Migraine as text – text as migraine: Diagnosis and literature

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Chapter 3

Migraine's existence in discourse

> Parallel to the processes by which symptom-clusters gain recognition as specific entities are the equally complex strategies with which clinicians and others try to legitimize the existence of these entities
>
> Robert A. Aronowitz, 2001

> Our pain, now officially emptied of meaning and merely buzzing mindlessly along the nerves, is the product of its own specific modern history
>
> David B. Morris, 1991

> We are doomed historically to history, to the patient construction of discourses about discourses, and to the task of hearing what already has been said
>
> Michel Foucault, 1994

There is no objective biological test for migraine, although great efforts are being made to create such tests (Winther Schytz and Olesen 2016). A diagnosis of migraine cannot be proven with a scan, blood test or EEG.[26] Also neurological examination during and outside attacks is usually normal and therefore only contributes to the diagnosis by showing no abnormal signs. As migraine patients tend to visit their doctors almost always outside an attack, a diagnosis of migraine can solely be made based on the words with which they recall their past experiences. Many patients, however, seem to be unable to give an accurate description of their past complaints. They often underestimate, for example, how long they have had the headache attacks. Some 'even have to be reminded that they suffered these from childhood' (Schiller 3). Nevertheless, they must be appropriately 'read as a text' to get a diagnosis and treatment, as argued in the previous chapters. In this context it is problematic that different patients use a broad spectrum of descriptions for their pain, so it seems that no general linguistic rules may be applied. The metaphors used to describe headache vary from stabbing, pulsating, pressing or dull, to 'a stone on the head', 'a birds' nest', 'a coin', 'an explosion', etcetera. These signifiers of headache (used to describe the remembered pain) do not refer to 'real' objects in reality (such as a real explosion or birds' nest) but are metaphors in which two signifiers are connected to one signified. However, based on the sparse, remembered and metaphorical

[26] 'EEG' stands for electroencephalogram, an electric investigation of cerebral function. This method of investigating the brain was discovered by the German psychiatrist Hans Berger (1873-1941) in the nineteen twenties (Stone and Hughes 2013). It is extremely useful in the diagnosis of epilepsy and certain infectious and degenerative diseases of the brain, but not at all in migraine.

information given, doctors worldwide make a diagnosis of 'migraine' and inform and treat their patients on this basis. In this process, they distinguish 'migraine' from, for example, 'tension type headache' or 'cluster headache', which are diagnoses that, like that of migraine, are based on the words of the patient. In the interpretation of the words of the patient, several choices must be made. Thus, meaning is produced rather than acquired (Moscoso 2).

According to Biro in his book *The Language of Pain*, 'if we're not sure about a word or concept, we ask another person for his judgement or we refer to some standardized set of rules or reference guide' (52).There are indeed internationally applied rules to make a diagnosis of migraine and other headache-types. These rules depend on an agreement. The tool that is broadly and inevitably (see below) used to translate the words of patients into a diagnosis of 'migraine', 'tension type headache' or 'cluster headache' is formed by 'criteria'. About these headache-criteria it is said that 'the main objective of a classification is to use a universal language when defining a disease or a set of disorders, to "make order out of chaos"' (Ramadan and Olesen 157). The criteria advise doctors about how to make a certain diagnosis in one patient and how to make another diagnosis in another one. Again, the criteria, and as a consequence the diagnoses they lead to, depend on an agreement. Meaning is produced. For example, according to the criteria the diagnosis of 'migraine' can be made when a patient tells having had at least five headache-attacks that lasted between 4 and 72 hours, that the pain has had at least two of the following characteristics: throbbing/pulsating, moderate to severe, unilateral, or worsened by activity. Furthermore, the pain was accompanied by at least one of the following two: nausea and/or sensitivity to sound, light or smell (International Classification of Headache Disorders 2013). As may be seen, these criteria are based on quantity ('five'), duration ('between 4 and 72 hours') and subjective complaints (such as the severity of pain, pain translated into metaphors, like 'throbbing/pulsating', nausea and sensitivity to external stimuli light, sound and smell). All of these factors have no reference in reality, except for the words of the patient. This leads to the question whether these criteria indeed lead to 'order out of chaos'.

