I am very at ease now, that he said it is with 30 at the earliest.

The counsellor waits until Mr Richter regains his attentive body posture and moves on to lecturing about the basics of genetics. After this incident, the atmosphere has changed, and Mr Richter is much calmer and more composed.

A similar but less tense situation arises later when the counsellor asks if Mr Richter has any other questions. When Mr Richter enquires about the likelihood of “getting cancer again, if you have the gene”, the counsellor shakes his head evasively and says that he currently has no precise statistics and that it would be best to discuss this matter at the next consultation when they have the results of the gene test. He does confirm, however, that somebody will not necessarily develop cancer, even when he has inherited the genetic mutation that predisposes him to it. Mr Richter reacts in a slightly disappointed way, but is also relieved and reassured. During our later conversation he says that he would have liked more concrete information on the issue, but is basically very content and reassured even though he is curious about the result of the genetic test; all in all, he has considerable hope. Later during the day, the counsellor tells us that he put off discussing the issue because on the one hand he did not want to trouble Mr Richter unnecessarily, but also because he did not have concrete risk assessment figures to hand; he will have to look them up for the next consultation.

What is most at stake for Mr Richter is his affectedness. He attends the genetic counselling because he wants to clarify whether “it is genetic” and learn more about the possible threat to his and his family’s future wellbeing. His motivation to know (even if only partially and tentatively) makes him (as well as the counsellor) come to and stay in the consultation room, because this is what genetic counselling (at least in this particular form or “logic”) is about: generating knowledge about a threat and exploring its meaning for particular lives. Because Mr Richter’s desire for knowledge initiates the genetic counselling and drives it onwards, it is not merely his private motivation, but instead an integral part of genetic counselling as social practice. This is what RECKWITZ (2016: 172) argues from a praxeological perspective for social practices generally. For Reckwitz any social practice needs to include an affective appeal that interpellates subjects to participate in the practice. Such an appeal can take the form either of an *offensive pleasure appeal* (*offensiver Lustreiz*) or a *defensive unpleasure-avoidance appeal* (*defensiver Unlustvermeidungsreiz*). Genetic counselling has both: the knowledge to be gained promises relief from

uncertainty in the present (Is it genetic or not? How does it affect my son right now? Is it certain that I will get cancer again?) and hope for possible positive futures (finding out that it is not genetic, my son can handle cancer when he is 30, not developing cancer, merely having to have regular check-ups); avoiding knowing potentially implies more suffering (when cancer strikes again unnoticed, when the defective gene is passed on to offspring, and when ill children, nieces and nephews make accusations of not having been informed about the threat). However, the two kinds of appeal are reciprocally connected. As they closely link diagnostic knowledge in the present with divined health states in the future, they create expectations about the future that in turn organise feelings and actions in the present.

Concluding remarks

In this chapter I have tried to demonstrate how a focus on affect as a generative force for sociality can foster our understanding of diagnostic practices, in particular genetic counselling. I argued that by way of reciprocal affective coordination counsellor and counselee perform certain diagnostic procedures. The strategic affordances that are manifested privilege the counsellor in that he guides the counselling while the counselee follows. The affective style cultivated in the counselling session is one that favours rationality, fact-based decision-making, client-centredness and the professional compassion of the counsellor, and helps confirm genetic counselling as a basically biomedical setting. In addition, affectivities revolving around the desire for knowledge about individual affectedness bring about and sustain the counselee's engagement in genetic counselling and drive it forward as diagnostic certainty is pursued and possible futures are explored. Rather than being private emotional states, the related feelings of hope and fear, strain and relief are "built into" genetic counselling as social practice and hold together its doings and sayings. Thus, affectivities give genetic counselling order and direction as well as relevance and temporal depth.

In this connection I want to raise two points for further exploration. One important conclusion to be drawn is that the categorical differentiation between rationality on the one hand and emotionality on the other is misleading as it produces false dichotomies. It is certainly the case that affects —flows of various modes of (bodily) agitation— may (temporally)

“end” in emotions as we usually conceptualise them: culturally elaborated states of feeling. But, as I have tried to show, the same is the case for what we refer to as “rational”; the “rational” may follow the same generative path and also constitute a (preliminary) end point of joint action. When looked at from the perspective of affective flows both rationality and emotionality emerge as culturally specific solutions to coordination problems. In my view, this has so far been largely overlooked in most studies of affect and emotion and definitely deserves closer attention, particularly when we want to get a better understanding of how subject positions (of doctors and patients) and authoritative knowledge (by means of which the situation is defined and power exerted) become manifest and embodied in biomedical practices.

My second point concerns the ways in which we think about diagnosis and prognosis. In the case of genetic counselling for pre-symptomatic diseases, what perhaps becomes more visible than in other diagnostic procedures is that the focus on merely diagnosing cannot fully account for the meanings that are implied for those who are affected. Since these meanings are heavily dependent on which futures are imagined, the prognostic techniques that help create such expectations are crucial for the meanings that patients give to a diagnosis (or a preliminary diagnostic endpoint such as a genetic test result in genetic counselling). Genetic risk lays out possible futures for wellbeing in probabilistic terms, as has often been noted in the literature. Genetic risk also frames possible futures in biological terms, as has been less often noted. Both dimensions envision possible futures “beyond the reach” of the individual: one, because statistics cannot account for the individual case; the other, because our genetic make-up is (until further notice) beyond the scope of human intervention. Framing individual futures in terms of genetic risk, then, structures expectations about the future in particular ways (it selects some futures as possible and disregards others). But at the same time genetic risk leaves space for individual appropriations in terms of hope and fear for the very reason that it lies beyond individual reach. For those who are affected, genetic risk is not merely the informational result of a technical calculation of statistical data, a technologisation of the threat of future loss (cf. COLLIER, LAKOFF and RABINOW 2004). Rather, it is felt. As analogous mechanisms can be expected to play a role in other diagnostic settings, a more inclusive view that integrates diagnostic and prognostic practices is advisable when looking at processes of diagnostic meaning-making.

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“I’M HERE TO HELP WITH PAIN”: DIAGNOSING AND
RESOLVING TOTAL PAIN IN HOSPITAL PALLIATIVE CARE

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Abstract: Palliative care was initially developed to address the multifaceted symptoms unique to end of life, and gave rise to the diagnosis of “total pain”. This chapter considers the origins of total pain within the genesis of palliative care as a medical specialty and then explores how total pain is diagnosed, and treated, in contemporary hospitalized palliative care in Canada. Through the story of one patient, I suggest how the diagnosis of total pain may best be understood as both enabling and constraining particular forms of conduct as end of life nears.

Keywords: Total pain, total care, palliative care, hospital, end of life, affective labour

“Estoy aquí para ayudar con el dolor”: Diagnosticar y combatir el dolor total en paliativos

Resumen: Inicialmente los cuidados paliativos se desarrollaron para afrontar los síntomas multifacéticos propios del final de la vida y desencadenaron el diagnóstico del “dolor total”. Este capítulo trata de los orígenes del dolor total en el marco de la génesis de los cuidados paliativos como especialidad médica y explora cómo se diagnostica y se trata el dolor total en paliativos hoy en día en Canadá. A través del caso de un paciente explico que el diagnóstico del dolor total puede entenderse mejor si pensamos en cómo permite y limita determinados comportamientos mientras se acerca el final de la vida.

Palabras clave: dolor total, cuidado total, cuidados paliativos, hospital, final de la vida, trabajo afectivo

A cry to be rid of pain is not worthy of man...Man by his very nature finds that he has to question the pain he endures and seek meaning in it (SAUNDERS, quoted in CLARK, 1999: 733).

The official origin story of palliative care begins in 1976, with the opening of the first specialized hospital units in Canada. Given this geographic lineage, it is also a fitting location to examine perhaps the most enduring, if ambivalent, component of palliative care—total pain. My interest in total pain emerged as a result of studying how the dying process is negotiated in Canadian hospitals. At its inception, palliative care was based on the free-standing hospice model emerging in England and shared the same mandate: focus on quality of life for those in the terminal stages of illness, open communication about diagnosis and prognosis, comfort rather than curative efforts, relief of physical and emotional suffering, championing patient autonomy, and help with bereavement, all achieved through a multi-disciplinary approach (Mount, 1976; Saunders, 1978). In order to meet these objectives, palliative care practitioners were required to identify and engage with a patient’s “total pain”—the sum total of their physical, mental, social, and spiritual pain. However, while the requirement to address total pain continues to be referenced as a foundational aspect of palliative care 40 years after its inception, there has been virtually no scholarship examining it as a diagnosis.

I have a three-fold interest in examining total pain as a diagnosis. First, I am interested in the history of its production, and so I begin by exploring the rise of palliative care as a medical specialty which required naming, claiming, and legitimizing certain symptoms of distress as uniquely associated with end of life. Second, I am interested in how the diagnosis is currently “used” by hospital palliative clinicians, including what care practices and outcomes emerge from the act of diagnosis. Through reconstructing the story of a patient named Ruby,¹ I explore how the diagnosis of total pain attempts to order her emotions and conduct in ways that both enable and mandate a good—or “good enough”— death. Ruby’s story also highlights how this work is an ambivalent practice, and exemplifies the ways in which everyone involved are required to negotiate the end of life within environments never entirely of their own making. This leads to my final interest; how contemporary practice tensions

1 All names have been changed.

in hospital palliative care both shape and reflect clinicians' capacity to diagnose, and attend to, patients' total pain.

My thoughts are informed by spending a year (2008-2009) following clinicians who specialize in palliative care, both within dedicated palliative units and as consultants, in two large hospitals in Western Canada. I spent more than 1,000 hours observing a range of daily clinical activities including medical rounds, individual bedside consultations, medical, administrative, and family meetings, and innumerable hallway conversations. I also followed 36 consenting patients and their family members to the point of discharge or —more commonly— death; sometimes this occurred within days, other times weeks and even months passed. To compliment my observations, I undertook comprehensive chart reviews of the patients I followed and conducted 43 interviews with palliative and non-palliative clinicians, as well as several hospital administrators. During this time I observed how a diversity of patients, their family members, and palliative clinicians collectively negotiated the dying process.² At times these negotiations were relatively straightforward, and a good death was achieved for everyone involved. More commonly, I observed a range of ambiguous, shifting, and at times contested understandings of appropriate care practices as end of life approached, the outcome of which I came to term a “negotiated good enough” death. Here I focus on one particular patient in this latter category –Ruby– who, as she nears end of life, is diagnosed with total pain. Although her story is her own, Ruby's dying process shares many features of the palliative care trajectories that I witnessed. To understand how clinicians comprehended and acted on Ruby's pain, it is first necessary to locate the genealogy of their knowledge and actions within the rise of palliative care as a medical specialty.

2 The dying process within hospitalized palliative care encompasses: (1) a medical understanding of a person's unfolding physical state as one of terminal decline; (2) the organization of their care during this time; and (3) the social and emotional impacts of this work on everyone involved in the provision and uptake of care. In defining the dying process, I borrow from STRAUSS, FAGERHAUGH, SUCZEK and WIENER's (1982) encompassing term “trajectory” to “refer not only to the physiological unfolding of a patient's disease but to the total organization of work done over that course of illness plus the impact on those involved with that work and its organization”(p. 257).

Origins of Total Pain

In the 1950s pain became an area of medical specialization as other aspects of illness and disease were organized, observed, and spoken about in new ways. Previously conceptualized from a purely positivist view (where pain was the result of physiological signals sent to the brain when a part of the body was injured), researchers now began to understand pain as a complex situation (rather than a discrete event) that could be read for knowledge about the individual as well as their pathology (BRAUDE, 2012; CLARK, 1999; SHUTE, 2013). Pain was no longer reducible to a purely physical experience, and addressing pain now required an awareness of the patient's interpretation of the experience, including their personality, past experiences, and social relations.

This change in perspective was both informed by, and reflected within, the emergence of hospice care. Although clinical interest in pain management became an increasingly "legitimate" concern in post-WWII medicine, expertise in addressing late-stage cancer pain remained relatively underdeveloped. SEYMOUR, CLARK, and WINSLOW (2005: 3) trace how newly specialized knowledge about pain specific to end of life began to emerge from an interest in translating "clinical wisdom into clinical practice" in caring and sitting with those who were dying, the increasing importance of "evidence and scientific credibility," and the burgeoning interest in "phenomenological and social understandings of the body". Collectively, they identify these changes as emerging from accumulating clinical evidence and the influence of "conceptual revolutions" in pain research, including the nascent field of end of life care. However, what SEYMOUR and colleagues (2005) do not discuss is how the *lack* of knowledge about end of life pain was in part generated by newly *emerging* knowledge about the needs of dying patients. The successful establishment of end of life care as a medical specialty required that practitioners not only identify a unique care population with unique needs, but also required that they establish unique medical practices to meet these care needs. The emergence of end of life care as a medical specialty both enabled and required end of life pain to be understood as separate from other forms of pain.

Although now in common use, Cicely SAUNDERS, the founder of the modern hospice movement, was responsible for coining "total pain" in the early 1960s. CLARK (1999), a sociologist and historian of SAUNDERS' work,

recounts that as she evolved from nurse to social worker to physician, she developed certain ways of listening to, and talking with, dying patients that enabled them to be active subjects. Through this work, SAUNDERS began to understand end of life pain as having an affective dimension that did not differentiate between the physical and spiritual concerns of dying; it was "indivisible from both the body and the wider personality" (CLARK, 1999: 733). She started using the term total pain to describe instances of patients' lived experience where the combination of physical, mental, social, and spiritual components of pain coalesced into suffering, or in the words of one of her patients, where "all of me seems wrong" (SAUNDERS, 1964: viii).

SAUNDERS was not only interested in *understanding* a patient's experiences of suffering, but also in *transforming* these experiences. This required clinicians "to analyse, to assess and to anticipate" through two forms of intervention (SAUNDERS, quoted in CLARK, 1999: 733). The first intervention was articulated through a conventional medical dimension, focused on the prevention rather than alleviation of pain, provided through regular doses of opioids that proactively anticipated, rather than merely responded to, pain. Specialist knowledge (and advocacy) of analgesics that worked best on specific types of terminal pain became necessary. Yet diagnosis of total pain required the ability to read the patient for signs and symptoms that included, but surpassed, the purely corporeal. This was a multifaceted pain that could not be relieved solely by pharmacological expertise; it also demanded that a particular presence and set of skills where "[l]istening has to develop into real hearing" (CLARK, 1999: 731). The second intervention therefore linked clinicians' ability to manage physical pain with their ability to elicit patients' experiences of illness, including its impact on meaning-making and biography. As the subjective aspects of end of life became a legitimate site for clinical intervention, therapeutic relationships also became increasingly important for helping patients achieve catharsis. Saunders was clear that "[t]he last stages of life should be seen...as life's fulfillment. It is not merely a time of negation, but rather an opportunity for positive achievement. One of the ways we can help our patients most is to learn to believe and expect this" (SAUNDERS, 2006: 79). This required what theorists variously term "affective labor" (HARDT, 1999) or "emotional labor" (HOCHSCHILD, 1979), which defines the work that caring professionals undertake in shaping the affective or

emotional states of those they care for³. For example, in palliative care, studies have examined how clinicians engage in “hope work” where, as death approaches, they actively work to replace hope for a cure with hope for physical comfort, emotional closure, and dignity (BENZEIN & SAVEMAN, 2008; FANOS, GELINAS, FOSTER *et alii* 2008; PENSON, 2000; PERAKYLA, 1991). Other affective labour techniques to transform suffering include talk therapy, family meetings, and legacy work (COHEN & MOUNT, 2000; FOLEY, 2005; MEHTA & CHAN, 2008). Diagnosing and attending to total pain can then be understood as emerging from, and reflecting, a burgeoning medical specialty concerned with the totality of a patient’s end of life experiences.

Collectively, these two dimensions of intervention at end of life—pharmacological and affective—became the cornerstone of “total care”. They remain central to the contemporary identity of palliative care, and the majority of professional descriptors continue to use palliative care and total care as synonyms⁴, as well as to mark their specialty as clinically and ethically superior to conventional forms of medical care for the terminally ill. There are, however, no clinical parameters for the diagnostic process, nor for practices of care once diagnosed. Some may argue that, due to this lack of standardization, total pain is better understood as a concept rather than a diagnosis. To bolster that position, in my observations I found that the term was used only in conversations with other clinicians and/or in chart notes as a back-room “cultural script” (TIMMERMANS, 2005), never with patients or family members. How then does constructing it as a diagnosis help to understand how the dying process is currently negotiated in hospital palliative care?

Total pain as diagnosis

The space within which medical specialists invoke a diagnosis, whether public or private, does not alter its core function. Like conventional diagnoses, total pain operates as a nomenclature—a system of ordering

3 In recognition that the definition of affect varies from author to author, I define an affect as an emergent physical state accompanied by certain modes of thinking that include emotions.

4 For example, the WORLD HEALTH ORGANIZATION (2014) defines palliative care as: “The active and total care of patients... [where] control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount” (para. 1).

through naming and categorizing—that generates new *knowledge* about the patient's symptoms and signs of embodied distress.⁵ Diagnosis also generates the need for clinical *action*. These characteristics are reflected within the sizable amount of clinical literature on how to identify and treat total pain, even as practitioners acknowledge that formal diagnostic processes remain elusive (LEMAY & WILSON, 2008; MEHTA & CHAN, 2008; SCHUTE, 2013). The "messiness" of this particular diagnostic process is not unique to palliative care, but rather is evidenced across a range of proliferating syndromes and symptoms in 21st century Western allopathic health systems, and is subject to ongoing interest (cf. BORGSTROM, BARCLAY & COHN, 2013; JUTEL, 2009; LOCK, 2013).

Yet the problematic still remains that the process of diagnosing total pain does so without sharing the diagnosis with those who have been diagnosed. This suggests that, as a classification project, total pain functions on more than one register, operating simultaneously as what CLARK (1999: 727) refers to as a "nomenclature of facilitation" and a "nomenclature of inscription". On the one hand, CLARK argues, total pain requires clinicians to engage to explore, understand, and transform their patients' experiences, and therefore addresses the "phenomenological connectedness between individual experiences of pain, distress and suffering" (CLARK 1999: 734, see also GUNARATNAM, 2012). Total pain foregrounds an awareness that pain is a multidimensional process fundamentally shaping our capacity to be in the world, and creates individual, social, and specialist meaning from a process previously seen as devoid of anything other than the autonomic physiological responses of a decaying and socially devalued body. The diagnosis of total pain provides both a clinical signifier and a social status for the patient's experience as suffering, thereby legitimizing forms of distress that previously have been ignored, pathologized, and/or seen as moral "weakness". By requiring therapeutic practices utilizing affective labor to facilitate the production of meaning, clinicians can increase the capacity of the dying person and their social networks by "help[ing] the

5 I define embodied distress as any expression where a person uses their body (including speech) to communicate a significant and unwelcome decrease in the capacity to strive. This can include, but is not limited to: physical expressions of anxiety (such as hyperventilation, increased heart rate, and trembling), crying, insomnia, turning away from the person speaking, refusal to talk, verbal "outbursts," and compulsive and/or repetitive behaviours (such as picking at an object or self).

patient to reconstruct his world and his relations with others” (SAUNDERS, quoted in SEYMOUR, CLARK, & WINSLOW, 2005: 9). Consequently, suffering can be resolved and healing can occur even when there is no longer hope of a cure.

Total pain can also be read as an expansion of the medical gaze forming a new mode of surveillance and domination. Specialist end of life care now requires that patient narratives be read for deeper significance, where clinicians undertake affective labor in their penetrating search “for signs of trouble, in the social network, in the psyche, even in the soul itself” (CLARK, 1999: 725). This search constructs suffering at the end of life as an abnormal state and a “disease-like object” (BORGSTROM, BARCLAY & COHN, 2013). Resolution of total pain then also requires docile bodies willing to align their conduct with normative expectations of a good death. As the sociologist Carl MAY articulates, this requires the collaboration of all parties, where “the patient, after a series of [therapeutic] encounters that lead her to accept the inevitability of death, recognizes this inevitable outcome and thus renders herself unproblematic” (MAY, 1992: 596). In the hospital setting, if a patient become “problematic” by refusing to accept this inevitability and/or challenges the purpose of care in other ways, they are also blocking efficient transitions along the institutional care pathway. In these instances, a diagnosis of total pain then not only signifies patient suffering but also demarcates contested relations of power that have material consequences, thereby requiring further intervention(s).