In his landmark article "Taxonorics. Formulation of Criteria" (1970), Alvan R. Feinstein describes the principles of 'methods for coding data' (679). He mainly addresses the coding of data for use in (at that time very new) computers, but expands this to other fields, including medicine. This is probably one of the reasons why his article was published in *The Archives of Internal Medicine*. He points at the need for fixed criteria, as judgmental decisions are constantly made by research workers and practicing clinicians, but without contemplating, forming, or stating specific rules for the activity (682). According to Feinstein, medical ratiocination is in an 'amorphous state', and improvement of the scientific precision in reasoning came from improvements in the data and not specifically from the reasoning itself. In his opinion the process of clinical reasoning includes many categorical conversions (688). For him, 'the absence of criteria in contemporary medicine is particularly lamentable for the many decisions that are performed as arbitrary conjunctions, designations, or clusters that would require only consensual validation to support them' (690). Thus, he stresses the importance of consensus. He adds that 'although many appraisals of normality or interferences about diagnosis and prognosis are difficult to justify with rigor because the requisite external data are not available for substantiation, many other categories of clinical decision would require only an accepted agreement about their principles' (690). As example of a disease that benefitted from the using of criteria Feinstein describes 'rheumatic fever', of which he says that:

> it is not a morphologic entity and has no pathognomonic tests, its diagnosis is a matter of arbitrary decision, based on certain clusters and conjunctions of data. For more than a century, however, physicians made the diagnosis of rheumatic fever without stipulations of criteria; consequently, the case material of one physician could not be strictly compared with the cases reported by another. (690)

So, for a diagnosis that cannot be proven by objective tests, every doctor was using his or her own interpretations. It is not very hard to see that by replacing 'rheumatic fever' with 'migraine' the quote remains also true.

Feinstein takes his definition of 'criterion' from the Webster's New International Dictionary of the English Language as 'a standard on which a judgement or decision may be based' (682). The term 'taxonorics' is introduced by him as the domain 'that deals with the development of methods for coding data', basing the name on the Greek ταχις, arrangement, and ορει, to assign (679-680). Importantly, he points at the fact that the making of criteria includes selection, choice, conversion of data, construction of data, principles of justification, consensual validation and specification of purpose, among other factors. He mentions the importance of 'designation', in which 'an arbitrary name is given to a collection of information for which a categorical "value" is needed' (686). 'Migraine' is a good example of such an arbitrary name given to a collection of information, or, to use the Wittgensteinian 'beetle' again, we let an outsider look in a number of boxes and accept that he or she claims to see a similarity in the beetles, which he or she then gives a name.

Due to their nature of an 'agreement' and not that of a biological test, criteria are subjected to choices, interpretation and sometimes even to ideology or politics. There is always the possibility of 'wrong' choices, selection and principles of justification. As such, criteria strongly resemble the basis of a 'discourse', and this may also be the case in migraine. Therefore, the main research-question of this chapter is: Is so-called 'migraine' a designation or diagnosis that reflects reality, or is it only to be seen as a 'self-fulfilling prophesy' of the agreements made about it by its criteria/discourse? To answer this question, I will first delve into the notion of what a discourse is, and how I can make use of it here.

> Among the many ways of producing a representation of the world, or of representing it, are asserting a sentence, having a thought, expressing a belief. What these acts have in common is that they can be assessed for correctness or incorrectness according to how the world is. For what is produced (the representation) will have content, *that* things are thus and so, and it will be correct if and only if things are indeed thus and so. If they are, we shall say that the representation is made correct by the state of affairs which consists of their being so
>
> Adrian William Moore, 1987
> (emphasis in the original)

> People do things with words (e.g. blame, accuse, excuse, disclaim, etc.) and they construct versions of reality in conversation with others
>
> Carla Willig, 2000

What is discourse?

The French philosopher Michel Foucault proposed an influential theory about discourse, which he called 'a dissociation from structuralism' (*Archeology* 199). The discourse theory goes a step further than the linguistic theory of 'signified' and 'signifier' or 'denotation' and 'connotation' of, respectively, Ferdinand de Saussure and Roland Barthes. Whereas structuralism dealt with meaning, the discourse-theory describes the collective *production* of meaning. As Foucault expresses it, post-structuralism is 'something other than to play with the structures of a language' (209). His emphasis is that by producing meaning language also creates 'reality'.

To define 'discourse' is not possible in a straightforward way. As Julianne Cheek (2004) explains, 'there are diverse and numerous definitions of discourse'. She gives some examples of definitions from various disciplines, such as 'various methods, the structural features and relations which characterize these linguistic constructions' (1141), 'a system of statements which construct an object' (1141), or 'a group of ideas or patterned way of thinking which may both be identified in textual and verbal communications and located in wider social structures' (1142). For Foucault, 'a discourse provides a set of possible statements about a given area, and organizes and gives structure to the manner in which a particular topic, object, process is to be talked about' (1142), or reworded somewhat by Stuart Hall in his book *Representation*: 'a group of statements which provide a language for talking about – a way of representing the knowledge about – a particular topic at a particular historical moment' (Hall 29). An important aspect of all definitions is that discourses 'construct' and even 'order' reality in a certain way (Cheek 1142).

In this sense, they parallel the criteria of headache. As criteria, discourses include and exclude, they form the way of thinking or the state of knowledge at any one time. Foucault also defines 'discursive practice' as:

> It must not be confused with the expressive operation by which an individual formulates an idea, a desire, an image; nor with the rational activity that may operate in a system of inference; nor with the "competence" of a speaking subject when he constructs grammatical sentences; it is a body of anonymous, historical rules, always determined in the time and space that have defined a given period, and for a given social, economic, geographical, or linguistic area, the conditions of operation of the enunciative function. (*Archeology* 117)

Thus, Foucault makes a distinction between 'activities in a system of inference' and rules that are determined by a given period, which may be read in a certain context as the state of the art of the present scientific knowledge. Discursive practices define and determine. They include and exclude. And, again in the words of Foucault: 'The manifest discourse, therefore, is really no more than the repressive presence of what it does *not* say' (*Archeology* 25; my emphasis). Indeed, 'criteria also define what is *not* present' (Göbel 770; emphasis in the original). Discourses are based on choices

and rules, and thus one may ask 'what rules allow for the construction of a map, model, or classificatory system?' (Cheek 1142).

In his book *Birth of the Clinic* Foucault argues that classifications of diseases stood at the basis of the development of medicine. Of this, he gives some historical examples:

> From the *Nosology* of Sauvages (1761) to the *Nosography* of Pinel (1798), the classificatory rule dominates medical theory and practice: it appears as the immanent logic of morbid forms, the principle of their decipherment, and the semantic rule of their definition. [..] But at a deeper level then this spatial "metaphor", [..] classificatory medicine presupposes a certain "configuration" of disease: it has never been formulated for itself, but one can define its essential requisites after the event. (*Birth* 4)

In such a system sometimes a set of common assumptions may be taken so for granted as to be invisible or assumed. In other words, one may lose sight on the alternatives and the reasons for some of the choices made. Or, to go a step further, 'texts not only represent and reflect a certain version of reality, they also play a part in the very construction and maintenance of that reality itself' (1144). This may be seen in the light of a general human need, as 'one of the deepest and most urgent philosophical questions is that of how much, in our representation of the world, is perspectival' (Moore 4). Paul Ricoeur argues that:

> whereas the signs in language refer only to other signs within the same system, and whereas language therefore lacks a world just as it lacks temporality and subjectivity, discourse is always about something. It refers to a world which it claims to describe, to express, or to represent. It is in discourse that the symbolic function of language is actualized. (Ricoeur *Model* 92)

It appears that he distinguishes between the Saussurean and Peircean meaning and signification of language and what language as discourse can produce in terms of reality.