Diagnosis therefore designates patient distress *and* patient conduct as mutually constituted objects of work. Clinicians’ compassionate attempts to identify and resolve multifaceted suffering at end of life are the very same practices that further expansion of medical surveillance, require certain forms of normative conduct, and promote institutional efficiency. However, while this discussion provides analytic clarity as to how diagnosis of total pain operates on multiple registers, or what CLARK (1999) termed nomenclatures of “facilitation” and “inscription”, it does not enable insight as to how total pain functions *in situ* of the uncertain, shifting, and ambivalent contexts that constitute contemporary hospital palliative care.

Ruby: Fall 2009, Acute Care Unit

An attending physician requests a palliative consult for a “goals of care” conversation with a younger female patient who has been relatively recently diagnosed with an aggressive relapse of cancer. The patient, Ruby, has interacted with palliative services on a previous admission, but the attending physician reminds the palliative consultant Kelly⁶ that both the patient and her husband are “very sensitive to the word ‘palliative’”. On entering the room Kelly, who has not met Ruby before, states that she is “here to help with pain” and identifies the purpose of her visit as “discussing a possible ‘tune up’ with the goal of going home”. Ruby states that her goal is to stabilize her symptoms and to be discharged home as quickly as possible in order to start a new course of experimental treatment. She and her husband then recount, in detail, other possible treatment pathways if the current one becomes unavailable due her disease progression. Kelly does not reference these possibilities, and instead focuses on Ruby’s current pain management needs. Once the meeting is over, both the attending physician and Kelly privately agree that, given the extent of the patient’s disease progression, associated symptoms, and “suffering”, Ruby “would be better served on the palliative unit”. A family meeting is convened several days later to discuss a possible transfer, but neither Ruby nor her husband expresses any willingness to be transferred as they believe they are getting the care she needs in her current location. Afterwards Kelly’s chart notes state that the patient and her husband felt “pressured” by the conversation. The note also states that the patient is “experiencing total pain”, and highlights that “this may cause potential challenges for clinicians in determining the appropriate care pathway”.

In my conversation with Ruby, she asks “Why me? I see all kinds of people on the street who are abusing their body by drinking and doing all kinds of things. I’ve never smoked or drank, and how come they’re not sick? I’m really angry. It still doesn’t make sense to me, but I’m doing it day by day”. After discussing how hard both she and her husband have worked, she recounts the trauma of her previous round of surgery and

⁶ All the clinicians I include in this chapter occupy senior positions and have worked in the field for more than a decade. I have purposely left individual characteristics of both clinicians and patients vague as, given the relatively small community of specialists where I conducted my fieldwork, further details could easily serve to identify them and/or those they cared for.

chemotherapy and how it made her so ill she thought she was going to die. She says “I’m a worrier; people tell me not to worry. Well you try being in my shoes for a couple of hours knowing what [the doctors] have told me, and knowing what I know. I haven’t been sleeping much.” I ask what is worrying her and she talks about how her youngest son is “not doing so well” with her diagnosis. She says that the doctors are “now saying no [experimental treatments] because it will make me deathly ill” but that she’s focused on trying to find out more about her options.

Over the next two weeks, the chart notes trace ongoing conversations with multiple clinicians (both palliative and non-palliative) that “a palliative transfer is in the best interest of the patient”. During this time Ruby’s physical symptoms fluctuate and remain poorly controlled. Finally, although she says she’s “very torn about the decision”, Ruby and her husband accept a transfer “for symptom management needs” as long as current treatments continue (a framing which is also echoed in the chart notes).

While her clinicians initially agree that Ruby is suffering, she is not diagnosed with total pain until it becomes clear that she presents a blockage to efficient trajectory work, or, in the language of the chart notes, “potential challenges for determining the appropriate care pathway”. The designation therefore encapsulates not the patient’s physical pain, but also her (and her husband’s) resistance to accepting her poor prognosis, expressed through their repeated requests for experimental curative treatment and corresponding resistance to a transfer to the palliative unit. However, while identifying Ruby as suffering and as a site of contested practices of care, the diagnosis does not initially facilitate any new practices of care other than a continued focus on physical symptom management. In turn, the mutually agreed public framing of palliative involvement only to address physical symptoms legitimizes Ruby and her husband’s continued resistance to transferring location of care. Eventually, through negotiations of increasingly visible relations of unequal power where clinicians repeatedly “recommend” transfer, everyone conditionally agrees on the transfer, citing better access to specialists in the best interest of her “ongoing symptom management needs”.

On admission to the palliative unit, due to the instability of Ruby’s symptoms, several staff express uncertainty if they are providing symptom management for purposes of stabilization and discharge (as stated in the chart notes) or end of life care (based on their observation of her deterioration). Over the next several days, while palliative clinicians are

able to better control her physical pain, staff report how they frequently find her crying in her room. When asked what is upsetting her, she replies that she "doesn't want to talk about it" and that "they wouldn't understand". Although the chart notes state that "the patient and her family are slowly coming to understand the role and benefits of palliative care", during another meeting to explore Ruby's suffering, she and her husband continue to aggressively advocate for the continuation of intensive testing in order to pursue further interventions. They cite her relatively young age, the fact that she is a mother, her "right" to all possible treatment given her previous remission, and that others have survived this disease. While the palliative unit clinician [Kirsten] frames Ruby's current admission as focused on stabilizing her symptoms, after which they can "revisit" other possible treatments, she also tells Ruby that "I understand that you need to hope for the best, but you also need to prepare for the worst". In weekly rounds the next day, Kirsten remarks on the "challenging nature of [Ruby's] total pain". The team agrees that they will make a concerted effort to spend more time with her, although as the next few days pass they express continuing frustration in their inability to do so due to task-based care with other high needs patients. Ruby's physical decline is now visibly accelerating (increasing weight loss, fatigue, and shortness of breath) yet both she and the clinicians continue to make tentative preparations for an upcoming surgery for "symptom management". At this point several team members begin to ask, "What is her quality of life?" and "Are we prolonging her life or are we prolonging her dying?"

Ruby's clinicians want to transcend the purely corporeal and address her suffering. Due to Ruby's insistence that they focus only her physical symptoms and curative care pathway, however, all clinicians can do is invoke a framing rule of proper behavior regarding the appropriate corollary of hope ("prepare for the worst"). Without access to Ruby's subjective experiences (as exemplified in her repeated refusals to discuss the source of her distress), clinicians remain blocked in their ability to engage in any other forms of affective labor. Yet in spite of Ruby's resistance, her clinicians persevere and consciously attempt to increase their efforts, only to be frustrated by the instrumental requirements of task-based care with other patients. Overall, the inability of Ruby's clinicians to resolve her suffering complicates efficient trajectory work, troubles the unit's sentimental order of "niceness" (LI, 2004), renders visible relations of power, and challenges clinicians' professional identity as both compassionate and efficient.

During an afternoon when she has “a bit of energy”, I ask Ruby how she’s getting along with Kirsten [her physician]. She says “I always like it when Kirsten comes in”. When I ask further questions about her experiences on the unit, she says she “feels cared for”, then re-directs the conversation, telling me about her love of Elvis and corresponding “life dream” to go see Graceland, and about her dogs who she misses (a picture of them is in a frame on the window ledge in the room, along with another older photo of her kids sitting on Santa’s knee). She recounts how one of her sisters died five months ago and that she and her family haven’t got over the loss. She turns the discussion to her elderly parents, how supportive they’ve been but also how she’s aware how much her illness has “taken” from them. She says that “some days I’m still ready to go, to fight—other days I’m tired”. Ruby turns her head towards the opposite wall, and we are quiet for a moment before she adds, “I’m a bit tired now”. Within three days of this conversation Ruby is no longer able to get out of bed or feed herself. She begins to openly discuss with the team her sense of loss and sadness about the things “I wanted to do but now will never be able to”. Through these conversations Kirsten suggests she create a “legacy project” for her children, and her husband brings in pictures and other mementos of their life together to create a scrapbook. As she continues these conversations and activities over the course of a week, her husband acknowledges to Kirsten that his wife is approaching the end of her life. He requests that she be able to stay on the unit until her death as she “takes comfort” in the relationships she has developed with the staff. She loses consciousness several days later and dies with her husband and remaining sister by her side.

Ruby acknowledges and begins to accept that she is dying only once her physical deterioration becomes irrefutable. The emotional expressions that accompany this awareness provide staff with a language to coauthor appropriate behaviors, including curating memories for her family, to acknowledge the end of her life. As this time visibly nears, everyone is then able to mutually collaborate in creating an affective environment that facilitates a negotiated “good enough”⁷ death.

7 In using the term “good enough” death, I borrow from McNAMARA (2004) who coined the term to describe the increasing failure by end of life care providers in Australia to facilitate a good death due to increasing medicalization and bureaucratization, although they remain proactive in alleviating physical pain.

Ruby's experience enables us to understand how the diagnosis simultaneously operates as a nomenclature of facilitation and inscription. Here, the affective labour triggered by diagnosis (family meetings, talk therapy, hope work, and legacy project) are understood as compassionate work for transforming overwhelming and disordered distress into ordered emotional expressions of grief, sadness, and other aspects of suffering which can be addressed. This was done for the best interest of the individual patient and her social networks in concerns for personal catharsis. At the same time diagnosis and attendant practices of total care attempted to naturalize and extend the reach of the biomedical gaze into Ruby's subjective experiences of dying, and shaped understandings of her conduct to fit within an appropriate "normalized" way of living, even at the very end of life.

Negotiating total pain in hospitalized palliative care

While clinicians are the privileged cultural brokers of hospitalized palliative care and engage in affective labor to frame "appropriate" emotional orientations to the dying process (cf. KAUFMAN, 2005; PERAKYLA, 1991; TIMMERMANS, 2005), these orientations are negotiated, validated, and/or contested through the rights and obligations generated by everyone involved. As evidenced in Ruby's story, clinicians work within institutional environments that, similar to their patients, are never entirely within their control. Palliative specialists' capacity and interest in diagnosing total pain reflects heterogeneous tensions in contemporary practice: evolving understandings of the primary purpose of care, the use of earlier and more complex interventions, prioritizing acute physical symptom management, increasing patient and family member claims to authority in directing care, and the rise of business modeling within hospitals.

Framing the purpose of care primarily for acute physical symptom management needs is contiguous with the expansion of palliative expertise. The shift away from the centrality of total pain and attendant practices of total care is evidenced in the changing definitions of palliative care. In 1990, the WORLD HEALTH ORGANIZATION defined palliative care as "the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount" (WHO, 1990: 11). While

the current definition still addresses the need for “relief of suffering” caused by physical, psychosocial and spiritual issues, practices are now centered on “early identification and impeccable assessment...applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life...and includes those investigations needed to better understand and manage distressing clinical complications” (WHO, 2014: 1). Some practitioners are even more assertive in merging palliative care with conventional biomedical priorities, stating that their specialty is an appropriate form of care for those still pursuing curative treatments (BYOCK, 1998; MEGHANI, 2004; MEYERS & LINDER, 2003).

The integration into new and earlier phases of disease trajectories and/or with curative care requires that palliative clinicians work with patient populations that have increased prognostic uncertainty and complex symptom management needs. As palliative care extends its reach beyond the body with terminal cancer, patients with organ failure, cardiac problems, dementia, ALS, Parkinson’s, and other chronic or life-limiting diseases are all now constructed as benefiting from palliative expertise. Yet many of these patients have not had a physician tell them in clear language that their disease is considered terminal, or if they have, may live with their symptoms for many years, experience several near-death episodes but, with aggressive medical intervention, once again stabilize for significant periods of time. Based on these past experiences, patients may then expect this cycle to continue indefinitely, as even some forms of cancer are now characterized as a “chronic illness” (BRICKNER, SCANNELL, MARQUET *et alii*, 2004; EDMONDS & ROGERS, 2003; MACK & SMITH, 2012). Consequently, many patients and family members assert an autonomous “right” to continue pursuing curative, experimental, and/or investigative treatments. Even when curative therapies are no longer available, the embedded moral position is that patients and family members are justified in continuing any treatment to *extend* life. In these instances many palliative clinicians are challenged to do anything other than default to continuing aggressive interventions, even once the patient has been transferred to the palliative unit. In turn, the continuation of these treatments even as the patient nears end of life necessarily increases the probability they will have heightened symptom management needs requiring further medical interventions that once again prioritizes physical symptoms over affective concerns. In the most extreme of these cases, these practices create “zones of indistinction” (KAUFMAN, 2005) where patients are neither actively dying nor can they be discharged from the hospital.

This evolution of care has led to two sets of—at times contradictory—discourses that define contemporary palliative care. The first discourse constructs it as a specialty designed to meet the unique needs of those at the end of life while *at the same time* appropriate for those who are not at the end of life. The second discourse champions empathic claims to patient and family member autonomy *and* clinicians’ authority to define direction and outcome of care. This discordance both reflects, and can further create, irreducible tensions in framing the purposes of hospitalized palliative care.⁸ One senior physician ruminated about how these complexities emerge from her specialty’s integration within mainstream hospital care:

June: It’s interesting; I know everybody wants maximal medical care. Everybody wants everything done, of course they do. Why wouldn’t they want it, unless they’re really, really suffering? Of course they will. What we have to do is be very careful as clinicians not to offer things that are not appropriate... So a lot of it [providing palliative care] is being very aware what is appropriate for that patient at that time. And I think what is frustrating a little bit is people are aware much more of what they can have and are requesting things and we’re kind of going along with it. Like the chemotherapy; why are we giving all these [treatments], so many of these people chemo that we didn’t give years ago? A lot of it is that the oncologists say, “Why not? It’s not really harming them.” Well, it’s taking away from the real work patients should be doing... We shouldn’t be making these poor patients and families make the decision when they don’t have all the background. So, instead of saying to patients and family members, “Do you want to be tube fed?” We should be saying, “Tube feeding is not indicated in this situation,” rather than offering it in an inappropriate manner just because we can. And that’s what’s happening more and more.

Yet not all patients or family members express a desire to undertake what June calls the “real work” as end of life nears. Ruby and her husband evidence how patients and family members may express reluctance, and even sustained resistance, to clinicians’ attempts to access and transform their subjective experiences and instead choose to frame the purpose of all care—including palliative—within the conventional biomedical paradigm.

8 In hospice contexts, these tensions are structured as “institutionalization” and “medicalization” of care (c.f. ABEL, 1986; CLARK, 2002; GEORGES, GRYPDOK, & DIERCKX DE CASTERLE, 2002; JAMES & FIELD, 1992; and McNAMARA, WADDELL & COLVIN, 1994).

This perspective is further informed by the business framing rules and organizational mandates of hospitals which construct the good death as either occurring in the community or as institutionally “quick, cost-efficient, [and] no risk” (MOR, GREER, & KASTENBAUM, 1988: 3). Although concerned with ethical patient care at the end of life, hospital administrators also champion palliative care with the expectation of cost savings accrued by decreasing length of stay or reducing resource use associated with terminal hospitalizations (DAVIS, WALSH, & NELSON, 2002; RODRIGUEZ, BARNATO & ARNOLD, 2007). Many of the clinicians I worked with spent a great deal of time detailing how their daily care practices are influenced by institutional imperatives reflected within continual meetings regarding bed counts and length of stay, internal health authority guidelines meant to streamline care processes for purposes of efficiency, and administrators concerned about the statistical averages of their departments in relation to lowering costs. In focusing on acute physical symptom management, stabilization, and rapid discharge, the impetus for care prioritizes organizational efficiency regarding the biological processes of dying. This valorizes a “bureaucratic model” of task-based care over therapeutic relationship building, where palliative clinicians are institutionally rewarded for adopting system characteristics as the determining factor rather than patient or even clinician preferences in end of life care (BRUCE & BOSTON, 2008; DROUGHT & KOENING, 2002; GEORGES *et alii*, 2002).

The capacity to diagnose total pain, or attend to it through comprehensive total care, is fundamentally problematized when clinicians are confined to, or choose, narratives that primarily reference life-extending therapies and physical symptom management, as evidenced in the following quote.

Penny: I was talking [with a patient] this morning and she was saying that she’s so lonely and afraid, and I don’t know what to do for her, the psychosocial. What do we do? It’s total pain, what can we do because the pills aren’t working, what else can we do? We don’t know how to deal with her suffering so we give her another pill. It’s so ridiculous. Why can’t [clinicians] cope with [witnessing] anxiety? Because we can deal with the physical pain. I want to fix it [patient’s anxiety], so if I can sedate then at least she’ll be calm. I don’t know how to fix it, and I’m not there to fix it...the psychosocial is not dealt with ...I know that if it was physical pain we’d be all over it, but because

it's psych-social [sic]... we recognize it but we don't know what to do with it...
We just medicate people with anxiety.

Penny, in speaking from her position as a palliative clinician, locates total pain as outside both her specialist affective labor skill set ("I don't know how to fix it") and her professional mandate ("I'm not there to fix it"), even as she continues to invoke the diagnosis ("it's total pain") that defines her expertise. This articulation of her and her colleagues' inability to "sit" with, resolve, or ignore suffering evidences how contemporary practice tensions foster ambivalence in trying to live SAUNDERS' dictate that, when resolution of total pain fails, the role of clinicians is "not... to take away or explain, or even to understand, but simply to 'watch with me'" (2006: 219).

Concluding remarks

Not all hospital patients who are at end of life express distress or challenge the purpose of care to the degree that they are diagnosed with total pain. Conversely, not all patients who express significant distress or resist palliative care as they near death are diagnosed with total pain. The reasons for this differential diagnosis remains for future researchers to explore more fully. For the patients that I observed who were so diagnosed, it functioned on multiple registers of knowledge and action to organize the dying process in ways that facilitated a good (or "good enough") death. In naming and claiming certain pain as unique to end of life, the corresponding affective practices for resolving this pain—active listening, talk therapy, hope work and legacy work—compassionately help patients and family members achieve individual meaning and emotional closure while simultaneously ensuring their appropriate conduct as end of life approaches. In turn, this work is both grounded in, and justifies, the reach of palliative care as a medical specialty ever further into the processes of dying for the population as a whole, even as its success generates tensions in practitioners' capacity to diagnose and treat total pain. Yet rather than attempting to reconcile these tensions, my goal has been to construct total pain as a reflection of contemporary palliative care as a whole, defined as much by disjunctures and ambivalence as by empowerment and catharsis.

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THE ROLE OF PATHOLOGY IN DIAGNOSTIC WORK

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Abstract: Pathology is the keystone of medical diagnoses. However, a case story of a young woman with potentially fatal head injury and suspected abdominal trauma demonstrates how the logics of organization may trump pathology as the driving style of reasoning in diagnosis. The relation between pathology and organization in clinical practice is made an object of inquiry and the impact on diagnostic decision-making and on professional socialization of doctors is found to be significant, but is rarely presented openly in medical communication.

Keywords: diagnosis, clinical reasoning, pathology, professional socialization, Denmark

El rol de la patología en el proceso de diagnóstico

Resumen: La patología es el elemento clave del diagnóstico médico. Sin embargo, el caso de una mujer joven con una herida en la cabeza potencialmente letal y un presunto traumatismo abdominal demuestra cómo la lógica de la organización puede acabar determinando más la manera de pensar a la hora de realizar un diagnóstico que la patología. La relación entre la patología y la organización en la práctica clínica es objeto de estudio y el impacto en la toma de decisiones diagnósticas y en la socialización profesional de los médicos ha resultado ser significativo, pero rara vez se habla abiertamente de ello en la comunicación médica.

Palabras clave: diagnóstico, razonamiento clínico, patología, socialización profesional, Dinamarca.

Advocates of evidence-based medicine and decision analysis methods can tell us much about what should influence management decisions... but can tell us little about how practitioners actually weigh up the many factors, medical, social and psychological to arrive at a particular course of action (NORMAN, 2005: 425).

This quote is from Geoffrey R. NORMAN's review of research of clinical reasoning from 2005. His wondering about this core activity in clinical work for doctors became my own wondering and a driver in my fieldwork in 2007-2008 in which I followed a group of young doctors in Denmark to find out how they learned to make decisions as an integrated part of their daily work. This is a return to and development of one of the themes from the thesis that resulted from the fieldwork (RISØR, 2010) —the role of pathology— as a field of scientific knowledge and as a style of reasoning—in the thoughts and actions driving towards a diagnosis for a patient. Always present in the reasoning and writing about patients' problems, but as only one of many voices in clinical practice, pathology became more elusive as fieldwork progressed. I did not manage to successfully present, far less resolve, this ambiguity in my thesis, but it felt important.