Obviously, the urge to name and classify stems from the human need to provide order. Unfortunately, however, this urge often may have negative effects, as 'discourse is precisely what blocks new thought, and prevents us from thinking otherwise' (Johnston 807). The discourse will become the paradigm and will make a paradigm shift very difficult. This is – in my opinion – the matter with 'the discourse of migraine', as I will explain below.

> Discourse analysis has allowed us to explore the way in which 'health' and 'illness' are constructed through language
>
> Carla Willig, 2000

> The classificatory systems change with new knowledge or understanding, but they begin in an attempt to locate phenomena in a systematic way
>
> Carol A. Bowman, 1992

Medical discourses

Maybe it is difficult at first sight to see how discourses may be important when we are dealing with biological processes such as diseases and the way how these affect patients. Medicine is about making the best conclusions and decisions concerning a patient's health. One of the reasons why discourses play a role here is that natural and biological processes are not 'fixed' and often depend on interpretation. As phrased by Charon (1992), 'medical practice relies on the incantation, the word that seems to have power by virtue of being said' (*Build a Case* 115), and to quote Foucault again:

> clinical medicine is certainly not a science. Not only because it does not comply with the formal criteria, or attain the level of rigor expected of physics, chemistry, or even of physiology; but also because it involves a scarcely organized mass of empirical observations, uncontrolled experiments and results, therapeutic prescriptions, and institutional regulations. (*Archeology* 181)

Thus, in Foucault's opinion, medicine depends on shared opinions and therefore on a discourse that is haronbased on general, controlled investigations, restrictive regulations and, finally, subjective observations. When we accept that 'every representation is always a representation from some point of view within some frame of vision' (Brown 188), the diagnosis made by doctors can be seen as emerging as something that is simultaneously certain and uncertain, fixed but also chaotic. Except for the so-called 'evidence-based medicine', which exists only between very narrow borders and must apply to very strict rules, diagnoses and diseases are conceptual entities. They 'have been extrapolated from an aggregate of similar illnesses on the basis of what is thought to be common to the illnesses so classified' (Fleischman 7). It has even been said that patients visiting a doctor face two dangers: 'to fall into medical discourse or to escape to a view of illness as a metaphor' (Rimmon-Kenan 246). In both options, patients are subject to linguistic and discursive constructions. Kathryn Vance Staiano (1982) points at the fact that 'since the symptom gains meaning only through its transformation by the physician, the emphasis is on the "correctness" of the physician's interpretation' (332). And in this interpretation, unfortunately, much can go wrong. The risks of such interpretation are formulated by Pethes as follows:

> Medical texts are no mere carriers of knowledge, but play a constitutive part in the process in which an observation becomes a scientific fact by following certain argumentative and narrative patterns as well as by generating a scientific community that shares the same texts through letters, journal articles, and textbooks. (24)

This indeed is a description of what one may call a 'medical discourse'.

One may question how bad such a discourse is for the patient. On the one hand, to fall into a medical discourse seems a negative option, as it determines, excludes and does not give space to alternatives. On the other hand, being treated according to criteria, protocols, articles and scientific texts seems to be the best choice a patient can make. But, how 'scientific' are these scientific texts? According to Foucault, 'the doctor has gradually ceased to be himself the locus of the registering and interpretation of information, and because, beside him, outside him, there have appeared masses of documentation, instruments of correlation, and techniques of analysis, which, of course, he makes use of, but which modify his position as an observing subject in relation to the patient' (*Archeology* 33-34). In other words, patients are better off with criteria (discourse) than with doctors. It still

seems, however, a choice between negative options. To illustrate these options, here, some examples of such medical discourses, that highlight three aspects of the force of discourse, will be given.