In this chapter, I wish to examine what the diagnostic reasoning inherent in pathology looks like in a clinical case with a patient in need of emergency care. I will examine this from the perspective of a young doctor learning to manage herself in clinical work, and I use the term *diagnostic work* to describe the activities she engages in to synthesize the different kinds of information into diagnoses consistent with the logics of pathology. How does diagnosis emerge from this process and what is the role of pathology in diagnostic work?

Before diving into the case, however, we must briefly consider the research that will allow analysis of the case. Not just medical scientists, but also social scientists have found diagnoses and clinical reasoning a rich empirical field. Spread over several decades, researchers in anthropology and sociology have explored diagnosis as both process of and result of construction and classification, creating a landscape of perspectives and actors—human and non-human—that impact the human practice of diagnosis (GARRO, 1998a, 1998b; HAHN, 1995; KLEINMAN, 1980; MATTINGLY, 1998; SMITH-MORRIS, 2016). This research landscape allows us to explore the construction of illness and disease, but it also allows us important insights into the social processes and structures, which drive

the constructions. Recent books (JUTEL, 2011; JUTEL & DEW, 2014) and research journals with entire issues on diagnosis (JUTEL & NETTLETON, 2011; NIELSEN, PETERSEN, RISØR *et alii*, 2016) illustrate this. But there is a gap in the literature. There is a part of medical practice not given to scrutiny by the social sciences. It is the part where the research discipline pathology has the strongest claim as a foundation for reasoning.

I illustrate this from a starting point in medical research literature on clinical reasoning and diagnosis. Diagnosis is a labelling or framing of clinical problems. In clinical practice, it is a way to reduce and focus the relevant actions and therapies to something manageable and relevant for a particular clinical problem. In medical research literature it is described as the result of “clinical reasoning”, a cognitive process in which the doctor examines all the available information from the patient’s story and the findings from the clinical examination of the patient, and draws a conclusion about how the individual pieces of information may be connected (EVA, 2004). The term “differential diagnosis” is used to describe how several diagnoses are often possible from the same collection of data, but also to describe the process and actions through which the doctor assesses the likelihood of each of these possible diagnoses.

In medical anthropology, information about patients is understood as constructed in a contextual and inter-relational process rather than seen as the only true representation of the patient’s condition. In contrast, medical students and doctors—including this author— learn to aim for a specific kind of precision in the description of the patient’s complaints, the clinical findings from the examination of the patient’s body, and the various tests including blood work and clinical imagery. The language for this description is the language of pathology; the categories, the processes, the terminology, the legitimate ways to reason. This apparent divide between a perspective on sickness and illness as socio-cultural constructions and disease and diagnoses as biological entities is often difficult to bridge for physicians; even those with experience with medical anthropology and ethnography¹.

¹ There are exceptional scholars who manage to bridge the divide—like Arthur KLEINMAN and Paul FARMER— but my experience from dialogues and conferences in medical anthropology is that physician-anthropologists often find themselves in a continuous negotiation of professional identity to the extent of feeling betwixt and between.

The literature on clinical decision-making (CDM) describes the activity as core to finding the right diagnosis in medical practice, yet difficult to understand despite a large number of studies of CDM (NORMAN, 2005). The paradigmatic case used to illustrate CDM is when the doctor sees a new patient with an acute medical problem and needs to reach a diagnosis that will suggest therapy, most often located in a university hospital (EVA, 2004; NORMAN, 2005). Prevailing models on how to manage these kinds of situations draw from cognitive psychology and statistics and describe how doctors use hypothetico-deductive reasoning (ELSTEIN, SHULMAN, & SPRAFKA, 1978), pattern recognition (SCHMIDT, NORMAN, & BOSCHUZEN, 1990), scheme-induction (CODERRE, MANDIN, HARASYM *et alii*, 2003) or a number of other ways to go from symptoms and signs to diagnosis.

Studies in social sciences extend the medical models for reasoning into the social context, for example by demonstrating how clinicians build up schemata for thinking and behaving in response to certain patterns of information and how these schemata are modifiable over time and from social interaction with peers (DAVENPORT, 2011; GABBAY & MAY, 2004; REES, 2011) and are often adapted from existing local patterns of diagnostic work (RISØR, 2016). However, if we look at the diagnoses and the contexts most often studied in this field in social science, we find that quite often it is the chronic diseases rather than the acute ones that are in focus (BARKER, 2011; BROWN, LYSON, & JENKINS, 2011; EBELING, 2011; OLAFSDOTTIR & PESCOLIDIO, 2011; SALTER, HOWE, McDAID *et alii*, 2011; SINGH, 2011; TRUNDLE, 2011). These conditions are mostly studied in the very young and the very old (PRIOR, EVANS, & PROUT, 2011; Salter *et alii*, 2011; SINGH, 2011; TRUNDLE, 2011), and rather than internal medicine and surgery, the context of the studies is predominantly gynaecology, psychiatry and primary care (Armstrong, 2011; BARKER, 2011; BERGER & JOHANSEN, 2016; BROWN *et alii*, 2011; DAHL, 2016; EBELING, 2011; Møller, 2016; OLAFSDOTTIR & PESCOLIDIO, 2011; RINGØ, 2016; SINGH, 2011; TRUNDLE, 2011; ULRICH, 2016). There are important studies on how powers and drivers from outside the clinical context —notably pharmaceutical industry, new technology and national politics— may impact the classification system of diagnoses (BARKER, 2011; BOURRET, KEATING, & CAMBROSIO, 2011; DANHOLT, BOSSEN, & KLAUSEN, 2016; EBELING, 2011; SCHUBERT, 2011), but these are described as outside influences on classification rather than part of diagnostic work itself. There are exceptions to this sketchy representations of the literature: studies on acute disease, but mostly on less serious cases (PRIOR *et alii*,

2011); studies from internal medicine, such as cardiology and neurology, but these focus mostly on mental aspects or risk rather than the biomedical diagnosis (GARDNER, DEW, STUBBE *et alii*, 2011; HALPIN, 2011). An interesting field of study focus on cancer diagnoses, but most examples I find bring forward the significant consequences for the patient's life and for the lives of those in the family (OLSON, 2011; SCHAEPE, 2011; WILLIG, 2011) and do not question the diagnosis or the diagnostic work itself.

This leaves the domain of acute medical and surgical diseases in the highly specialized hospital context almost untouched by social analysis. Why is this important here? It is important because the diseases in that domain are the most high status conditions in the medical community and the specialties working with these conditions receive the highest acclaim with doctors from all specialties. This status-hierarchy is learned by students and maintained throughout professional life and it is found to be stable over decades (ALBUM, 1991; ALBUM, JOHANNESSEN, & RASMUSSEN, 2017; ALBUM & WESTIN, 2007). Album notes that the diseases with the highest status are those that arise suddenly, affect an organ in the upper half of the body, preferably in a young adult male, and where the patient is unconscious at arrival and —after the heroic use of highly technical interventions— leaves the hospital healthy and thankful. The subjects studied by social science have few of these characteristics, and therefore, in effect, we have a domain of high status diseases where pathology is the dominant scientific perspective and where social sciences rarely venture.

To study the clinical reasoning inherent in pathology as I set out to do in this paper, the high status domain of acute disease in a university hospital should provide the ideal ground on which to explore the ambiguity I sensed but could not grasp in the fieldwork; the high status but almost invisible presence of pathology as a framework for understanding and managing disease.

The case below fulfils many though not all of the criteria for high status found by ALBUM. It affects a young adult; it is the result of a sudden event, which left the patient briefly unconscious; it involves the brain and (later on) the upper abdomen. We also see the use of several kinds of diagnostic imagery employed. However, as it will turn out below, the emergence of a diagnosis over time and in this specialized setting presents some challenges to established medical theory about clinical decision-making despite having all the characteristics of an archetypical medical case in a context where state-of-the-art technology and competence are present.

Before turning to the fieldwork, we need just one more detour to present an image of what pathology is as a field of knowledge. Descriptions of clinical reasoning always to some extent include the bi-directional process of both searching for the objective truth within the patients body and —at the same time— the reflective inner stance of the clinician weighing for and against, sensitive to context. This ambiguity does not feature in formal descriptions of pathology, however. Here, there is a clear and coherent rationality about the nature of disease:

Pathology is the study of disease by scientific methods. Disease may, in turn, be defined as an abnormal variation in the structure or function of any part of the body. There must be an explanation of such variations from the normal —in other words, diseases have causes— and pathology includes not only observation of the structural and functional changes throughout the course of a disease, but also elucidation of the factors which cause it. It is only by establishing the cause (aetiology) of a disease that logical methods can be sought and developed for its prevention or cure (MACSWEEN, 1992: xiii).

This short extract indicates, that pathology —as a science and as a prescription for practice— has what HACKING termed “a style of reasoning”: a historically grounded way of connecting facts and producing valid statements in a scientific context (HACKING, 1982). I find the concept useful here because HACKING finds that styles of reasoning are situated in time and space, and that historically different styles of reasoning have waxed and waned in various fields of science. This also indicates that pathology is not static and that other styles of reasoning may become more powerful. As a style of reasoning, pathology is thus not just a body of knowledge, but a way to interpret and connect information about the patient’s condition; it is a way to create meaning from uncertainty, but a way that may also be challenged by other styles of reasoning, and which is itself subject to change. HACKING coined the term with the intent to describe scientific practice. In this case, the scene and the practice is, however, practical and clinical, and although pathology can be seen as a style of reasoning, it does not follow that it is a style of reasoning in clinical practice as well. Clinical practice have been seen as a ‘practical synthesis’; a joining together of apparently unconnected fields of knowledge with a difference in epistemological grounding that —from a philosophical viewpoint— makes them incompatible. But in medical practice these unconnected fields are connected through their application to a problem to establish a practical synthesis (HOVDENAK & RISØR, 2015). My curiosity here concerns the role of pathology in that synthesis.

Fieldwork 2007-2008

I experienced the happenings of the case below as part of a fieldwork I did in 2007-2008 and which provided the empirical material for my PhD thesis in 2010. The purpose of the fieldwork was to study how young doctors learn to make clinical decisions. I recruited nine interns fresh out of medical school who allowed me to follow them at all hours in their daily clinical work and interview them about decisions made in that work. Over a period of eighteen months, they had three 6-months placements—in surgery, internal medicine and family medicine—that together made up internship: the transition period between medical school and specialty training, mandatory for all doctors. From the hundreds of hours of observation and almost fifty hours of interview, I had to conclude that doctors do not learn to make decisions as much as they learn to participate in decision-making (RISØR, 2010).

In the case below, I am with the intern Karen. She was an excellent informant in the sense that she was able to reflect about what she was doing and why, *while* she was doing it, and thus providing me with much information about her perspective and her weighing of many factors and information as the action unfolded.

The case of Karen and Alice

It is fall, and Karen is on evening duty in the orthopaedic emergency ward. Patients are coming and going. Karen moves from one patient to the next, talking to nurses, instructing medical students, conferring with her colleagues as she does so. She is relatively new to this setting, but already she seems to be adjusting well, even enjoying her work.

About 4.45 PM Alice, an 18-year-old woman is brought in on a stretcher. She has had a bike accident. She is awake but confused and does not recall what happened. The papers from the paramedics in the ambulance give some information: She fell on her bike going down a specific street (which I know to be quite steep). Apparently, there was no one else involved in the accident. She has been unconscious, how long is uncertain. She has pain in neck and head. She has bruises in her head and on her left hand.

Karen goes to the next room, checks on the stitches of a medical student, goes back to Alice and examines her leg, then her left hand. She notes to herself that 'we need an x-ray of the hand, especially fifth finger'. The nurse,

Lone, enters the room and asks Karen how many rooms she is working in. 'Only this one now' says Karen, focusing on Alice. The nurse gives her Alice's values: BP² 131/84, p³ 74, sat⁴ 89 %. Karen shines a light into Alice's eyes, examines the bruise in her forehead. Karen goes out to get help to turn Alice over. She meets her second-call⁵ in the hallway and asks him about the relevant regime for Alice. He asks a few supplementary questions. Then Karen, he and I go back to the patient and turn her over. Karen finds no tenderness of the back. She examines her neck, where there is some diffuse tenderness. Alice complains about her headache again. Karen decides to get an x-ray of Alice's neck and writes the requisition for x-ray of neck and left hand. A porter comes to take Alice to x-ray, still on the stretcher.

The nurse comes in and asks Karen: 'Shouldn't you examine the neck before the back?' She asks about the use of the "spine board" on which the patient was placed, and suggest that Karen and her colleague did not make correct use of it. 'It's not to sound grumpy' the nurse says, 'it's just that...'. Karen explains that she was only given a cursory glance of the board when she started in the ward and was not aware of some of the specifics. The nurse shrugs. Karen makes the entry in Alice's journal.

Karen goes to see a 42-year-old woman who has had an accident in her car. When she returns to the small office with me, Lone, the nurse, asks Karen: 'Can Alice go home?'

Karen: 'The last time I had one like her, who had had a head trauma, I almost sent him home with a hole in his eardrum. Then he became nauseous, was admitted and two hours later his blood pressure suddenly fell, so...'

Karen looks at an x-ray on another patient who hit her hand. Then she sees another patient with a distorted ankle. The porter returns with Alice from x-ray: 'She vomited again', he says. Karen asks her colleague how reliable an x-ray of the neck really is. In other places it is not standard, but at this ward it is. Why not just do CT scan if you get a clinical suspicion of serious injury to the head or neck? He says that he does not know. 'I'm going to admit her', says Karen and informs Lone, who says that 'she is still a little dizzy, confused. Her family has just arrived'.

We enter the room, where Alice lies, and Lone tells Karen that Alice has recently had mononucleosis and according to her mother, she has an enlarged spleen as a result of this. Alice then throws up again. Lone helps Alice, Karen leaves, goes to the office and asks her second-call, who only has three more months of experience at the department, what to do:

2 BP: Blood pressure

3 p: pulse

4 sat: saturation; the level of oxygen in the blood. Normal range is 94-98 %.

5 A more experienced colleague from the same department; the one she should consult with first in case she needs advice or help.

Karen: Shouldn't we do the CT⁶ now? She has pains in her stomach as well?

Second-call: Ask at [department of abdominal surgery]. CT is relevant. You may order it.

Karen calls the first-call at the department of abdominal surgery. She says she will come and take a look at Alice.

Alice is a good example of how the logics of pathology can help diagnose a patient so that the search for a relevant therapy can begin. She is a healthy young woman who has been exposed to a powerful and specific factor —the high-speed downhill bike accident— which has resulted in specific clinical symptoms —unconsciousness, headache, dizziness, followed shortly after by nausea and vomiting. All these symptoms are compatible with cerebral concussion and with possible intracranial bleeding. In addition, the enlarged spleen is a known complication to mononucleosis, the accident combined with the pathology of the spleen being sufficient aetiology for an abdominal bleeding that manifests itself in abdominal pain and possibly contributes to the reduced state of consciousness in which Alice finds herself.

The Cynefin Framework by SNOWDEN and BOONE (2007) can help us understand the situation further. SNOWDEN & BOONE describe four different kinds of problems that leaders face and the relevant ways to analyse problems in context and respond to them (SNOWDEN & BOONE, 2007). I use it here, because all four kinds of problems can be identified at various times in the case. To be able to understand the role of pathology in problem-solving, I found this a useful manoeuvre, but this is not to imply that the Cynefin Framework necessarily is a useful way to analyse clinical practice. It is merely a help to fertilize reflections below. In this part of the case, we can observe the first two kinds of problems. First there are simple contexts, characterized by clear cause-and-effect relationships. Here, the decision-maker must first sense, then categorize and finally respond. The diagnosis *cerebral concussion* is such a problem and this is where “best practice” is relevant: standardized solutions to known problems. Second, there are complicated contexts. Now, cause-and-effect involves more factors that may even affect each other. The decision-maker now needs

6 Of the head because of the trauma to the head and of the abdomen because an enlarged spleen due to mononucleosis easier starts to bleed and the trauma and the abdominal pains suggest that this is the case now.

to analyse, before categorization and response is possible. The risk of *intracranial bleeding* and the added factors of *mononucleosis* and *enlarged spleen* take the problem from the simple to the complicated domain. This is the domain for experts and we see how Karen starts to involve more experienced colleagues in problem-solving. The logics of pathology provide the doctor with ways to analyse the complicated and suggest the proper response: to search for intracranial and abdominal bleeding and do so right away, so that the relevant treatment can be given. In actual practice, however, the logics of pathology ran into difficulties.

Karen & Alice, part II

Karen is in doubt about what she is expected to do. Is the radiologist waiting for her answer on the x-ray of Alice's neck? There are two different radiological departments in the hospital. Which one should she call to ask for a CT scan? Or should she wait for the intern from abdominal surgery? Karen says to me: 'We usually wait for an answer from x-ray before we move on to order CT of cerebrum'. The intern from abdominal surgery, Agneta, arrives. Karen knows her. Karen tells the story.

Agneta: But she is going to get a trauma-scan then.

Karen: No. Not automatically.

Agneta: I'll just have a talk with them then.

Agneta calls the radiologist who is just going to see the images of Alice's neck. Agneta and Karen go to see Alice again. Then the radiologist calls Karen: There is no fracture and no indication for CT of the spinal column. Agneta has examined Alice and finds that "abdomen is soft and not tender to palpation"⁷. Agneta calls her second-call and tells about Alice: bike accident, abdomen not tender, enlarged spleen. "Is there reason for CT abdomen?" Apparently, she gets no certain answer and keeps retelling the story and asking what to do. Karen fills out the requisition for CT cerebrum and CT abdomen while Agneta talks. At last, Agneta gets the advice from her second call that the scan should be made as a trauma-scan, including the head, the thorax and the abdomen in the CT scan.

⁷ The Danish term is *abdomen blødt og uømt*. Directly translated, this means that the stomach is soft and without tenderness when examined. This indicates to the reader of the patient record that the entire abdominal region (not just the "stomach") has been thoroughly examined — inspection, palpation, percussion— and that no evidence of pathology has been found, thus making it unlikely that the patient is in need of immediate medical or surgical intervention.

Karen calls the radiological department to get the scan done, but they tell her they can only do the head scan. Then she calls the other department of radiology, where she is told that they can only do the abdominal scan. It turns out that only a patient who enters the emergency ward categorized as a “trauma patient” can get the CT scan of both head and abdomen at the same department. It is possible to change the status of the patient to be a “trauma patient”, but that will usually imply that her condition is very serious, potentially fatal, and the call put out on such a patient will bring a number of surgeons, anaesthesiologists and nurses running to the emergency ward, leaving whatever they do at the time. Karen finds this to be a bit drastic. Agneta calls her senior colleague again, explaining the situation. The senior surgeon then changes his opinion and says that the CT abdomen can wait but should be done if she develops abdominal pain. Agneta is clearly tired of all the bureaucratic problems, but tells her second-call’s decision to Karen, adding “I don’t believe this is happening”.

Karen goes to tell Alice and her parents that Alice will be admitted and that her head should be scanned. It is now 6.35 PM and Alice has been at the ward for almost two hours. Karen goes back to the office, waiting to accompany Alice to CT cerebrum. The nurse goes to find the ‘emergency bag’ containing medications for transporting patients, so that Karen can give her immediate treatment if Alice’s condition should deteriorate on the way to the scanner. Karen notes to me that the medication in the bag is for intravenous administration, but that there are no utensils for this in the bag. As she does not have the tools to inject the medication, the bag is, in point of fact, useless.

Karen sees a boy with a minor injury. Then two porters come to bring Alice to the scanner. Karen tells a nurse what should happen to the boy, and runs to catch up with Alice’s bed. We all go through the basement —the two porters driving the bed with Alice in it, Alice’s parents and her boyfriend, Karen, a medical student and me. We take the elevator to the right floor. Go to the scanner. The young male radiologist receives us. Alice is taken into the scanner and the scan is done. “IA”⁸ says the radiologist to Karen. We go back the way we came and Alice’s bed is taken to the same room in the emergency ward. Karen tries to find her second-call to discuss if a CT abdomen should be done after all, as Karen is uncomfortable with the knowledge of the enlarged spleen, the trauma and that Alice earlier complained about abdominal pains. It is 7.30 PM and Alice has been at the ward for almost three hours.

I leave to get something to eat and some fresh air. Karen continues the work in the ward. When I return Karen has finally gone to the other department of radiology with Alice to get the scan of her abdomen. She

8 IA: *Intet Abnormt* (Danish). It means “nothing abnormal”.

returns about 8.15 PM and tells me that, fortunately, there was no sign of bleeding in the abdomen either.