Daneski, Higgs and Morgan (2010) describe how epistemological shifts in medicine have shaped the history of so-called apoplexy and stroke. The term 'apoplexy' comes from the Greek 'apoplexia', which means 'struck, as though by a thunderbolt' (Quest 440). The term was used originally to describe a number of conditions in which consciousness was lost and later specifically for certain cerebrovascular disorders (Tsoucalas et al)[27]. At present, it is still sometimes used for a hemorrhage (bleeding) in the so-called 'basal ganglia' (deep structures in the brain), most often due to high blood pressure. The word 'stroke' is related to the word 'struck' and implies the sudden loss of the senses, paralysis, and the terror so engendered (440). The term thus refers to something which affects a sufferer suddenly, as a 'stroke'. At present, it is used in a broad sense for every cerebrovascular accident in the brain (such as a bleeding or an infarction). The World Health Organization defines a stroke as 'rapidly developing clinical signs of focal (at times global) disturbance of cerebral function, lasting more than 24h or leading to death with no apparent cause other than of vascular origin' (Hatano 541). Daneski, Higgs and Morgan (2010) have investigated which biomedical discourses have played a role in stroke and apoplexy. Basing themselves on a historical analysis they conclude that the discourse of apoplexy/stroke changed the topic 'from a disease with a gloomy prognosis to a condition for which greater expectations [..] are expressed' (370). The favorable expectations, however, were not based on a new cure or treatment, but on 'better organization of services' (370). In other words, the change was not caused by 'reality', but by an artificial discursive shift from 'gloomy' to 'great expectations'. The authors discuss how Foucault in *The Birth of the Clinic* analyzed the way in which medical theories developed in relation to changing beliefs, and how 'medicine was based on ordering a new medical language that translated symptoms into signs' (372). They describe how Foucault mainly conceptualized medical practice as the 'medicine of spaces'. First, the open space outside the body was important. Second, the 'seat' of disease was identified through its location in the body. Third, the patient was moved to 'closed spaces' (hospitals et cetera), to be 'observed' by the medical 'gaze'. As fourth – post-Foucauldian – space one may (as the authors suggest) propose 'a new "clinical gaze" that penetrates the cavities of the living brain', mainly by means of CT and MRI (378). The message of Daneski, Higgs and Morgan is that discourse can shape medical topics by (the choice of) words, based on institution, practices and technology.

The former case uses words and practices related to clearly noticeable bodily phenomena to build an argument within the limits of a discourse. It is, however, also possible that a discourse is built around a phenomenon that is not seen 'from the outside'. In their article "Signification and Pain: A Semiotic Reading of Fibromyalgia," John Quintner and colleagues discuss such an aspect of discourse. The term 'fibromyalgia' is used for a syndrome that combines chronic muscle and joint pain with fatigue and mental complaints that have no other explanation. It is a diagnosis of exclusion surrounded by controversy and stigma. The diagnosis is often made by patients themselves and not by physicians. Quintner and colleagues stress that pain lacking a detectable underlying structural lesion challenges the 'biomedical mind-body discourse' and argue that in such a case a diagnostic labeling is a 'vulnerable interpretative endeavour', often not leading to more than the giving of a name. To

[27] Cerebrovascular disorders are diseases caused by abnormalities of blood vessels, such as rupture leading to a hemorrhage or occlusion leading to an infarction.

illustrate their point, they discuss the diagnosis of 'fibromyalgia' as a construct that 'sought to define a discernable reality outside the play of language' (345). In their opinion, this process, however, 'failed both clinically and semiotically' (345). The authors point at the fact that when the relationship between symptoms and signs is uncertain, often concepts or constructs are communicated by language and in texts. Then, recurring clinical patterns are assigned the status of syndromes. In the case of fibromyalgia, the symptoms (without signs) were so inclusive that they constituted 'a tautology' and thus became meaningless (347). For them, the diagnosis of 'fibromyalgia' was constructed through discourse.