Karen: “Okay, now I can finally admit her to the department.” She dictates, but finds it difficult to find out what to say: “I think now it is me who can’t remember”. The nurse says: “It’s because you haven’t had anything to eat yet.” Karen tries to go on, but then there is a technical problem with the Dictaphone. “Oh no — It seems to be going in circles. I’d better count to ten.” Karen goes to find a secretary who can help her with the technicalities. The secretary comes back with Karen to the office and they try to fix the problem. They can’t. Karen: “Damn! Damn! Damn!” Secretary: “Not a day goes by where there aren’t any problems with this system.” Karen goes to another room to repeat the dictate that failed, hoping that the voice recorder is better there. It is. Alice gets admitted and leaves the emergency ward.

Organizational logic

It took three and a half hours from the time Alice enters the ward until the CT scan of the head and the abdomen are done: plenty of time for a patient to die from a possible internal bleeding. All kinds of bureaucratic barriers prevented Karen from doing what the logics of pathology told her to do: the division of the department of radiology into two sections, the need to contact the department of abdominal surgery, the need for the patient to have a certain status or category to get a certain kind of scan. The busyness and the breakdown of technical aids are additional nuisances. Karen finds it very hard to perform her basic duties as a doctor. Moreover, there is no way she can change this. Even the more experienced doctor from abdominal surgery gives up: he decides to change his decision about a CT of the abdomen when it turns out that there are organizational obstacles. The organizational logic overrules the logics of pathology.

In the Cynefin Framework referenced above, I mentioned the simple domain and the complicated domain and the proper response to them. The framework has two more domains that may help us understand the practice observed: The complex and the chaotic domain. The complex domain is the realm of “unknown unknowns”. There are few right answers and understanding may be more difficult to find. What the problem is emerges gradually rather than being present and analysable from the outset. It is often tempting to treat a problem as complicated rather than complex (SNOWDEN & BOONE, 2007).

In this case, Karen seems open to the possibility of complexity as does Agneta from abdominal surgery, but the spatial lay-out itself makes it difficult. The patient is in the reception ward and the CT scanners are placed elsewhere in two secluded areas where specialists in radiology adhere to the regulations about who should —and who should not— have access to the scanner. If Alice had become unconscious or if her heart stopped, this would have taken the situation into chaos. Here, SNOWDEN & BOONE claim, the right approach is to ‘stanch the bleeding’. It is no longer a first priority to find cause-and-effect relationships, to analyse the situation. You need to act first and, secondly, monitor results and adjust response. If Alice was categorized as a “trauma patient” there would be routines and organizational roles in place to manage the situation. So the problem is when the patient is in the complex domain and organization is set up to manage either simple or chaotic problems.

In this case, the patient’s conditions lay within the spectrum of problems that are considered common in this particular context. Most clinical settings have such a ‘spectrum of normality’ (RISØR, 2016). It is common to have patients exposed to trauma to the body entering the ward, and the nurses, the porters and the doctors move between each other in patterns directed at managing these kinds of patients and problems. This spatiality, this organization of rooms and patterns of movement, is coordinated with a local temporality: unspoken agreements about the order in which things should be done, and when to involve additional actors and in which order. The intern is aware of this and directs her attention —her sensing and perception— to the visible signs of trauma. There is a clear logic of pathology that can be followed in the management of those signs.

But as the level of complexity of the case is found to increase —from simple to complicated to complex— the barriers for action rise for Karen. Her ideas about management —with the desire to do a more extensive CT scan as the case in point— challenge established spatiality (because radiology is split into two) and temporality (because the patient must be a “trauma patient” first to allow this). She tries to probe the problem (as the Cynefin Framework suggests as relevant for complex issues) by involving different actors, but she must give in at the end. Although she does go through with the abdominal scan although an abdominal surgeon had decided that it was not necessary. She feels guilty about it, but actually she is the one who stays with the reasoning of pathology, one that indicates a risk of internal bleeding.

Could Karen do anything to change the limits of the organization and the way this logic forces clinical practice away from the line of action suggested by clinical reasoning? When I met her again, a couple of weeks later, I suggested to her that she could write a letter to her superior, explaining the incident and the potential danger that these structures pose to patients. I offered to help with the letter, using my fieldnotes to document what happened and when. Karen was not too keen on this, however. She said:

I found out that a letter had been sent out a few months ago, explaining the procedures of the two radiological sections and that there was a specific number I should call, or rather have my second-call call if a situation arose where a patient's status in the emergency ward should be changed to "trauma" to make a "trauma scan" possible. If I had known that, I would have known what to do. So, it is not really a fault on the part of the department of radiology.

This seemed to be the end of it. Karen felt that she was to blame in this case. The fact that she had not received the letter in question and that no one else in the case seemed to know about it, did not do anything to ease this self-blame. This story is an example of a process I observed many times during fieldwork, which clearly impacted how doctors felt about their work and themselves as professionals. The young doctors try to do their best for their patients, but they are continuously dispirited by organizational restrictions. Restrictions meant to ensure efficient use of resources apparently has the effect of teaching the interns that they should not show too much initiative in diagnostics and treatment, but instead accept the department's procedure and bureaucracy.

Reflections on pathology

Let us return to pathology. If the construction of clinical information is not founded on pathology (as the case suggest) and if the very definition of pathology says that all diseases are based on pathology, what is the logical conclusion? That the phenomena I have described have not to do with disease (thus not having a pathological foundation)? Or that the definition of pathology is wrong?

The Muir textbook cited above is a wonderfully clear (and extensive) presentation of a very diverse and difficult subject. The problem therefore does not lie in its contents. It lies in its non-contents. The definition of

disease cited leaves out a wide range of phenomena that are very much part of the spectrum of human suffering that a health care system needs to be able to handle. How often is there a specific aetiology? How often is it possible to locate an “abnormal variation in the structure or function” in the body? Even in departments as specialized as the ones in a university hospital where the case of Karen and Alice takes place, the spectrum of suffering is much wider than the spectrum of disease for which the “logical methods” of pathology applies. The style of reasoning of pathology includes a complex and detailed language for describing states of the body from the cellular to the systemic level. But it includes no language for describing the temporality, the spatiality, or the emotionality that frame and impact the body and drive the decision-making in real-world, real-time interactions between positioned actors. This limits pathology to influence decision-making to situations where clearly defined symptoms or signs, verified through the use of diagnostic technology, are present. The same limitation is true for the patient record, thus making the most significant part of clinical action and decision-making invisible and non-verbalized.

The definition of pathology is not wrong. But the idea of pathology as the epistemological foundation of medical practice apparently is. It may be an effective style of reasoning for research on a number of clinical problems. But it does not provide the knowledge that may help the intern determine *when* it is relevant to employ the tools of pathology. That knowledge would be of a different order. Medical students and the interns, however, still learn to live with the ideal of pathology as an integrated part of daily practice and they —as Karen in this case— learn to blame themselves when they are unable to live up to the ideal.

In the above case, the first-call surgeon, Agneta, voiced her frustration when the logics of pathology were overruled: “I don’t believe this is happening.” The young doctors try to resist the factors that had a negative influence on their practice, and instead they try to work out beneficial solutions for their patient. Karen actually made sure that Alice —eventually— had a CT scan of the abdomen. In doing so, she exercised a kind of disobedience to a superior and to the system. This was a recurring theme for the doctors I worked with during fieldwork and often led to beneficial outcomes that would not have been reached otherwise. The doctors themselves, however, experienced shame and self-doubt in these situations and did not discuss these among themselves or with their supervisors.

In most cases, the interns have to learn to accept the organizational restrictions. One of the factors that strengthen this learning process is language, specifically the language of medicine. This is the language of textbooks and scientific journals, but it is also a spoken language with a wide range of phrases and slang words that are learned in the practice of a local setting and used in that setting or others like it. It often sounds like Danish, but the language spoken carries underlying connotations and implications known only to the doctors like, for instance, the *IA* said by the radiologist in the case of Karen & Alice. A number of standard verbal expressions are employed in taking the patient's story and in narrating it in the journal and at conferences.

Mary Delvecchio GOOD and Byron GOOD did fieldwork at the medical school at Harvard in the nineties, and found the issue of language to be very important. They found that learning the language of anatomy and learning the narrative and linguistic techniques of presenting *the case* were important steps in the process of creating the students' professional identity. Mastery of the language made communication with colleagues possible and signalled that they had reached an understanding of medicine and their professional role in the field (GOOD & GOOD, 1994). Learning the language was also important for structuring the students' thoughts, thinking and reasoning (GOOD & GOOD, 1993). Bo JACOBSEN (1981) concluded the same thing in his study of university students in the humanities compared to medical students. He noted how the medical students learned to think of knowledge in terms of *blocks of information* that ideally were transferred unchanged from teacher to student, while the students of language, for instance, learned to think of knowledge as relational, depending on positions and actors, modifiable according to the situation (JACOBSEN, 1981). This produces a specific focus on the world, which makes doctors effective at some things, but blind to others; blind to certain possible decisions and to certain kinds of information that cannot be expressed in a medical terminology.

The interns were therefore strongly conditioned towards a specific linguistic style which guided their identity and thinking, and from which it was difficult to divert. This style was extensive in the description of symptoms, diseases and pathology with regard to simple problems, but less developed as a means of speaking of relations and knowledge that did not fit the blocks-of-information pattern and for which "best practice" did not exist, because it was, in effect, a complex problem. In situations

where relational knowledge was needed they therefore had to fall back on their personal experience from before and outside medical school; an experience that some were aware of and were able to use actively. But to all of them it took an effort to step out of the spectrum of phenomena that could be described in the professional tongue, the language of clinical pathology, and instead trust personal experience.

The logics of pathology may not be sufficient to determine action in the clinic, but it is still the logic we adhere to, when we create our representations of the patient in our communication with our medical colleagues in conferences or in the patient's journal. This is the appliance of the exquisite and precise language the interns learned in medical school and the language they are expected to use when representing the patient's story and their findings in the patient record. Pathology and diagnosis come to the fore in the text in the patient record, but at the expense of temporality, spatiality and emotionality. This is perhaps understandable if the only aim of the patient record was to provide a short-hand version of the patient's experience and the objective clinical findings. But the journal is increasingly being used as the documentation not only of the patient's condition, but also of the quality of care provided. Not a word is found in Alice's record about how the temporal and spatial organization of work and decision-making impacted management and extended her stay in the ward to 3.5 hours before initial assessment was concluded. Not a word to express the frustration of doctors and nurses about management.

Conclusion

It should be uncontroversial to state that the diagnoses a doctor writes in the patient's journal are not simple results of collected data compared with knowledge about pathology. The case of Karen and Alice could perhaps be argued to be a special case, but when I have presented it, several times over the last few years and to medical doctors of many different specialties, the response is primarily one of recognition; recognition of organizational challenges of the nature described in the case. Doctors will then voluntarily share their own experiences and their own emotional striving, their own disillusion. It seems that the case of Karen and Alice is not unique in that regard.

Diagnosis as category is strangely absent in much of the case. One or more diagnoses are expressed in the different written communications: In the requisition for x-ray or CT-scan, in the entry in Alice's journal. It could be mentioned in retrospect, as mononucleosis was in the case. But in the communication between doctors, and between doctors and nurses, diagnoses are only alluded to indirectly or in a very general way. Given the importance allocated the diagnosis this is quite interesting. But others have found the same almost-absence of diagnoses when observing clinical practice in real-time (DONNER-BANZHOFF *et alii*, 2017). It appears that diagnosis share the characteristics of pathology in the decision-making: It is an ideal or goal for the doctor, but is only expressed clearly in retrospect.

Diagnostic *work*, however, is very much present and the young doctor's knowledge about pathology is a sounding board for reflection and a provider of hypotheses all through the case. One could take the view that organizational logic impedes or influences diagnostic work, but a fairer and more constructive perspective would be to accept organizational logic as ever-present; a part of diagnostic work as much as the patient is. SCHÖN described a case of how architects work, where ideal forms and structures in the training of the architect must be connected with the physical conditions of the site for a new building. It is in this interaction that the possibility for a creative construction happens (SCHÖN, 1983). This idea resonates with the case of Karen and Alice, but here, contrary to the architect, the young doctor feels limited and shameful about the process.

The interns in all the departments where I did fieldwork learn to adapt to local conditions for clinical practice, and they learn to identify and work with the kinds of decisions and styles of reasoning that are considered valid in the local context. In their many encounters with the patients, they get to experience a number of clinical cases that they can compare with their knowledge on symptoms, diseases and possible treatments, adjusting and supplementing their mental schemata as they do so. In this process they learn to focus their attention and their senses in a way that makes them efficient in the local setting, but they may also learn to neglect certain pieces of possible information, which may have an effect on patient outcome. There may be patterns of local organization, which help direct their attention to certain problems and certain ways of management. But it also teaches them to downgrade the importance of what the patient tells them and the reflections this generates. There are situations where they need to accept bureaucracy and traditions to an extent that they have

to modify and dilute sound medical reasoning to adapt. It is worrying to find that the interns tend to turn these problems inward and blame themselves for conditions, which are largely organizational. The process of making diagnoses and making decisions is also a process of making doctors; of creating emotional restraints in the doctor that encourage the doctor to look for certain kinds of problem —especially simple or chaotic problems— and avoid complexity.

The role of pathology in this learning and in the diagnostic process is to provide a framework for reflection and an ideal for linguistic expression, which they must then try to achieve in the entries they generate for the patient's journal. This is a precise vocabulary, supplemented by numerous clinical expressions, slang words and short-hand, but pathology is not, however, a powerful logic in practice. Pathology may supply the words, but organizational logic and norms determine their use.

This analysis, primarily aimed at understanding the ambiguity of pathology in clinical practice, raises a few new questions. It is tempting to see the changes in hospital administration and organization in recent decades as the cause of some of the difficulties in the case. Change in organization may lead to change in decision-making and not necessarily to a better result for the individual patient. Further studies with micro-analysis of practice seen in the context of organizational change could give important insight to this field.

In the introduction, I briefly touched on the rich literature on diagnosis in social science. If my impression from that literature is correct, social science has left the high status areas of medicine outside the scope of research. Thus, the pinnacle of medical knowledge from which medicine draws status and standards for practice receives little critical reflection from outside medicine. What would a program of social science studies into the high status domains of medicine look like and what kind of dialogue on diagnosis and diagnostic work could this lead to?

The socialization of medical students and young doctors is intensive, both as a process and as a research field developed from the 1960s and onwards. However, there are still few studies on how this process happens as an integrated part of clinical practice. Perhaps the new questions above —how organization manifests in and changes clinical practice— and social science studies of high status medicine could together help us understand and potentially impact the process of how we make doctors and how they learn to participate in decisions-making.

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PART 3
THE POWER OF CHANGING DIAGNOSTIC CATEGORIES

OFFSTAGE: MADNESS, THE OB-SCENE, AND COMMON SENSE¹

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Abstract: Throughout European history, madness has been associated with two states: movement and confinement. These apparently contradictory states converge in an ob-scene state, in the etymological sense of the word: offstage. In this chapter, based on data from ethnographic work in the Catalan mental health care network, it is argued that “being ob-scene” results when madness challenges hegemonic social processes of inculcation and persuasion that induce acceptance of behavioural patterns considered appropriate and lead patients to identify with the interests of therapists. Madness defies not reason, as it is widely supposed, but common sense understood as a cultural system. Its refractory nature leads to the management of madness by expert systems that seek to subsume the experience of affected persons in predictable nosological categories.

Key words: madness, ob-scenity, common sense, ethnography, biopolitics

Fuera de escena: la locura, lo obsceno y el sentido común

Resumen: En la historia de Europa, la locura ha estado asociada con dos estados: el movimiento y el confinamiento. Estos estados, aunque aparentemente contradictorios, convergen en un estado obs-ceno, en su sentido etimológico de fuera de escena. En este capítulo, y tomando como base mi trabajo etnográfico en la red de salud mental de Cataluña, se argumenta que esta “obs-cenidad” deviene cuando la locura desafía los procesos sociales hegemónicos de inculcación y persuasión que inducen a la aceptación de los modelos de comportamiento que son considerados apropiados y que promueven que los pacientes se identifiquen con los intereses de los terapeutas. La locura no desafía la razón, como

¹ This is a translated and slightly shortened version of previous publications in Portuguese (MARTÍNEZ-HERNÁNDEZ, 2012; 2013a) and Spanish (MARTÍNEZ-HERNÁNDEZ, 2013b).

² Translation: Susan M. DiGiacomo and Mary Savage

generalmente se indica, sino el sentido común entendido como un sistema cultural. Su naturaleza refractaria conduce a una gestión de la vida por los sistemas expertos que busca subsumir la experiencia de los afectados en categorías nosológicas predecibles.

Palabras clave: locura, obs-cenidad, sentido común, etnografía, biopolítica

In European history madness has always been associated with two social practices: movement and confinement. Movement receives one of its finest depictions in *Don Quixote*, in which the witless hero wanders endlessly in search of something at once so near and so remote as his own fantasy. Among other modalities, confinement includes the insane asylum as a means of containing... what, precisely? Unreason, chaos, lack of common sense, disorder, fear, difference, dissidence? In any case, confinement has persisted for centuries as a form of social control. Although apparently contradictory, movement and confinement as related social practices define an *ob-scene* condition in the etymological sense of being "offstage." While movement becomes a departure, either voluntary or forced, from the play of social life, confinement annuls the civil rights of those affected (MARTÍNEZ HERNÁNDEZ, 2000).

As we might expect, what links movement and confinement is the same thing that joins madness to psychiatry, a profession that, in its early years, was considered "special" (CAMPOS MARÍN, 2001; COMELLES, 1988). Psychiatry is a body of knowledge and practice whose object is alterity, although with the passage of time this otherness has come to constitute a diffuse and weakly formulated terrain of abnormal states that include depression and anxiety; being at risk for mental illness; disconcerting or unsettling behaviours associated with aggressivity, gambling, or sexuality; discomfiting social interactions; and minor memory loss. Among many others, all of the foregoing have been transformed into psychiatrically treatable conditions, as historical work (CAPONI, 2009, 2012) and the most recent versions of DSM-IV-TR (AMERICAN PSYCHIATRIC ASSOCIATION, 2000) and DSM-V (AMERICAN PSYCHIATRIC ASSOCIATION, 2013) have shown. If the biopolitics of psychosis were an exercise in concealment, the new biopolitics of neurosis and minor mental disturbances require persuasion in order to resolve a supposed anomaly considered to be reversible, and put in its place a hyper-normality that links the subject to a consumer culture and political economy (MARTÍNEZ HERNÁNDEZ, 2013c).

By contrast, “madness” does not appear to be responsive to persuasion, or at least not initially (GOFFMAN, 1988 [1961]; CAUDILL, 1958; DUNHAM & WINBERG, 1960; FOUCAULT, 1999; ROSEN, 1974 [1968]). In the biomedical tradition, psychosis is not seen as susceptible to understanding and still less to dialogue, perhaps because it is considered to be the simple expression of disordered judgement and thought, as KRAEPELIN (1907) believed. Instead, what it tends to generate is a monologue in which therapists, family members and the supposedly sane find what they were looking for: unreason, the inability of the affected person to maintain social connection, and diagnostic categories understood as absolute truths that generate the idea of the “total patient” in need of “total therapy”³.

Why the need to locate madness offstage? What is being concealed in the very act of hiding it from view, and what is revealed by the attempt to render abnormal states invisible? Is it something as simple as the Kraepelinian axiom that delusions are the expression of disordered judgment, or does it involve other dysfunctions and short-circuits between madness and culturally defined forms of power-knowledge? The aim of this chapter is to reflect on the social construction of madness as an *ob-scene* object that does not deserve a hearing, but should be located off the social stage because it disrupts the logic of common sense in the Geertzian sense of the word, as the naturalization of cultural convention.

3 Total nosology takes as its point of departure a definition of the patient self as a predetermined entity incompatible with the possibility of a subjective self formed through social action, including the professional cultures of mental health care. In this way, the damaged self is perceived as a psychopathological island, a stable and naturalized entity that responds to therapeutic interventions that are also stable and naturalized: total therapy. This model manages distress in terms of a self-referential expert system and its personified world of disorders and treatments more than in terms of human needs. Centred more on mental illness than on mental health, it is organized through treatment protocols rather than as the outcome of a clinical reflexivity that recognizes in affected persons knowledge born of experience, and is oriented more toward a politics of life than toward a politics for life. For an analysis of the idea of the “total patient”, see CORREA-URQUIZA (2010). For more on the concept of “total therapy,” see MARTÍNEZ-HERNÁEZ (2009).

Common sense and ob-scene sense

Over the course of approximately one year, I interviewed Babu two days a week with the idea of writing his life history.⁴ At that time Babu was an inpatient in a Barcelona residential treatment centre for chronic psychotics, along with some 20 other patients who were also my informants, although to a lesser degree. Among the resources available for the treatment of mentally ill persons, residential treatment centres, along with supportive housing, are understood to be one of the levels closest to reintegration into the community, although no one defines what this “community” consists of; it often appears to be an idealized entity that has little to do with pragmatism based on empirical knowledge of social reality.⁵ In this context, Babu and his companions enjoyed greater freedom of movement than would have been possible in other institutional settings.

Babu divided his time between the residential home where he lived and a psychosocial rehabilitation workshop, run by the same foundation that managed the residential home, where he spent a few hours each day. The workshop’s activities included painting, bookbinding and some small assembly jobs; it also had a newsagent and stationer’s shop that was open to the general public where Babu was usually in charge of the till. Most of our conversations took place in the shop, in a small office adapted for therapy-related interviews, or during long walks around the neighbourhood.

Babu told me he was from the Konkani people who belonged to India’s Catholic minority, and that his family had aristocratic roots. He related how his childhood had been marked by the continuous torture perpetrated by his alcoholic father. Each night his father would fire an unloaded shotgun at the child’s head, and inflict corporal punishments on the boy that the next day would be dismissed or ignored by the entire

4 These interviews were carried out in the context of a broader research project on the mental health care service network in Catalonia that included both observation and in-depth interviews. Fieldwork was mainly carried out between 1990 and 1993 in different institutions in the city of Barcelona that included inpatient treatment, outpatient treatment, and psychosocial rehabilitation. Since then, I have continued to follow processes of mental health care in this network as both a researcher and an expert consultant. For reasons of confidentiality pseudonyms have been used, and the names of institutions do not appear in this chapter.

5 See CANALS (1994) for a detailed discussion of the concept of community and its use in medical contexts.

domestic group as though nothing had happened. As in the logic TAUSSIG (1995) has explored in his writings on the role of silence and the denial of torture in the amplification and management of terror, Babu, his siblings and his mother lived with the unpredictability of torture and the torture of unpredictability. He said he had been a diligent child at school until he became ill with typhus at the age of fifteen, that he found relations with women difficult because of his shyness, and that as soon as he was able he left to study in London. There he met his wife with whom he came to live and work in a city close to Barcelona. He was an executive for a well-known American multinational.

According to Babu's account, his problem began unexpectedly in Barcelona. He suddenly found it difficult to concentrate at work. This difficulty was followed, he explained, by an intense feeling of "depression" and a "need to stay at home" away from all social contact, repeatedly going over his childhood problems of torture. What happened next is best explained in his own words:

I remembered the nights of torture with my father. The time that he whipped my brother and the shots to the head, always hoping that he would kill me once and for all, and that he would not kill me. I thought that because I had suffered so much, I was Jesus Christ. I had sometimes had fantasies when I was a child, like being a great footballer or tennis player and being cheered by the crowds. Or I was a great scientist and I had made a great discovery, or that I was Swedish and I had been adopted by some dirty Indians. Now too I thought I was very important. Things were not going well at work. I was very anxious and my brain was paralysed, I couldn't work and I had to stay behind longer than everyone else. I knew I would lose my job, but I made myself ill with nerves before that and took sick leave.

During my last days at work silly ideas were going through my head, like the North American bosses would come to Barcelona and appoint me director. My boss would then fall at my feet and beg my forgiveness. Everyone was praising me. And the truth is that when I went past the office I thought I heard voices saying [cheering] 'boss, boss'. Then I thought I was the president of all the foreign multinationals in Barcelona and they would come to ask me for work and favours. When I was walking in the street I thought all the women wearing blue and white wanted to be my lovers and all the men dressed in those colours, my collaborators. President Bush had stood down to give me an opportunity because I was more intelligent. When I saw American satellite television I thought they were talking about me because they had put an electronic device in my house to protect me against attacks. But by then president of the USA wasn't enough, and I had to be king of the whole world,

and as I had suffered so much as a child it was as though I had been crucified by my father, because I had never heard another story like mine anywhere else. That was terrible, continuous torture. Then I had come back to life to help everybody. I had stopped being Babu to be Jesus Christ.

Babu's experience, although private and personal, had a major impact on his relationship with his work colleagues. Anyone who is convinced he is president of the United States of America or Jesus Christ will not easily go unnoticed in the work environment. Straight away, Babu met first with perplexity from his colleagues, and was then completely ostracised until his sick leave and the start of psychiatric treatment. So why did this exclusion from the social stage happen? Babu's experience clearly takes on forms that are not accepted socially, but what threat does it represent?

Madness is often regarded as the antithesis of reason or even rationality, the first being understood as a quality and the second as the systematisation of that quality. The opposite of an idea of "reason", which supposedly allows things to be evaluated in the right way, would be defective judgement, confusion of internal and external reality; in sum, madness as unreason, and its manifestation in delusions. However, the problem is that a therapeutic context can hardly be understood as the embodiment of rationality. What is more, analysis of the practices of containment, rehabilitation and treatment I observed during my fieldwork shows that, rather than this abstract entity called reason, madness seems to be the opposite of the more day-to-day level of common sense, understood in the terms CLIFFORD GEERTZ uses in his essay as a "cultural system" (GEERTZ, 1983:73-93).

GEERTZ defines common sense as a cultural system characterised by the following attributes or "quasi-qualities:" "naturalness," "practicalness," "thinness," "immethodicalness," and "accessibleness" (GEERTZ, 1983:85). Although it may seem obvious, it is worth emphasising that these qualities are not attributes of things, but rather qualities attributed to things by common sense. And it is precisely in the interplay of these attributes and attributions, and interpretations of their presence or absence, that I believe the social construction of madness takes shape.

GEERTZ stresses that the most defining quality of common sense is naturalness, understood as its meaning of "of-courseness" and a sense of "it figures." As would be expected, this idea of naturalness is not applied to the sphere of all things and representations, but rather centres on matters that appear self-evidently obvious. Although GEERTZ does not say so, one

does not have to be very perceptive to see that naturalness is essentially an attribute of any cultural system because it is what allows the construction of what he defines as an aura of factuality (GEERTZ 1973:91): the condition by which representations appear unmistakably real for social actors. One way of defining this condition is the cultural principle that things are as they are because they correspond to a pre-established “natural” logic that legitimises them.

If we analyse Babu’s story, we can observe two distinct registers. In the first, events occur following a logic similar to the elementality of common sense: if Babu had been tortured by his father, from this perspective it stands to reason that he would be affected by it, would have problems concentrating, or that he would have childhood fantasies that he was an adopted Swedish boy. Ultimately, this type of fantasy that FREUD once called the “family romance” (*Familienroman*) of the neurotic (1981:1361)—thinking that one is the child of other parents, one has been adopted and on that basis, imagining a whole other world of family relationships—is probably inherent in everyone’s imaginative and performative capacity. But this naturalness in Babu’s story breaks down in a second register that begins with “During my last days at work silly ideas were going through my head,” leading him to think he is the president of the USA and then Jesus Christ. Here, delusion emerges in opposition to the obviousness and naturalness of common sense. What alerts the family, friends and colleagues of a person like Babu to the fact that he has become disturbed is this lack of elementality, or put another way, the break with the aura of factuality. In certain circumstances, it is acceptable within the domain of common sense (or of alternative common senses) to see the Virgin Mary and hear the voice of God, or to imaginatively unmask hegemonic common sense and its naturalisation of the world, as some artistic movements do. However, if one thing characterises delusion it is a subjective rupture in which, paradoxically, the biographical and the outrageous combine to reveal the arbitrariness that underlies all naturalisation, to strip bare the artifices of a social world of conventions. Expressed in the language of structuralism, it is as though event and structure were entirely at odds.

The specific nature of Babu’s experience also clearly threatens all the other attributes of common sense. His fictitious world in which he heads all the North American multinationals in Barcelona and later becomes president of the United States can hardly be consistent with the principle of practicalness (GEERTZ, 1983). Even less so can Babu’s experience be

associated with the special connotations of sagacity and “ability to make projects thrive” which, according to Geertz, must be interpreted within this attribute (GEERTZ, 1983:87).

Babu’s fantasising is also key to understanding the absence of other attributes of common sense, such as “thinness” (GEERTZ, 1983:83), in his narrative. If, as GEERTZ says, the common-sense view of the world can be summed up by the 18th-century English theologian and philosopher Joseph Butler’s affirmation that “every thing is what it is and not another thing”, then Babu’s story is premised on the reverse: *every thing is not what it is but another thing*. This is evident in Babu’s subjective world and his certainty that he is not who he is (an executive and engineer in a multinational corporation), but something else (president of the USA, Jesus Christ), but also in his interpretation of social reality because there, too, what is (passers-by dressed in blue and white) is obviously something else (the women are his lovers and the men, his collaborators).

The next attribute is asystematicity or “immethodicalness” (GEERTZ, 1983:90). Although GEERTZ does not put it quite in these terms, immethodicalness refers to the flexibility and elasticity of every assertion about the nature of things, to the inconsistency of experience —and this does come from GEERTZ— reflected in the American poet Walt Whitman’s “I contradict myself, so I contradict myself. I contain multitudes”: a principle that, in the acute phase of his illness, was the opposite of Babu’s experience as he did not question his delusion but regarded it as a certainty, the only certainty. While this was not the case in his later reflection on his own experience once his delusion had abated, his account of that experience clearly conveys the absence of malleability, and therefore the rigidity, of the system of beliefs and convictions that characterised it.

GEERTZ’s final quality is “accessibleness,” which tells us that common sense is a general property of all social actors, or at least a majority of them, since as GEERTZ tells us “any person with faculties reasonably intact can grasp common-sense conclusions” (GEERTZ, 1983:91). It is no coincidence that GEERTZ himself commonsensically offers us this contrast between common sense and madness, although he does so almost in passing. Babu’s experience, for example, shows how a largely inaccessible idiosyncrasy can contrast with commonly shared judgements.

In sum, in Babu’s experiences we can see a narrative artificiality that contrasts with naturalness, a fantasy that counters practicalness, a codification that contradicts thinness, a rigidity that is a retort to the

flexibility and immethodicalness required to get by on a daily basis, and an idiosyncrasy that leans towards the inaccessible. Experiences like Babu's defy common sense, replacing it with a kind of "ob-scene" sense.

Refractions

The modification of this ob-scene sense is a basic, although tacit, objective of most care facilities charged with the treatment and rehabilitation of people diagnosed with a psychosis. During my fieldwork, and in subsequent research, I have observed how these facilities function as schools of common sense that set out to reconstruct the aura of factuality of social actions and representations in an attempt to turn affected persons into socially credible individuals; that is, reproducers of common sense (MARTÍNEZ-HERNÁEZ, 2000). These facilities cannot, therefore, avoid a moralising function, although paradoxically most therapies consider themselves to be unconnected to social and moral spheres, as their understanding of human afflictions is based on an individualistic epistemology and methodology. For this reason, mental health professionals tend not to seek out strategies that would allow affected persons to join their against-the-grain narratives to a critical and/or reflexive purpose, to a social function that emerges from their particular view of the world.

In the treatment context in which Babu found himself, affected persons were not encouraged to develop their own vision of the world, and much less to do so in a critical, creative and reflexive way. Rather, they were oriented toward adopting and participating in the most stereotypical and normative social conventions without questioning them, becoming what we might define as "good patients". Thus, it was considered inappropriate for patients to read books on esotericism, to join minority religious groups, or to reflect on abstract problems: resources and activities that are usually understood as amplifiers of delusion. In this vein I observed a curious discussion between a psychiatrist and her patient, who had been diagnosed with schizophrenia a year earlier and had begun to study philosophy at the local university. While the patient spoke about his interest in philosophical questions about the meaning of existence or the nature of things, the psychiatrist pressured him to abandon this course of study and switch to one more closely related to practical reality. The therapist thus reoriented her patient not to the sphere of rationality,

but to the more elemental, practical and supposedly accessible sphere of common sense. The conversations generally held in the group therapy sessions also show a risk-free preference for topics considered practical and elemental, such as public transport, how to find work, or the price of goods in the market. These and similar subjects are generally chosen because they link in with managing daily life and are therefore considered essential to the affected person's rehabilitation.

One of the aims of group therapy is to recreate a vision of common sense that can be shared by all those taking part in the session. This mechanism attempts to retrieve each participant's individual remnants of common sense and use them to build a collective common sense that each individual can then adopt. For example, one of the institutions in which I did fieldwork ran a session about public transport in which a participant, Emilio, said that he refused to travel on double-decker buses because they were not safe and were constantly overturning; his rejection of this form of transport was even stronger if the bus had an odd number because the day, month and year of his birth had even numbers and he reasoned that even numbers meant life and odd numbers, death. The therapist sought a critical response from the rest of the participants, who argued as a group that the bus manufacturers took safety requirements into account when designing double-decker buses, and that they had not noticed these vehicles overturning any more than others. But when the discussion turned to matters such as "fate is written in the numbers" or "who can guarantee that these buses will never turn over?", the therapist began to insist they must be practical and accept that if things are as they are, that is, if double-decker buses are being driven around cities, then there is a reason for it. The therapist thus guided Emilio to an attitude of assuming the aura of factuality of cultural representations and artefacts. Faced with Emilio's insistence on imploding cultural conventions, the therapist positioned himself as a bastion of common sense, pushing the dissenting voices to the margins of the stage.

During my fieldwork, I observed therapists using two mechanisms to reconstruct their patients' common sense. The first was an explicit system of negotiation and coercion dependent on a logic of rewards and punishments. In the second, the therapist encouraged the patient to identify with his or her own judgements. Neither strategy, however, met with more than limited success because of the patients' tendency to what has been called derealisation: an involuntary deconstruction of the

cultural codes that allow the world to be naturalised. The therapeutic stage thus became a scene of continuous struggle between common sense and its deconstruction by the patients: a deconstruction that reaffirmed the therapists' commitment to common sense, and a common sense whose arbitrariness was exposed by deconstruction.

In the group sessions the identification strategy entailed motivating the patients to respond to and contradict any statements that were not considered to be practical or commonsensical, such as the emphatic assertion that double-decker buses overturn or, as another informant stated, that the State pays for ships where homosexuals and dissidents are kept and then abandoned out at sea. A simple glance from the therapist to the patients considered to be more "recovered" could be enough to prompt them to comment in ways that corresponded to the therapist's expectations. In this way a hierarchy of proximity to the therapist that placed a premium on obedience and mimesis was established among the group participants. But for this to work, the therapist needed first to establish a relationship of transference or idealisation that was absolutely necessary for the affected person to identify with his or her interests – or perhaps "desires" would be more accurate – since without this connection the therapist would not easily be able to use his or her disappointment as a strategy when patients responded with bizarre judgements.

In the individual sessions, although the therapists did not have recourse to the other patients to act as their mouthpieces, they appealed to the patient's supposed remaining fragments of "common sense", and to their own position as the personification of this common sense. However, the trust between the two was easily broken. The therapists would insist that patients trust the treatment and let themselves be guided. The patients probably thought it highly unlikely that they would be able to trust someone who did not trust them. New patients tended to give more explicit accounts of their experiences, delusions or hallucinations, but they soon realised that this frankness came at a high cost in the form of increased medication, the therapist's distrust, and panic among close friends and family. And so the process would continue until the patient decided to offer what he or she thought the therapist wanted to hear: an impression of common sense performed by a domesticated individual who has purged any traces of *ob-scene* sense from their story and takes a critical view of the experience responsible for their being in treatment. This was Babu's strategy as he described it to me. There was no question of trust, only of

meeting the therapist's expectations; telling stories colonised by narrative conventions that concealed the outrageous and the unthinkable, and thus allowed him to reclaim a small place on the social stage or, at least, a more comfortable and tranquil day-to-day existence.

By way of conclusion

Madness is an offstage voice in both social and therapeutic contexts. As a narrative that must be domesticated, delusion is hidden psychopharmacologically and psychotherapeutically until it can re-emerge purified and adjusted to common sense. In many cases, however, this task leads to a series of failures, not only because madness is resistant to hegemony, inculcation and persuasion, but also because it implodes common sense by confronting it with opposing quasi-qualities: artificiality, impracticality, codification, rigidity, and inaccessibility. This is why managing afflictions of this kind is exhausting for affected persons, their families, and mental health professionals alike, who find themselves caught in the tension between common sense and idiosyncratically ob-scene sense.

Madness is feared because it reveals the contrived nature of common sense, including its most basic contrivance: its naturalisation. Madness is denied any social use or function; for example, as an instrument for rethinking the arbitrariness of our social world. Doing so would mean allowing madness onstage as a meaningful social resource. Most therapeutic strategies, however, do not seek to engage psychosis in dialogue or cede it social space but instead treat it as an anomaly to be domesticated, even though this mission seldom meets with success. The resulting reproduction of "total therapy" models of treatment reduces the possibility of dialogue and social communication, and this in turn facilitates an emphasis on management over narrative, nosology over experience, bureaucratic pigeonholing over lived identity. And finally, on the preeminent rhetoric of evidence, with its ability to objectify human affliction through nosologies, categories, diagnostic criteria, reductionistic hypotheses and possible treatments, over what, in the last instance, is the most evident: suffering.

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THE MEDICALIZATION OF DIAGNOSIS: FROM CULTURAL AND ENVIRONMENTAL NOSOLOGIES TO LAY MEDICAL CONCERNS¹

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Abstract: This chapter examines the concepts that doctors have used to classify their ethnographic and clinical observations regarding their patients' physical signs and symptoms, and their demands for care, in diverse cultural contexts. Ever since the Renaissance, when treatises on "errors", "superstitions", and "commonly presumed truths" began to appear, doctors (and anthropologists) developed disease classifications such as "ethnic", "comparative", and "historical-geographical" pathology, among others, before arriving at 20th-century concepts such as 'ethnic disorders' and "culture-bound syndromes", a terminology closely connected to the concept of folk medicine, which was developed to identify culture areas. We analyse the meaning of these concepts, their implications for clinical observation, diagnosis and treatment, and their role in the relationships between doctors, patients and their social networks, as well as in the historical process of medicalization. It concludes with a discussion of the emergent concept of "medical concerns", a product of multiple social

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processes including the widespread use of Internet sources of information on health and illness.

Keywords: medical anthropology, history of anthropology, history of medicine, medical nosology, folk medicine

La medicalización del diagnóstico. De las nosologías de base cultural y ambiental a las preocupaciones médicas de la población

Resumen: Este capítulo explora los conceptos mediante que los médicos han utilizado para clasificar sus observaciones etnográficas y clínicas de los síntomas y signos de sus pacientes, así como sus demandas de atención en contextos culturales distintos. Desde la aparición, desde el Renacimiento de tratados sobre «errores», «supersticiones» o «prejuicios», médicos (y antropólogos) desarrollaron clasificaciones como patología «étnica», «comparativa» e «histórico-geográfica», entre otras, hasta conceptos del siglo xx como «desórdenes étnicos», «síndromes delimitados culturalmente» muy vinculados al concepto de folk-medicina, desarrollado para identificar áreas culturales. Analizamos el significado de tales conceptos, sus implicaciones en la observación clínica, el diagnóstico y el tratamiento y su papel en las relaciones entre médicos, pacientes y sus respectivas redes sociales, en el marco del proceso de medicalización. Concluye con una discusión sobre el concepto de *medical concerns* (preocupaciones médicas), un producto de procesos diversos entre los cuales el cada vez más amplio uso de Internet como fuente de información en salud y enfermedad.