In his article "Illnesses You have to Fight to Get: Facts as Forces in Uncertain, Emergent Illnesses" (2006), Dumit gives some other illustrations of how discourses are used to make diagnoses on symptoms alone. He describes the cases of 'chronic fatigue syndrome' and 'multiple chemical sensitivity'. Both syndromes lack conclusive biomarkers, tests or consensual objective criteria for their definition, and they are very '"emergent" and "contested" illnesses precisely because they have names but not codes' (579). Problematic is 'the intense interplay between diagnosis and legitimacy: without a diagnosis and other forms of acceptance into the medical system, sufferers are at risk of being denied social recognition of their very suffering and accused of simply faking it' (578). The author summarises the discursive characteristics of these two illnesses, which may be easily applied to a large number of similar illnesses/diagnoses:

1. They are chronic conditions and share with other chronic conditions the difficulty of fitting acute disease models of treatment, the sick role, and the determination of health care costs.
2. They are "biomental": their nature and existence are contested as to whether they are primarily mental, psychiatric, or biological. They are causally undetermined: their etiology is likewise contested as to social, genetic, toxic and personal possibilities.
3. They are therapeutically diverse: the nature and reimbursement of competing therapies, including alternative medicine is wide open.
4. They have fuzzy boundaries and are each cross-linked to other emergent illnesses as subsets, mistaken diagnosis, and comorbid conditions.
5. They are legally explosive: each condition is caught up in court battles, administrative categorization and legislative maneuvering. Disability status, for instance, is haphazardly applied. Therefore, they are highly contested: the stakes are high, and many of the players have significant resources. (578)

These five characteristics define a group of diagnoses that exist because 'the reductionist framework of biomedicine encouraged physicians to create functional diseases (such as fibromyalgia, chronic fatigue, and irritable bowel syndrome) to explain symptoms, oblivious to the fact that this rendered the process of diagnosis tautological: disease was diagnosed by its symptoms and those symptoms were explained by the disease' (Bourke *Story* 137).

Thirdly, 'medical' discourses may go beyond the scientific/medical to the ideological. An example of such a situation in which a 'disease' was ideologically constructed by discourse is the diagnosis of 'hysteria', of which Foucault writes:

> In the face of general paralysis, hysteria was "bad madness": there was no fault that could be identified, nothing organic to be blamed, no possible communication. The general

> paralysis/hysteria duality marks the extremes of the domain of psychiatric experience in the twentieth century, the perpetual object of a double and constant preoccupation. It could and should be demonstrated that explanations for hysteria (up to and excluding Freud) were all taken from the model of general paralysis, but the model was purified, made more psychological and more transparent. (*History* 643)[28]

Foucault thus uses the case of hysteria to show that a construction of thoughts about a certain disease was built upon interpretations and the application of models. In his book *The Culture of Pain*, David B. Morris describes in the chapter 'Hysteria, Pain, and Gender' the rise, fall and 'near disappearance' (103) of the 'constructed' diagnosis of hysteria. As the author states: 'hysteria, both ancient and modern, provides important evidence that pain is constructed as much by social conditions as by the structure of the nervous system' (104). The term 'hysteria' referred to the uterus or to the 'wandering womb', symbolically seen as an animal lingering within the female body (Foucault *History* 283-284). Foucault cites a text of the 17th century English doctor Thomas Willis from his book *Of Convulsive Disease* (1667) about this topic:

> The hysterical passion is of so ill fame, among the diseases belonging to women, that like one half-damn'd, it bears the faults of many other distempers. For when at any time, a sickness happens in a woman's body, of an unusual manner, or more occult original, so that its cause lies hid, and the curatory indication is altogether uncertain, presently we accuse the evil influence of womb (which for the most part is innocent), and in every unusual symptom, we declare it to be something hysterical. (Willis, cited by Foucault 278-279)

Hysteria was often diagnosed in virgins and widows, and according to Morris this diagnosis 'tells us as much about male doctors as about female patients' (*Culture* 108). The diagnosis is even called 'an assault against women, conducted [..] in the name of science' (108). Pain was considered one of the hallmark symptoms of hysteria (Merskey *History* 158). Remarkably, 'at issue was the question whether a woman's pain was real' (Morris *Culture* 112). On the other hand, another hallmark symptom was numbness (feeling nothing) which emphasized the protean, 'positive' and 'negative' aspects of the disease (Slater 1395). As treatment, hysterical patients 'were confined to bed, completely isolated from friends and family, fed a high fat diet around the clock, forbidden any form of activity, even reading or sewing, and regularly subjected to edifying lectures on women's household and moral obligations' (Morris *Culture* 113). They were allowed 'but two hours' intellectual life a day' (113). The patriarchal nature of these measures may easily be seen; 'hysteria was in part a response to social conditions that particularly oppressed and constricted women' (120).