Palabras clave: antropología médica, historia de la antropología, historia de la medicina, nosología médica, folk medicina

During the 19th century, academic medicine, military and colonial doctors, and general practitioners (henceforth, GPs) were faced with two related problems: first, how to classify certain illnesses observed in overseas colonies and among European peasants, ailments known only by local names like “evil eye”, “tarantism” or *susto* and characterized by symptoms that defied easy categorization in Western medical terms; and second, how to determine the prevalence of these local diseases. These concerns arose out of the demands of local patients for medical treatment, and the medical screening of colonial troops, immigrants and colonists. The interpretation of such diversity was related to the development of anthropology as a field of study. Since the founding of the *Société des Observateurs de l’Homme* (Society of Observers of Man) in Paris in 1799, the first professional society of anthropologists (COPANS, 1978; STOCKING, 1968), many physicians actively participated in the anthropological and ethnological societies created during the 19th century (BOUZA VILA, 2002; COMELLES, 1998a; STOCKING, 1995) out of professional interest as well as intellectual curiosity. In Italy and Spain, they also joined folklore societies.² Given this confluence of interests, Spanish physicians called for the teaching of anthropology in medical schools (CALLEJA, 1892; BOUZA VILA, 2002), following the example set in France by the physician and anthropologist Paul Broca (see DIASIO, 1999; DIAS, 2004). The close involvement of doctors in the founding and development of anthropology as a discipline beginning in the late 18th century is fundamental to an understanding of the rise of medical anthropology.

The participation of doctors during this foundational period helps to explain why the development of a new scientific nosology (ACKERKNECHT, 1967; FOUCAULT, 1981) in the 19th century required the creation of disease categories specific to the disorders observed in overseas colonies and among European peasants. In both cases this was a consequence of medicalization.³ In the colonies, this process of

2 For an extended discussion of medical interest in ethnology and folklore, see COMELLES (1996). See also COMELLES (in press), CHARUTY (1997), DIASIO (1999) and BOUZA VILA (2002).

3 Here we distinguish between the concept of “medicalization” as defined and used in the social sciences beginning in the late 1960s (BUSFIELD, 2017) to mean the redefinition of human conditions as objects of medical diagnosis, prevention and treatment, and the notion of ‘medicalization’ as a *longue durée* historical and acculturative process involving the gradual expansion of access to and increasing recourse to medical knowledge, services and

taxonomic expansion was driven by the need to protect colonists and colonial troops from local risks to health. In rural Europe, the increasing presence of GPs made these categories necessary instruments in the process of acculturation as peasants began to seek medical assistance for their problems as an alternative to traditional healers. As a result, new terms were coined: in Germany *Medicinish-praktischen Geographie* (FINKE, 1795) and *Historisch geographischen Pathologie* (geographical and historical pathology) (HIRSCH 1860; 1883); in France, *pathologie ethnique* (BOUDIN, 1861) and *pathologie comparée* (BOUDIN, 1848), which referred, although not exclusively (HEUSINGER 1847; 1853), to comparative human and animal pathology (ANON. 1864); and in Italy *medicina popolare* (PITRÈ, 1896), which was a Romance-language adaptation of the German concept of *Volksmedizin*, a German synonym for “domestic medicine” (HEIDENREICH 1826). Although the majority of these terms are the product of an “etic” medical gaze, at the same time these same doctors developed a terminology that emerged from an “emic” gaze as a consequence of their attentiveness, in the course of their clinical work, to what we would now call the “explanatory models” of their patients: concepts such as “commonly presumed truths”, *préjugés*, *preocupaciones* and, recently, “medical concerns” (WHITE & HORVITZ, 2012).

This chapter, written from the margins of both medicine and anthropology, offers a genealogy of these concepts, which later developed into others: “comparative psychiatry”, “ethnomedicine”, “ethnopsychiatry”, “primitive medicine”, “ethnic disorders” (DEVEREUX, 1973), and “culture-bound syndromes” (KIEV, 1964; LEBRA, 1976; RUBEL, 1964; SIMONS & HUGHES, 1985) and, finally, “medical concerns”. Each of these has a meaning specific to the particular stage in the historical process of medicalization in which it emerged, with implications both for clinical practice and also for the health education strategies developed since the end of the 19th century. All of them are implicated in the construction of modern medical anthropology and its influence on clinical practice, medical education, health promotion and public health.

treatment, and the growing hegemony of medical diagnostic categories, which supplanted folk diagnoses. The roots of “medicalization” as a historical process in the societies of the western Mediterranean can be documented as far back as the Middle Ages (NUTTON, 1981), although some scholars (MILLER, 1985) argue that it is possible to trace its origins to classical antiquity.

Errors, superstitions and commonly presumed truths

By the 17th century, folk diseases and diagnoses such as the “evil eye” had already been incorporated into academic treatises (RUIZES DE FONTECHA, 1606), but most were considered “superstitions”, *erreurs* (errors), and later *préjugés* (commonly presumed truths).⁴ Some of the first works cataloguing popular medical knowledge from both a clinical and an ethnographic point of view were written for non-specialists in vernacular languages (CARLINO & JEANNERET, 2009; FISSELL, 1992). These include Andrew BOORDE’s *The Breuiary of Healthe, for All Maner of Sickneses and Diseases the Which May Be in Man Or Woman* ([1547] 2010) and Laurent JOUBERT’s *Erreurs populaires au fait de la médecine et régime de santé* (1578, 1586), both of which were seminal references for similar subsequent works until the 19th century. Joubert’s six-part book is divided into chapters on subjects that include “drinking”, “going to bed”, and “on healing”. This is not, then, a nosology properly speaking but a large compendium of local knowledge and practice that is the product of a double gaze, both clinical and ethnographic, characteristic of the doctors of the time. Its aim was to explain “errors”, some of which were the result of medical practice, and to offer alternatives, solutions and explanations. It should be seen as a pedagogical tool intended to correct wrong practices and, because of its wide circulation, included as one more strategy in this stage of the process of medicalization⁵. Table 1 lists some main works in this genre until the end of the 19th century. Many of these books were written by doctors, or copied from earlier works, and consist of both practical manuals and compendiums of curiosities that could be grouped together as popularization of medicine (PORTER, 1992).

⁴ “Commonly presumed truths”, a term found in BROWNE (1658), is a good translation for *préjugés*, the term used in France during the 17th and 18th centuries. For a more detailed analysis, see COMELLES (in press).

⁵ A description of the stages of the medicalization process can be found in EGBE, ALEGRE-AGIS & COMELLES, 2017, pp: 241-244.

Table 1. Examples of books on *erreurs*, *errores* and *commonly presumed truths* (1578-1900)

Year	Author	References
1578	JOUBERT, L.	<i>Erreurs populaires au fait de la médecine et régime de santé corrigés.</i>
1586	JOUBERT, L.	<i>Seconde partie des Erreurs populaires, et propos vulgaires, touchant la médecine et le régime de santé.</i>
1658	BROWNE, Th.	<i>Pseudodoxia Epidemica: Or, Enquiries into Very Many Received Tenents, and Commonly Presumed Truths</i> (3rd ed). Translated into French (1738), and Spanish (1774).
1726	LLORET Y MARTÍ, F.	<i>Apología de la medicina, y sus doctos profesores, contra los críticos, y defensa de la doctrina de Hypocrates, y Galeno, contra los errores vulgares.</i>
1757	FEIJOO, B. J.	<i>Teatro crítico universal, ó discursos varios en todo género de materias, para desengaño de errores comunes.</i>
1775	BIENVILLE, J. D. T. de.	<i>Traité des erreurs populaires sur la santé.</i>
1783	ILHARCE, J.-L. d'.	<i>Erreurs populaires sur la médecine.</i>
1810	SALGUES, J. B.	<i>Des erreurs et des préjugés: répandus dans la société.</i>
1812	RICHERAND, B. A.	<i>Des erreurs populaires relatives à la médecine.</i> Translated into Spanish (1826).
1834	ROUVEROY, F., et CHOPIN, J.-M.	<i>Le petit libraire forain ou la morale de Jacques le bossu: ouvrage dirigé contre les croyances superstitieuses, les préjugés et les erreurs populaires.</i>
1856	CHESNEL, M. A. de.	<i>Dictionnaire des superstitions, erreurs, préjugés et traditions populaires.</i>
1865	CHATELAIN, A.	<i>Des erreurs et préjugés populaires en médecine.</i>
1882	PAUC, E.	<i>Des erreurs et des préjugés populaires en médecine.</i>
1898	SALCEDO Y GINESTAL, E.	<i>Madre é hijo: doctrina científica y errores vulgares en obstetricia y pediatria.</i>

Along with *errores vulgares*, *erreurs populaires* (common errors) and superstitions, we find the first appearance in 1736 of the concept of *préjugés* (in Spanish, *preocupaciones*): “received ideas”, a concept very close to BROWNE’s (1658) “commonly presumed truths”. Some examples of works based on these categories are included in Table 2.

Table 2. Books on *préjugés* and *preocupaciones* (1600-1940)

Year	Author	References
1770	HOLBACH, P. H. Baron d'.	<i>Essai sur les préjugés, ou, De l'influence des opinions sur les mœurs et sur le bonheur des hommes: Ouvrage contenant l'apologie de la philosophie.</i>
1801	LAUGIER, J.-B.	<i>Des préjugés en médecine. Premier rabat-joie des vaccinateurs.</i>
1810	SALGUES, J. B.	<i>Des erreurs et des préjugés répandus dans la société.</i>
1827	SCOUTETTEN, H.	<i>Des préjugés sur la médecine.</i>
1831	VOISIN, J. C.	<i>De quelques préjugés relatifs à la médecine dans les départements de la Bretagne. Chez l'auteur.</i>
1834	ROUVEROY, F., & CHOPIN, J.-M.	<i>Le petit libraire forain ou la morale de Jacques le bossu: ouvrage dirigé contre les croyances superstitieuses, les préjugés et les erreurs populaires.</i>
1856	CHESNEL, M. A. de.	<i>Dictionnaire des superstitions, erreurs, préjugés et traditions populaires.</i>
1865	CHATELAIN, A.	<i>Des erreurs et préjugés populaires en médecine.</i>
1882	PAUC, E.	<i>Des erreurs et des préjugés populaires en médecine.</i>
1895	RODRÍGUEZ-LÓPEZ, J.	<i>Supersticiones en Galicia y preocupaciones vulgares</i>
1896	RODRÍGUEZ-LÓPEZ, J.	<i>Las preocupaciones en Medicina. Conocimientos útiles a la familia.</i>
1905	CODERA Y ZAIDI, N. F.	<i>Preocupaciones alimenticias. Examen de algunas ideas respecto a la alimentación del hombre y de los animales domésticos. Zaragoza: Mariano Escar, Tipógrafo.</i>
(101 1913	CARNEGIE, D.	<i>Ho How to Stop Worrying and Start Living: Tim Time Tested Methods for Conquering Worry. New York: World's Work.</i>
1932	ADRIANO, A.	<i>Carmi, tradizioni, pregiudizi nella medicina popolare calabrese. Arnaldo Forni editore.</i>

Holbach's concept of *préjugés* goes beyond the positivist notion of "commonly presumed truths", representing them as the product of ideological influences, mostly from religious discourses. While the gaze of the sources listed in Table 1 is predominantly "etic" and based on observation from a position of privilege, the notion of "commonly presumed truths" corresponds to a different cultural register: that of lay opinion, an "emic" register to which medical practitioners had come to be attentive.⁶

⁶ Today these books should be considered primary ethnographic sources for understanding practices related to health, illness and care among the common people from the 16th century

European doctors also wrote two types of neo-Hippocratic regional and local studies: “medical geographies” and “medical topographies” (JONES, 1967:2; PETER, 1967). Medical geographies such as the *Historia natural del Principado de Asturias* by GASPAS CASAL (1762) approached the regional prevalence of diseases through the Hippocratic concept of *katastasis* (“meteorological constitutions”), which stressed the relation between diseases and the environment. Medical topographies, however, were local monographs based on naturalist ethnography, and closely followed the environmental criteria of classification used by Hippocrates in *Airs, Waters and Places*. In 1795 Leonhard Ludwig FINKE drew up guidelines⁷ for medical topographies in his three-volume essay on the geographical distribution of diseases and, although no mention was made of their source, they served as a reference point for most of the subsequent works in this genre. Finke distinguished between “geography” and *Antropographie* (anthropography)⁸, which consisted of describing inhabitants

...according to their nature, color, physique, education, temperament, industriousness, diligence, indolence, endurance, hardness or weakness in bearing hardship, and so forth. Their occupations, crafts and trades [...]. Their foods, beverages and condiments deserve attention, no less than their clothing, habitations, games, amusements, and personal habits, such as misuse of warm and fiery beverages, or tobacco, hot rooms and the like. [...] He [the doctor] describes the modes of treatment commonly employed in the country, if they are not absurd, as is often de case, because some of them may actually be of a nature as to lead an alert physician to think about them, and often even to imitate them (L. FINKE, cited in ROSEN, 1946: 536).

Medical topographies are based on what we refer to as “neo-Hippocratic ethnography”, which is an ethnographic register based on the

to the beginning of the 20th century. Many were written by doctors for a readership that consisted of both GPs and the general public. Unlike 19th-century treatises on disease, these were compendia of practical advice on what to do for someone suffering from, for example, a stomach ache or cough.

7 An English translation of these guidelines is available in ROSEN (1946).

8 This is a synonym for the term “ethnography”, and was introduced into German academic discourse in the mid-18th century as a result of the work of August Ludwig von Schlözer, a cultural historian, on *Völkerkunde* (ethnology). A detailed history of the term can be found in VERMEULEN (2008), who makes no reference to Finke’s work. See also COMELLES (2000) on the significance of ethnography for medical practice.

authoritative gaze of doctors. PETER (1967), on the basis of his research on the late 18th-century medical topographies in the archives of the *Société Royale de Médecine*, believes that for local doctors, ethnographic writing was a useful way to make sense of the social chaos that accompanied epidemics. Medical topographies served to diagnose local conditions of health and disease based on environmental determinism, which then would make it possible to develop treatment strategies adapted to local reality. At the end of the 18th century, FINKE'S (1795) immense compendium of geographical and topographical sources (*Ueber die verschiedenen Arten der Geographien, hauptsächlich aber über medizinische Topographien und wie solche abzufassen*) on all the European, Asian, American and Arctic cultures documented at that time revealed that pathologies have enormous local variability.

From ethnic pathology to ethnic disorders

The term *pathologie ethnique* ("ethnic pathology") was formulated by Jean-Christian BOUDIN (1861), a French military physician in Algeria (LÉONARD, 1977) and member of the *Société d'Anthropologie*. He was also the author of one of the first treatises of "comparative pathology" (BOUDIN, 1848), in which he studied "*le non-acclimatement, les aptitudes et les immunités morbides de diverses races humaines, et la nature de leurs maladies*" (PÉRIER, 1868: XXXVII),⁹ a subject to which he would return years later in his *Essai de pathologie ethnique: de l'influence de la race sur la fréquence, la forme et la gravité des maladies* (BOUDIN, 1861),¹⁰ a work whose aim was to answer a question of great import at the time: "Les diverses races, les diverses nationalités, ont-elles un même degré d'aptitude, de prédisposition, pour les maladies, et ces dernières se présentent-elles sous des formes et avec des intensités identiques dans toutes les variétés humaines?" (BOUDIN 1861: 6).¹¹

9 [Failure to acclimate, propensities and immunity to disease of the various human races, and the nature of their maladies].

10 [Essay on Ethnic Pathology: On the Influence of Race on the Frequency, Form and Seriousness of Illness].

11 ["Do the various races and nationalities possess the same degree of propensity for or predisposition to diseases, and do these present in the same form and with the same intensity in all human varieties?"].

Si la solution du problème est d'un intérêt scientifique incontestable, elle n'est pas d'une importance moindre au point de vue économique et social. [...] le succès d'une expédition de guerre, soit dans les régions polaires, soit dans les portions insalubres des contrées tropicales, peut dépendre de la qualité des hommes dont on aura fait choix; il en sera de même du choix des travailleurs, Coulis, Chinois ou Madériens, que divers gouvernements dirigent aujourd'hui sur les colonies, particulièrement depuis la suppression de la traite et l'émancipation des noirs. Toutes ces grandes questions économiques sont dominées par la notion précise du degré d'aptitude des races aux diverses affections, [...] par la connaissance de leurs prédispositions morbides et de leur résistance respective aux milieux contre lesquels elles sont appelées à réagir (BOUDIN, 1861 :7).¹²

The argument he develops is based on a gaze that classifies racial difference according to body odor and skin color —“the black appears to be highly sensitive to the slightest decrease in temperature” (BOUDIN, 1861: 8)— among other considerations based on a broad knowledge of contemporary French, German and English ethnographic sources. Boudin's article connects numerous examples of ethnic pathology that correspond to classic folk illnesses such as the trance-like state and physical and psychic depletion of “second sight” in the Hebrides, as well as the influence of climate on propensity to illness, with what he calls “the differences, no less curious [...] in intellectual faculties” (BOUDIN 1861: 12). Boudin supports his argument for “racial” differences in human illness with statistical data drawn from veterinary medicine and the reporting of illnesses affecting different horse breeds. This use of statistics leads him to report that respiratory illnesses were twice as frequent and gastrointestinal diseases five times more frequent among British soldiers than among Maltese recruits.

12 [If the solution to this problem is of undeniable scientific interest, it is of no less importance from an economic and social point of view. [...] the success of a military expedition, whether in the polar regions or in the insalubrious areas of tropical countries, may depend on the quality of the men chosen to carry them out; the same may be said of the choice of workers, *Coulis*, Chinese or Madeirans, which various governments today dispatch to the colonies, particularly after the ending of the slave trade and the emancipation of the blacks. All these great economic questions are dominated by the notion of the degree to which the races are subject to different diseases, [...] by knowledge of their predisposition to illness and their resistance to the environments to which they are called to respond] (BOUDIN, 1861: 7).

A year before Boudin's article appeared, August HIRSCH (1860) published his *Handbuch der historisch-geographischen Pathologie*,¹³ which defines "pathology" as

...the expression of a process called forth and sustained, in organisms that are capable of life, by the sum of all the influences which act upon them from without. The form and fashion of this process, accordingly, are determined by the kind of individuality and by the character of the environment. Each of these two factors shows many differences in time and in space. As regards the human species, the differences are expressed, for the first factor, in the distinctive qualities of generations separated by years, and of races and nationalities scattered over the globe; for the second factor, they are expressed in peculiarities of the climate and the soil, and of the animal and vegetable kingdoms in so far as these are brought into direct relation with man, and further, in the vicissitudes of politics, of social affairs, of the food-supply, and of mental training. In these considerations lie the germs of a science, which, in an ideally complete form, would furnish a medical history of mankind, but which, treated more narrowly and so as to embrace only the pathological side of human life, will give firstly, a picture of the occurrence, the distribution, and the types of the diseases of mankind, in distinct epochs of time, and at various points of the earth's surface; and, secondly, will render an account of the relations of those diseases to the external conditions surrounding the individual and determining his manner of life. And this science I have named, [...] the science of geographical and historical pathology (HIRSCH, 2014, pp. 1–2).

Hirsch refers here to the description of pathology that derives from clinical, ethnographic and historical observations, suggesting that historical and geographic context has considerable influence on local diseases. Hirsch's ideas should be distinguished from the radical positivism of the concepts "comparative pathology" or "ethnic pathology". These labels should be seen in the context of discussions on racial differences and adaptability to different environments, the roots of which were present in anthropological debates regarding comparative anatomy (SALLES, 1849: 207). Many of Boudin's observations are grounded in an anthropometric gaze, in statistics and in an ill-defined concept of "race"—Jewish, Hindu, black—constructed in many cases on the basis of data on military recruits

13 There is an English translation with a foreword by HIRSCH (1883) that includes a review of the literature on "historical-geographical pathology" that appeared in print following publication of the German edition of his book in 1860. In this chapter, all quotations of Hirsch's work are from the 1883 edition.

and on morbidity and mortality statistics among the troops. He does not mention women. His concept of “ethnic pathology” is based primarily on clinical examination and only secondarily on ethnographic knowledge because of the position he occupied in the medical service of the French army. A few years later, in his *Memoria sobre un programa de patología general*, Johann Ullesperger wrote of a new branch of pathology, “ethnic pathology”, which he described as a “comparative analogy between etiological notions resulting from objective local differences in a country and the subjective individualities of a nation” (ULLESPPERGER, 1866: 15). He translated this concept into German as *ethnische Pathologie* in an article on dyspepsia (ULLESPPERGER, 1868), but without reference to the work of Hirsch and Finke. While the concept of “ethnic pathology” is connected to the Hippocratic notion of “temperament” and to constitutionalist approaches (KRETSCHMER, 1954), as well as to the later development of “psychosomatic illness”, in the 19th century it allowed doctors to construct a nosography attentive to phenotypic —to their way of thinking, “racial”— variability, and to environmental and cultural adaptability. Some examples of books in this genre are included in Table 3.

Table 3. Ethnic, geographic and comparative pathology

1795	FINKE L. (cited in Hirsch 1883)	<i>Versuch einer allgemeinen medizinisch-praktischen Geographie, worin der historische Tell der einheimischen Völker- und Staaten-Arzeneykunde vorgetragen wird</i> , 3 volumes.
1813	SCHNURRER, F. (cited in HIRSCH 1883)	<i>Geographische Nosologie oder die Lehre von den Veränderungen der Krankheiten in den verschiedenen Gegenden der Erde, in Verbindung mit physischer Geographie und Natur-Geschichte des Menschen.</i>
1847	HEUSINGER, C.F.	<i>Recherches de pathologie comparée.</i>
1848	BOUDIN, J.	<i>Études de pathologie comparée.</i>
1849	SALLES, E. F.	<i>Histoire Générale Des Races Humaines Ou Philosophie Ethnographique.</i>
1856	MÜHRY, A. (cited in HIRSCH, 1883)	<i>Die geographischen Verhältnisse der Krankheiten</i>
1860	HIRSCH, A.	<i>Handbuch der historisch-geographischen Pathologie.</i> English translation: <i>Handbook of Geographical and Historical Pathology</i> , 6 volumes (1883).

1861	BOUDIN, J. C. M. F. J (cited in HIRSCH 1883)	Essai de pathologie ethnique: de l'influence de la race sur la fréquence, la forme et la gravité des maladies. <i>Annales d'Hygiène Publique et Médecine Légale</i> , XVI-XVII, 5–50 64–103.
1864	POUCHET, G.	<i>De la pluralité des races humaines. Essai anthropologique par Georges Pouchet.</i>
1866	ULLERSPERGER, J. B.	<i>Memoria sobre un programa de patología general.</i>
1868	ULLESPERGER, J. B.	Die Pathologie und Therapie der Dyspepsien. Historisch, kritisch, theoretisch und praktisch dargestellt. <i>Zeitschrift Der K.k. Gesellschaft Der Aerzte Zu Wien</i> , 21-24, 107–123.
1877	LOMBARD, H. C.	<i>Traité de climatologie médicale: comprenant la météorologie médicale et l'étude des influences physiologiques, pathologiques, prophylactiques et thérapeutiques du climat sur la santé.</i>
1904	KRAEPELIN E	<i>Vergleichende Pathologie</i> (cited in BENDICK 1989)
1925	KUCZYNSKI, M.	<i>Steppe und Mensch. Kirgisische Reiseeindrücke und Betrachtungen über Leben, Kultur und Krankheit in ihren Zusammenhängen.</i>
1944	KUCZYNSKI-GODARD, M.	<i>La Vida en la Amazonía peruana. Observaciones de un médico.</i>

Table 3 includes two important figures. The first is Emil Kraepelin, who proposed a specific taxonomic group for psychiatric folk nosology, *Vergleichende Pathologie* (comparative pathology) (BENDICK, 1989; MARTÍNEZ-HERNÁEZ, 2000).¹⁴ This taxon did not correspond to particular cultural areas, but included a residual category for some disorders, as DSM-IV and DSM-V do today. Neither Kraepelin nor the creators of the DSM were anthropologists or folklorists; they were clinicians in search of a way to include *amok*, *susto* and *nervios* in scientific nosography with the aim of simplifying and rationalizing diagnosis, prognosis and therapeutics. Many came to accept the universal nature of pathogenesis (KIEV, 1973) while resigning themselves to retaining the diversity of patients' narratives about symptoms. What we have here is a clinical problem resolved by clinical means, in which the role of anthropology is subsidiary, its purpose being to guarantee a certain degree of rigor in the evaluation of signs and symptoms and the exploration of their underlying logic.

14 Kraepelin developed these taxa following his travels in Southeast Asia with his brother, a botanist.

The concept of “ethnic disorder” developed by Georges DEVEREUX (1973) in 1956 is an adaptation of the term “ethnic pathology”, substituting the more flexible notion of “disorder” for the concept of “pathology”, which suggested organic disease. However, elements of the organic aspects of “ethnic pathology” remain present in his work. The concept of “culture-bound syndromes”, its direct heir, is more relativistic, open and inclusive (SIMONS & HUGHES, 1985). Beyond its influence on the design of mental health care services, recognition of linguistic diversity as a problem to be resolved in clinical communication, and the promotion of “cultural competence” for health professionals and institutions, the ethnic pathology-ethnic disorder continuum has had little relevance for health education, perhaps with the exception of some issues in intercultural health.

The second case is the work of Maxime KUCZYNSKI GODARD (1889-1962) a medical doctor in the best tradition of social medicine. Kuczynski worked in Asia prior to World War I, using the concept of *ethnische Pathologie* developed in his manifesto *Neue Medizinische Aufgaben im neuen Russland* (KUCZYNSKI, 1925).¹⁵ This should not be confused with Boudin’s concept of *pathologie ethnique*; Kuczynski used *ethnische Pathologie* in the same way as FINKE (1795) and HIRSCH (1860) used “historical-geographical pathology.”

Because of his training, in the late 1930s while he was exiled in Peru, the Peruvian government commissioned him to write a report on health in Amazonia, which became the basis for his book *La vida en la Amazonia Peruana* (KUCZYNSKI-GODARD, 1944), published in Spanish. We consider this to be the first fieldwork-based monograph in modern medical anthropology in the tradition of what social medicine was capable of when it shifted its interest from the European and American lower classes and began to study the effects of capitalism on aboriginal communities. Kuczynski did not limit himself to describing the differences in the pathologies he observed, but applied to his data —not without a certain naiveté because of the novelty of what he was doing— a professional ethnographic gaze influenced by American cultural anthropology. He developed a sophisticated Marxist interpretation to explain the effects of the labor relations imposed by the rubber industry on the indigenous

15 [New Medical Tasks in the New Russia]. For a detailed discussion of this work, see KNIPPER (2005, 2009).

workers they hired, and it is likely that this is the reason why his work was not very well received by the new rightist government in Peru.

Kuczynski's book, and the work of two anthropologists, the Italian Ernesto de MARTINO (1961) on the Italian *mezzogiorno* during the 1950s and 1960s, and the Argentinian Eduardo MENÉNDEZ (1981) in Yucatán (Mexico) in the late 1970s, constitute three key sources for the political economy approach to processes of health, illness and care, and seminal references for a critical medical anthropology. The differences among them lie in the fact that Kuczynski was a classical Marxist while De Martino and Menéndez were strongly influenced by Gramsci's work.

The concepts of "ethnic", "geographical", "comparative" and "historical-geographical" pathology are of considerable importance in medical taxonomy. Their aim was to classify diseases and symptoms on the basis of clinical criteria and describe the local diversity of prevalent diseases. The emergence of these concepts is related to the development of the second step in the process of medicalization under the hegemony of the hygiene-sanitation model and the fight against infectious diseases. In the field of social medicine, they had effects on the further development of transcultural psychiatry (KIRMAYER, 2013) and on some features of intercultural health (AGUIRRE-BELTRAN, 1947), and eventually on the recent formulation of 'cultural competence'.

The American Medical Association (AMA) is committed to responding to the dramatic changes in the nation's demographics and in health care delivery systems in many ways. Recently, for example, the AMA signed a Memorandum of Understanding with the Henry J. Kaiser Foundation to partner on a nationwide initiative to increase medical professionals' awareness about racial and ethnic disparities in cardiac care. Representative of the AMA's work in this regard is the Cultural Competence Compendium, a 460-page resource guide to help physicians and other health professionals communicate with patients and provide individualized, respectful, patient-centered care (AMA, 1999).

From Volksmedizin to folk medicine

The term *Volksmedizin* appears for the first time in *Die vier Grundpfeiler der Volksmedizin, das Blutlassen, Brechen, Abführen und die äusserlichen Mittel* (HEIDENREICH, 1826).¹⁶ This brief manual, which resembles the popular “domestic medicine” books of the time, presents a critique of popular healing practices and the behavior of those who prefer home remedies to medicine: practices the author considers dangerous. The first chapter establishes when the doctor should be called, and the following four chapters explain the perils of bleeding, induced vomiting, enemas, and the use of homemade salves, ointments and plasters.

Table 4. Examples of books on domestic medicine and its terminology

Terminology	Year	Author	Title
Volksmedizin (D)*	1826	HEIDENREICH, Friedrich W.	<i>Die vier Grundpfeiler der Volksmedizin, das Blutlassen, Brechen, Abführen und die äusserlichen Mittel</i>
Domestic medicine (UK)	1827	GRAHAM, T.J.	<i>Modern Domestic Medicine; or, A Popular Treatise Illustrating the Character, Symptoms, Causes, Distinction, and Correct Treatment, of All Diseases Incident to the Human Frame; Embracing All the Modern Improvements in Medicine, with the Opinions of the Most Distinguished Physicians.</i>
Volksgeneeskunde (NL)	[1818] 1858, 1863	OSLANDER, OORT, & EEN,	<i>Volksgeneeskunde: nieuwe en eenvoudige wijze om de meeste ziekten spoedig en gemakkelijk te genezen</i>
Médecine populaire (F)	1824	COLON, P.	<i>Essai sur la médecine populaire et ses dangers</i>
Medicina popular (P, BR)	1851	CHERNOVIZ, PL.	<i>Diccionario de medicina popular III en que se descrevem, em linguagem accomodada à intelligencia das pessoas estranhas á arte de curar</i>

16 [The Four Pillars of Traditional Medicine: Blood-letting, Emetics, Purgatives and External Remedies].

The term *Volksgeist*, the basis of 19th century folklore studies (see VERMEULEN, 2008), gave rise to the use of the derivative term *Volkmedizin* in Germany (FLÜGEL, 1863).¹⁷ In the United Kingdom, G.W. BLACK adopted it in his book *Folk-Medicine: A Chapter in the History of Culture*, as did HOFFMAN (1889) in the United States, in *Folk-Medicine of the Pennsylvania Germans*.¹⁸ Some examples are shown in Table 5.

Table 5. The international translations of *Volksmedizin*

Terminology	Year	Comelles	Title
Volksmedizin (D)	1863	FLÜGEL	<i>Volksmedizin und Aberglaube im Frankenwalde: nach zehnjähriger Beobachtung dargestellt ...</i>
Folk medicine (UK)	[1878], 1883	BLACK, G.W.	<i>Folk-medicine: A Chapter on the History of Culture</i>
Folk medicine (USA)	[1886] 1888	W. HOFFMANN	<i>Folk-Lore of the Pennsylvania Germans</i>
Folkmedicin (SE)	[1846] 1909	HIRTE & LEIBERT	<i>Några ord om öronsjukdomarna i den skånska folkmedicin</i> [A few words about childhood diseases in Skåne folk medicine]
Folkmedisin (N)	[1918] 1922	FALK, H.	<i>Overtroiske kurer og folkemedisin i Norge/Frosken og padden i nordisk folkemedisin</i> [Superstitious cures and folk medicine in Norway/ The frog and toad in Nordic folkmedicine]
Volks geneeskunde (NL-B)	1891	COCK, A. de	<i>Volksgeneeskunde in Vlaanderen</i>
Medicina popolare (I)	1896	PITRÈ, G.	<i>Medicina popolare siciliana</i>
Medicina popular (E)	[1857] 1889	BLACK, G.W.	<i>Medicina popular</i> (Spanish translation by A. MACHADO Y ALVAREZ)

17 It was translated into Danish as *folkemedicin*, into Swedish as *folkmedicin*, into Norwegian as *folkmedicin*, and into Dutch as *Volksgeneeskunde*, to designate medical folklore specifically (see Table 4).

18 See MILLER (2008) for a discussion of the introduction of the concept of folk medicine into English.

Volksmedizin became, in Romance languages, *medicina popular* (Spanish Catalan, and Portuguese), *médecine populaire* (French), and *medicina popolare* (Italian). By contrast, in folklore studies of health and illness the preferred terms were *superstitions*, *supersticiones* or *préjugés*, and *preocupaciones*.

In his translation of BLACK'S (1883) book, the Spanish folklorist MACHADO Y ÁLVAREZ (BLACK, [1889]1982) used *medicina popular*. Machado probably chose *medicina popular* because of the advice he sought from a physician friend, Federico Rubio y Galí, while translating Black. Their correspondence, published as an annex in the Spanish translation of Black, is interesting. Rubio y Galí not only rejected the idea that folk medicine was a mere curiosity, but stressed its pragmatic value and the efficacy of botanical remedies, many of which had been incorporated into medical pharmacopeia (PERDIGUERO-GIL & BALLESTER AÑÓN, 2003). This pragmatism was also observed by an Italian folklorist who was a contemporary of Black:

Do not imagine that empirical remedies are always harmful. This is not always so. Most of the time they are based on centuries of experience. What would people do living in the country where they rarely see doctors, or call them only when the patient is already nearing the end, if they could not resort to traditional remedies? (DE NINO, 1891: Vol. V).

De Nino's position is close to that of some Italian *medici condotti* (rural GPs) of his time. Paolo MANTEGAZZA (1870), Zeno ZANETTI (1891) and Giuseppe PITRÈ (1896) were committed to providing medical care to the rural population (BARTOLI, 1984, PERDIGUERO-GIL & COMELLES 2014), but also to learning to understand their own health care practices (BARTOLI, 1984). They were not interested in "ethnic pathology", but in a much broader way of knowing similar to the early 20th century Austrian *Kulturkreise*¹⁹ school, identifying cultural fields or areas relative to health and illness through the use of ethnography rather than through the clinical gaze (COMELLES, RICCÒ, & PERDIGUERO-GIL, 2014; COMELLES, 1996).

¹⁹ *Kulturkreis* is the singular form, and *Kulturkreise* is the plural. This concept was rendered in English by the Boasians as 'culture areas'.

The ethnographic work of the Italian *condotti*²⁰ should be viewed as the foundational act of medical anthropology, not merely because of the data they collected but for their theoretical and methodological contribution to the delimitation of this field. Zeno ZANETTI (1892) began tentatively by identifying the primordial role of women in the production and reproduction of knowledge and practice; this was later more fully developed and systematized by Pitрэ.²¹ In his book *Medicina popolare siciliana* (PITRÉ, 1896) he lays out a research methodology that goes far beyond the notion of ethnic pathology when he writes:

If there is a genre that requires a specialist researcher, it is the field of medicine. Working from general knowledge alone it is possible to study mythology, dress [...] but it would be difficult, in my opinion, to study medical practices and beliefs unless one is a doctor. The reason is that in the field of medicine it is hard for non-doctors to distinguish what is considered error from what is science, the practices of today from those of times past, what was and is superstition. This is why there is confusion in the medical texts of non-doctors between scientific remedies treated as old wives' tales and frivolous remedies taken for things that have come directly from the scientific laboratory (Pitré 1896:VII).

Pitré did not think in purely clinical terms. He spent three decades of his life as a rural GP, during which time he was not only a doctor but an ethnographer and one of the most important professional folklorists in the Europe of his time. *Medicina popolare* presents the nosology characteristic of late 19th-century Sicily, using academic nosography but grounding it in extremely rigorous ethnographic fieldwork. The resulting Sicilian *Kulturkreis* is not simply a miscellaneous folk category like the *Vergleichende Pathologie* promoted by Kraepelin, but a specific cultural subcategory based on the notion of culture area found in the work of the cultural anthropologists who were his contemporaries: Boas, Rivers, and Graebner, among others.

20 The *condotto* was the medical officer in rural Italy. The term comes from the Latin *conductio* (hiring), and represents a contractual relationship between a town and a doctor (NUTTON, 1981).

21 For more on Pitрэ, see COMELLES (1996), CHARUTY (1997) and DIASIO (1999).

From folk diseases to culture-bound syndromes

PITRÈ'S (1896) work is also an exhaustive survey of the folk illnesses he observed and systematized. His book follows the structure of a treatise on pathology according to location in the body, but his nosography has an extraordinarily ethnographic quality, locating the description of the illness in specific contexts, using Sicilian terms to demonstrate the rigor of his observations. This breaks with the folklorists' classificatory criteria, as ZENO ZANETTI (1891) also did. The folklorists neither understood nor used this approach in their own work. Table 6 shows the main European sources for the classification of folklore on health, illness and treatment before 1939.

Table 6. Medical and health topics
in the classifications of European folklore

Country	Year	Author and title	Terminology
Portugal	1885	Teófilo BRAGA <i>O povo portuges</i>	Folk psychology Superstitions (religion and myth)
Germany	1903	R.F. KAINDL, <i>Die Volkskunde: ihre Bedeutung, ihre Ziele und ihre Methode mit besonderer Berücksichtigung ihres Verhältnisses zu den historischen Wissenschaften</i>	Folk medicine
Catalonia	1912	Cels GOMIS	Medicine: superstitious medicine, home remedies, private hygiene
Catalonia	1910-1920?	Rosend SERRA I PAGÈS	Family life: disease
Catalonia	1929	Rosend SERRA I PAGÈS	Life events: disease, tools related to disease and sick people Superstitions: therapeutics
Flanders	Before 1914	Isidoor TEIRLINK	Everyday life: superstitions about the human body Folk medicine
Flanders	1913	The Museum of Antwerp Guide	Sciences: medicine, tools, remedies Magic: healers
United Kingdom		Charlotte BURNE	Disease and folk medicine
Sweden	1915	C. W. VON SYDOW	Diseases and remedies

Denmark	1917	Dansk Folkemindesamling	Beliefs: body, magic, evil protection, pregnancy and delivery Superstitions: diseases, death, delivery
Norway	1917	Reider Th CRISTIANSEN. <i>Nordisk Folkemindesamling</i>	Supernatural arts: diseases and remedies
Switzerland	1917	Krayer HOFFMANN. <i>Questionnaire accompagné d documents et d'exemples.</i> Société Suisse des Traditions Populaires	Folk medicine
France	N.d.	Emile NOURRY, [aka Pierre SAINT YVES]	Popular science, folk medicine Domestic magic The cult of saint's miracles Social life: sick people. Care. hospitals and asylums
France	1933	Arnold VAN GENNEP, <i>Le folklore du Dauphiné</i>	Magic, folk medicine
Flanders	1935-36	Arnold VAN GENNEP <i>Le folklore de Flandre et du Hainaut</i>	Magic, folk medicine

These classifications reveal the gulf separating the folkloric gaze and its taxonomies from the physician-folklorists' concept of "folk medicine": the term used to identify studies of this type from the end of the 19th century until the mid-20th century in southern Europe. Pitre's ethnographic work and that of the other Italian and Spanish *condotti*²² should be understood as the product of a kind of medicine that required knowledge of the local pathologies that led people in remote rural areas to consult doctors when they could do so. Although these medical doctors were conscious of their acculturating and medicalizing role, as folklorists their concern was to preserve local cultural knowledge at risk of disappearing. The shortcomings of "medical folklore" lay in its positivism and the interpretive limitations of late 19th-century anthropology. It went no further than explaining these forms of knowledge and practice as a product of syncretism and interpreted them as survivals (PERDIGUERO & COMELLES, 2014).

22 An institution similar to the *condotti* existed in Catalonia, where public medical officers were called *conduits*.

The contributions of Pitrè and Zanetti to folklore theory and medical practice did not inspire many followers outside southern European medicine (PERDIGUERO & COMELLES, 2014). Their work – like Kuczynski’s at a later time —was forgotten, in part because Spanish and Italian were languages of marginal importance in scientific medicine (COMELLES, 2002). Even those who based the structure of their own medical folklore monographs on Pitrè’s work, such as Victor LIS QUIBÉN (1949) in Spain, did not even bother to cite him. Folklore studies would remain anchored for decades in the traditional classifications shown in Table 5. Medical folklore as such slowly vanished from southern Europe in the mid-20th century because of the growing lack of social commitment on the part of the southern European GPs (PERDIGUERO & COMELLES, 2014). In the English-speaking world, RIVERS (2010), a medical doctor and psychiatrist, is regarded as the point of departure of medical anthropology on the basis of a slender volume, *Medicine, Magic and Religion*, a collection of his lectures on anthropology addressed to a medical audience. Neither he nor professional anthropology, of which he was one of the main founders, showed any interest in the folklore of the European peasantry.

A worried world: from “folk medicine” to “medical concerns”

Earlier genealogies of international medical anthropology stressed the dissociation between the hegemonic clinical gaze and a subaltern ethnographic gaze in medicine, and between a hegemonic ethnographic gaze and a subaltern clinical gaze in medical anthropology. Today, ethnically based nosographies maintain their importance but in a different way. For some medical specialties such as psychiatry, clinical psychology or transcultural psychiatry, they are necessary tools for developing culturally specific diagnostic and therapeutic strategies adapted to ethnic and cultural diversity. Medical anthropology has made it possible to develop more culturally appropriate clinical and therapeutic practices, despite the reservations sometimes expressed by academic medical anthropologists, who often show little interest in the clinically applied dimension of their work, and little understanding of the practical uses to which doctors, psychiatrists, psychologists and nurses have put the theoretical approaches and analytic concepts the discipline has generated.²³ Nevertheless, at the

23 See COMELLES & MARTÍNEZ-HERNÁEZ, 1993; MARTÍNEZ-HERNÁEZ & COMELLES, 1994; MARTÍNEZ-HERNÁEZ, 2008; and SAILLANT & GENEST, 2007.

same time, the incorporation of qualitative research techniques into global health is not accompanied by acknowledgment of their origins in ethnography, or recognition of the fact that in the 20th century ethnography was an important tool of medical knowledge (COMELLES, 1998, 2000).

However, after World War II, the International Union for Health Promotion and Education (IUHPE) and three agencies of the United Nations – the World Health Organization (WHO), the Food and Agriculture Organization (FAO) and the United Nations Educational, Scientific and Cultural Organization (UNESCO) – all advocated a greater role for ethnography in the development of diversity-sensitive health promotion policies and an emphasis on maintaining health rather than treating disease (COMELLES *et alii*, 2014; TERRÓN, COMELLES & PERDIGUERO-GIL, 2017). As a consequence, Mexico and other Latin American countries developed intercultural health programs (MENÉNDEZ, 2016).

This new emphasis on health began to penetrate contemporary folk culture beginning in the second half of the 20th century and reveals a shift away from the old “disease-sanitation” model and toward a new model based on “well-being”. This transition implies changes in the agenda of medicalization and also affects the agenda of medical anthropology and of modern health promotion and education.

This shift in emphasis also affects the ways in which anthropologists and doctors classify forms of distress. Concepts such as social suffering, affliction, and emergent problems that affect wellbeing, such as bullying and mobbing, require us to revise some long-held notions. Today the rigidity of the ethnic and cultural typologies of earlier times as described in this chapter renders them unsuitable in the context of globalization, of which medicalization is one dimension. In a globalized world, the notion of culture has to be more dynamic and highly diversified. Appadurai (1996) characterizes it as an *ethnoscape*: a fluid, flexible and dynamic space in which people make decisions about health, illness and treatment. Its main feature is volatility as a result of continuous shifts in meaning, in which market processes and social media play a major role.

One example of this is corporate advertising of functional foods (foods designed to enhance health and prevent disease), a process that has escaped the control of health professionals and is being driven instead by specialists in mass communication (EGBE, ALEGRE AGIS & COMELLES, 2017). Danacol, for example, a popular low-fat fermented

dairy product enriched with plant sterols and advertised as “clinically proven” to reduce blood cholesterol levels and thereby reduce the risk of a heart attack, is a response to a widespread lay “medical concern” constructed through multiple social processes: biomedical research, the findings of which are reported in highly summarized, simplified and occasionally sensationalized form to the general public through news coverage in the print and electronic media; medical advice to individual patients concerning reduction of their cholesterol levels through dietary changes in order to avoid a heart attack; advertising; Internet sources of information and online information-sharing communities; and free-floating health anxieties in the general population that lead individuals to suspect that they may be heart attack candidates and wonder what they can do to prevent one.

“Medical concerns”, then, is not an etic category comparable to *susto* or *nervios* and constructed by anthropologists, but an emic folk category that reflects popular demands relative to problems of health and illness that take the form of constructions which, like “cholesterol” and “high blood pressure”, are built up out of the everyday flow of information and opinion. The very nature of contemporary ethnoscapes makes these medical concerns and demands fluid and changeable, sometimes with great rapidity. This new arena of health and illness takes us far from KLEINMAN’s (1980) three-part model of “popular”, “folk” and “professional” sectors of health care, which was bound to an idea of clinical response to disease through the classificatory and diagnostic criteria of biomedicine, and dependent on the concept of syncretism present in Ackerknecht’s (1985) definition of folk medicine, a notion that is no longer applicable. Today the face-to-face encounters that took place (historically speaking) between health professionals and their patients and served both to produce a diagnosis and to construct the diagnostic experience of patients and their social networks has now broadened beyond recognition. In a “worried and wired” world (EASTIN & GUINSLER, 2006), laypersons increasingly seek medical advice not only from their doctors; using ever more powerful search technologies, they have gained access to sources of medical information on the Internet, some more reliable than others, and their medical concerns are in part driven by exposure to direct advertising of new medications and functional foods in both the print and electronic media. This worried demand for information materializes in online medical search and web browsing behavior organized around

“medical concerns” (WHITE & HORVITZ, 2009a; 2012) arising from broad social conversations about health (see BARKSKY, 1988) that now take place in part through social media. At present, medical diagnosis is no longer based exclusively on responding to illness but increasingly on responding to these “medical concerns”. In some cases, patients search for additional information about an existing diagnosis, often sharing this information with their physicians; in others, they consult their physicians seeking confirmation of a self-diagnosis based on an interpretation of their symptoms through information found on the Web (WHITE & HORVITZ, 2009b). As an emic category, “medical concerns” may prove to be the basis of a new folk nosology that should be understood not in terms of biomedical disease categories but as a continuous process of construction and deconstruction of new threats to health and sometimes to life.

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24 <https://www.researchgate.net/profile/Josep_Comelles/contributions>

AFTERWORD
ANTHROPOLOGY AND DIAGNOSIS:
BIOMEDICAL DISEASES AND THEIR BORDERS

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The contributions in this volume, which follow on from a very successful workshop on the subject in June 2016, highlight the diverse ways contemporary medical anthropology can productively engage with the topic of diagnosis. The chapters have not only covered the practices and consequences of diagnosis, but also the broader context that both shapes, and is subsequently shaped by, individual encounters with distress and suffering. A key theme that can be traced throughout many of them is that studying diagnosis entails two inextricably linked perspectives. The first entails an extended account of what people do and how they interact with each other, both before and after a diagnosis may be reached. This charting of all the various actors involved might loosely be termed the “who” of diagnosis. The second perspective looks at diagnosis as a fundamental individual and social event, that not only names a condition, but often determines the hopes, expectations, treatment options and cultural meanings associated with the disorder. In other words, this perspective collectively addresses the “why” dimension of diagnosis.

By drawing on both of these, and thinking about them in combination, I want to introduce a third focus we might wish to adopt —one that is touched on by some of the contributions, but perhaps not explicitly so. I want to suggest some of the ways in which diagnostic practices are as much about “containing” as they are about “identifying”. By this, I mean that the intrinsically social and material processes of diagnosis do not simply uncover a pre-existing disease, but make it present through acts of discrimination and demarcation. This is not a new point of course, and has now become a central argument of more STS-informed research, such as that by MOL (see for example, MOL, 1999) and those influenced by her work. But here I want to argue it has the potential to stimulate medical

anthropology to do much more than highlight the more obvious ways in which cultural meanings are ascribed onto a biological reality, to include the ways in which forms of ill health are continuously delineated and acted upon in order to bring them in to the world as discrete entities. The consequence of this is that it can broaden the scope of our ethnographic enquiry beyond focussing on “who” and “why”, to also include the “what” itself. This, then, is a call to go beyond simply addressing how conditions might be socially constructed, which arguably has now become such a tired term that it offers little in the way of cultural insight or critique (HACKING, 1999), to emphasise how diagnosis is, ultimately, the process of “making up” disease. As a result, in addition to the more traditional concerns—such as how power and meaning might be articulated through diagnostic practices via the body of a patient—precisely how diseases emerge as biological entities is itself both a political and ethical matter.

Over the years, many studies have focused on biomedicine’s classification of disease - how categories come and go, split or collapse into each other —and the different kinds of evidential practices drawn on in these processes (see for example, CAMBROSIO, KEATING, SCHLICH *et alii*, 2006; TIMMERMANS, BOWKER & STAR, 1998). The point about any classification system, in the abstract at least, is that everything should fit together; individual entities should be unique and universal, and no element should overlap with another (TURNBULL, 2000). The overall taxonomic system is thereby understood as an exercise in segmenting an existing, singular, stable world. So it is not surprising that spatial analogies are everywhere in biomedical accounts of disease; the literature is full of references to mapping, pathways, routes, entry points, structures, regions, zones, even “archipelagos” —all reinforcing the root territorial metaphor which not merely helps organise and explain, but actively shapes how individual diseases are conceived, and hence what the work of diagnosis should be.

Of course, we are all too familiar with anatomical and pathological representations that follow on from a very particular gaze to establish where precisely a disease is located; one only has to think about latex models that point to *The Islets of Langerhans* within the pancreas as the location of Type I diabetes, or illustrations of cholesterol deposits within the major arteries as constituting the location of ischemic heart disease. What is key, though, is that it is the stance of the observer that determines the position, and nature, of the observed (CARTWRIGHT & CROWDER, 2017). In addition to such depictions, the very same diseases are also

routinely plotted on to geographical and political maps to represent such things as rates of incidence, prevalence or differential distributions that betray entrenched social health inequalities (see for example GATRELL, POPAY & THOMAS, 2004). The result is that diagnosing a specific condition serves to mark out a terrain not only “in the body” but also beyond it: In other words, locating a disease and demarcating its borders not only happens in terms of which specific part of a body might be affected, or even what whole-body physiological system might be disrupted, but also pertaining to what groups of people, what social circumstances, and what populations. The biomedical “what”, then, does not solely refer to organs and tissues within a body, but also beyond the body, to include its distribution and characteristics throughout the environmental plane. As a consequence, diagnosis frequently takes place across a very heterogeneous terrain, drawing together such things as bodily signs, subjective accounts and epidemiological trends, in order to solidify some sense of the disease that occupies a unique position in this multifarious space.

However, there are currently at least two major forces emerging within biomedicine that have the potential to unsettle this general sense of ordering and the underlying logic of segmentation. In the face of these, diagnostic practices are increasingly straining to maintain the idea that diseases can and do exist discretely, and that they have their own unique aetiology, distinctive pattern of symptoms and differential procedures. The result is that some diseases, at least, have already become surprisingly fragile objects as they jostle alongside each other in the clinical landscape, potentially blurring boundaries in a world that increasingly presents itself as complex, fluid and unstable. The first threat to the traditional organisation of disease is the direct result of contemporary post-genomic research. Proponents argue that these new forms of knowledge, many of which are driven by technological advances, will result in greater diagnostic precision, more accurate prognosis and new forms of treatment. Take the following proclamation:

With the complete sequence of the human genome a reality, and with a growing body of transcriptomic, proteomic, and metabolomic datasets in health and disease, we are now in a unique position in the history of medicine to define human disease precisely, uniquely, and unequivocally, with optimal sensitivity and specificity (LOSCALZO, KOHANE & BARABASI, 2007).

The central argument the authors present is that any gaps or uncertainties in the “old system” —especially between consolidating

clinical with biological knowledge— will eventually give way to definitive evidence from new fields of science, and hence that increased granularity will lead to more precision and clarity of the boundaries of individual diseases. Now, I do not question the sincerity or enthusiasm expressed in such a project. But I do doubt that the quest will be quite so straightforward. Indeed, already within both neuropsychiatry and physical medicine, new forms of knowledge and evidence are arising that simply do not fit into the old systems of classification. For example, attempts to demonstrate the underlying pathology of schizophrenia through brain imaging studies are not merely suggesting neuroanatomical correlates and specific “abnormal” activity patterns of certain regions of the brain, as might be expected, but are increasingly suggesting different and more particular ways to conceive of the condition, causing some to question the utility and uniqueness of the original disease classification itself (PANTELIS, YÜCEL, WOOD *et alii*, 2005). It is as though the biology, as it is being revealed through these new techniques, is emerging somewhat differently to the way the world had been understood and organised previously. The rise of new technologies and ways to conceive pathology may well introduce greater detail, but with that detail comes greater complexity, and in turn, new areas of ambiguity and ambivalence are almost inevitable. Although one might assume that the straightforward response is to split and subdivide existing categories, instead something far more fundamental is happening, whereby the very way in which categories are established at all is being questioned.

The second major force that is being exerted on the current way biomedicine conceives diseases, and hence what practices of diagnosis must entail, could be said to be happening in the opposite direction across the borders of existing disease entities. Rather than trying to understand current disease objects in greater and greater detail, a parallel trend is demanding a broadening of scope, to understand how they might intimately relate to each other. In an era when people are both living longer and are suffering from a greater number of non-communicable diseases globally, the rising prevalence of what is generally called *multi-morbidity* is presenting itself as a growing problem for medical care. Although sometimes used interchangeably with the term co-morbidity, multi-morbidity simply refers to the increasingly common occurrence of people living with more than one condition. This is obviously challenging the existing provision of healthcare resources and often requires intricate medication regimes. But, in addition, simply keeping individual diseases

distinct is becoming harder and harder to do (MANGIN & JAMOULLE, 2012). This is not only because they frequently need to be addressed in parallel, but because the conditions, therapies, and side effects commonly interact with each other.

In a much-cited paper published over 40 years ago, the clinician FEINSTEIN, originator of the disease-illness distinction, already foresaw that:

problems of classification of human illness were not particularly important in the days when so much epidemiological and clinical science was concerned with epidemics of acute infectious disease... But the problems have become major barriers to scientific progress in the modern era of chronic diseases, which have diverse clinical spectrum and a multiplicity of associated ailments (FEINSTEIN, 1970).

The current trend is that new, broader categories are regularly being employed to encompass this clustering of conditions that FEINSTEIN alludes to. Often these new constellations still make sense to current biomedical understanding and the existing classification of conditions. For example, following large scale longitudinal studies, the term “cardiovascular disease” is ever more used as an overarching category to encompass such things as hypertension, angina, atherosclerosis and heart disease (see KANNEL & MCGEE, 1979). Similarly, obesity, glucose intolerance, high blood lipids and elevated blood pressure are now often grouped under a generalised “metabolic syndrome” label, not simply because they are frequently associated together, but because in combination they raise the risk of Type II diabetes and coronary heart disease (ALBERTI, ZIMMET & SHAW, 2005). This use of broader clinical categories is not without controversy, of course, especially given the strategic role the pharmaceutical industry often play in these formulations, but the medical community is largely agreed that this is an appropriate way of acknowledging the reality of a constellation of conditions.

However, some examples of multi-morbidity are more problematic for the current biomedical paradigm to make sense of, and are thereby much harder to contain within the current understanding of what goes where, and how things relate. For example, Type II diabetes is statistically associated with clinical depression (ROY & LLOYD, 2012). It is not that one can be said to cause the other; large-scale studies have shown that being first diagnosed with depression does not increase the likelihood of becoming diabetic, and that having diabetes does not then lead to depression. As one clinician hesitantly told me, “They seem to go together. But we don’t know

why. I mean, they go together, but they shouldn't..." The problem is that by initially thinking about each disease as a separate entity, occupying its own territory, means that when they are regularly seen occurring alongside each other demands that they are understood as somehow being causally related. It is not surprising that a major line of enquiry has been to discover potential interactions between conditions that originally were conceived of as distant and unconnected. Lab scientists, clinicians, epidemiologists, statisticians, and others are now broadening their gaze and enlisting new elements, such as psychosocial variables that might trigger a biochemical stress response, or burdens on the immune system might radically alter hormonal activity. Despite these attempts, establishing any coherent and agreed understanding is failing to establish any definitive causal directions behind these increasingly common associations.

Perhaps as a response, such instances are frequently described as "complex", referring to the fact that they require multiple diagnoses, and multiple treatments at the same time. As one doctor told me, "we are increasingly having to deal with complex cases... complex patients...." But complexity is not an inherent feature of the world; rather, it is assigned by the observer in an the attempt to divide, separate, act and maintain a particular version of it. So by describing both cases and patients as "complex" can be interpreted as serving a very specific purpose – a pragmatic tactic to hold on to the existing biomedical world, and ultimately keeping diseases distinct by simply describing them as intertwined. The problem is that certain conditions appear to have a relational affinity with each other, which may never be able to be reduced to material causation, precisely because of their original partitioning. The result is that in combination they seem to manifest unique and emergent issues, that not only are novel and perhaps unpredictable, but have the potential to undermine the distinct nature of diseases from which the notion of complexity and multiplicity arises.

My general point —from both the challenges arising from greater details accumulated about specific conditions, and the challenges of trying to relate conditions that were once thought of as distinct— is that these processes cannot be simply conceived of in terms of lumping and splitting. The emerging categories do far more than merely circumscribe existing biological understandings of individual diseases; beyond merely a label, these new ways of ordering actively determine the nature of biological knowledge that is deemed applicable and germane. But I do not want to

end this discussion by suggesting that these difficulties of locating and discriminating different diseases arise without reference to real-world specificities. Rather, the very sense that there is an underlying logic is itself always the product of everyday practices, many of which are so routine and commonplace that they simply do not get acknowledged. And so it is here that anthropology has a particular role to play—to highlight the ways in which everyday social life serves to reproduce and reaffirm a sense of order. For example, with the continual division and multiplication of categories, and in the face of rapidly diminishing healthcare resources, one response in the UK has been the controversial strategy not only that general practice consultations should not only average 10 mins, but a “one appointment, one problem” policy. This was an attempt to stop those people who would regularly come with a long list of problems and block the system for everyone else – so called “repeaters”. But the act of an apparently innocuous poster on the waiting room wall that mandated this to patients meant that they too had to be complicit in the process of selecting and partitioning prior to their encounter with a doctor. This points to the fact that the commitment to discrete diseases not only establishes borders and boundaries, but demands ways to navigate, enter and pass through entry points and discrete zones.

I implied at the beginning that diagnosis, as it is currently practiced within biomedicine, is highly productive—in that the very reality of a disease emerges from the interactions of different people, the meanings that they assign, and the undoubted materiality of the body. And there is no doubt that a focus on diseases as biological things, rendering them as fixed, stable and located, has proved very useful. But I want to ask, at what costs? And what have been the limitations of this approach? In this volume several of the papers are already grappling with these questions, not only through a focus on the practices of biomedicine, but also the role of patients, their relatives, other health professionals and alternative healthcare providers. By exploring the wide range of people that are often involved, and their different understandings and representations of ill health and particular conditions, the notion that there is a definitive, and stable, disease object at the centre is unsettled. Here, I have simply taken this line of thinking just a little further, to question the very “reality” of discrete disease entities, not in terms of their manifestations in the present—which are often all too apparent and fleshy—but in terms of them existing as entities independent of those forces which produce them.

Looking both in terms of what falls within the territory of a disease, and how the boundaries of different territories might be blurring, I have proposed that the old logic of segmentation is increasingly under strain. Currently, diagnostic practices may well still be trying to circumscribe the old boundaries and defend the traditional way of ordering. But as a result, there seems to be little opportunity to escape its current constraints, and allow for different ways of thinking about ill health that might draw on different kinds of evidence, different approaches, and alternative ways of thinking about the living, and the failing, body. So perhaps as a beginning it falls to us as anthropologists to intervene, and find ways to avoid reproducing the spatializing way of thinking about disease entities and their boundaries that inevitably reproduce ideas of difference and contrast. We must instead listen, and recount, how people articulate their own experience and relate to their conditions as intrinsic and legitimate aspects of the lives they live.

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MEDICAL ANTHROPOLOGY AT HOME PUBLICATIONS

Medical Anthropology at Home: creating distance, E. VAN DONGEN & S. FAINZANG (eds), *Anthropology and Medicine*, Vol 5, n°3, 1998.

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Emerging Socialities in 21st Century Health Care, HADOLT B., HARDON A. (eds), Amsterdam: Amsterdam University Press, 2017.

Diagnostic procedures are emblematic of medical work. Scholars in the field of social studies of medicine identify diverse dimensions of diagnosis that point to controversies, processual qualities and contested evidence. In this anthology, diagnostic fluidity is seen to permeate diagnostic work in a wide range of contexts, from medical interactions in the clinic, domestic settings and other relations of affective work, to organizational structures, and in historical developments. The contributors demonstrate, each in their own way, how different agents ‘do diagnosis’, highlighting the multi-faceted elements of uncertainty and mutability integral to diagnostic work. At the same time, the contributors also show how in ‘doing diagnosis’ enactments of subjectivities, representations of cultural imaginaries, bodily processes, and socio-cultural changes contribute to configuring diagnostic fluidity in significant ways.



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