Remarkably, as late as in the nineteen sixties Eliot Slater (1965) still had to prove that 'hysteria' did not exist. In his articles and lectures, he argued that:

> the only thing that "hysterical" patients can be shown to have in common is that they are all patients. The malady of the wandering womb began as a myth, and a myth it yet survives. But, like all unwarranted beliefs which still attract credence, it is dangerous. A diagnosis of "hysteria" is a disguise for ignorance and a fertile source of clinical error. It is in fact not only a delusion but also a snare. (1399)

[28] The 'general paralysis' in this quote refers to the so-called 'general paralysis of the insane', a devastating form of insanity caused by the venereal disease syphilis (Davis 266). A synonym is 'dementia paralytica'.

He emphasized that virtually all patients with a diagnosis of 'hysteria' in the end received a neurological diagnosis after a thorough examination, and therefore advised to avoid the term (1396). His thoughts have, however, been seriously critizised. First, he was vehemently attacked by a Sir Francis Walshe, who describes 'Slater's nihilism in regard to hysteria' as an 'error' (1452). Walshe further argues that:

> hysteria commonly presents itself to our observation as a mimesis or as a caricature of disturbances on the physiological and morphological levels, and thus the psychiatrist is apt to encounter it only after a first clinical study has indicated that the presenting phenomena do not require an explanation on these levels, and also, what is not less characteristic, that they are not congruous with what is possible and known to occur on these levels. (1452)

Here, the 'possible and known' refer to the medical possibilities and knowledge at that time (1965), and these also depended on the discourse of medicine. More recently, Slater again was criticized in an article called the "Myth of the Non-Existence of Hysteria" (Stone et al., 2005). These authors first argue that so-called 'functional' disorders exist in which symptoms such as weakness remained unexplained by disease. The term 'hysteria' only is (has to be) replaced by terms such as 'functional weakness', 'conversion disorder', or 'psychogenic'. In another article called "The 'Disappearance of Hysteria: Historical Mystery or Illusion?" (2008), the same authors argue that 'it was not hysteria that disappeared, but rather medical *interest* in hysteria' (12; emphasis in the original). In their opinion, the disease exists, but only the terms to designate it have changed. Scheurich (2000) summarizes his thoughts on the topic by stating that 'all illness – not just that relegated to the limbo of the psychosomatic – is to some extent constructed by the belief systems of patients, the expectations of practitioners, and the surrounding cultural milieu' (465).

It may be argued that pain syndromes are very susceptible to 'discourse generation', as they often lack objective proof and depend on their translation into language. This language, therefore, is especially important in the making of meaning. Indeed, in their article "Making Sense of Everyday Pain" Aldrich and Eccleston, emphasize the 'importance of language and history in the construction of its meaning' (1631), where the 'its' means pain. Of this meaning, Morris wrote that 'pain in effect spends its existence moving in between the extremes of absolute meaninglessness and full meaning' (*Culture* 35). With regard to 'pain with meaning', he gives the obvious example of the important role of pain in religion, which is also the topic of Joanna Bourke's chapter called 'Religion' (88-130). Morris places chronic pain due to a chronic disease at the other end of the spectrum (meaningless). But, there, also meaning is produced, emphasized by Morris' quote that 'writers who describe something so inherently resistant to language must inevitably shape and possibly falsify the experience they describe' (*Culture* 3). This brings me to the discourse of how headache becomes migraine within – as labeled by Morris – 'the story of the modern reconstruction of pain' (*Culture* 4).

> It is, of course, possible to name, classify, and describe a phenomenon without any understanding of it at all
>
> Carol A. Bowman, 1992

> These boundaries are always at least somewhat arbitrary
>
> Sait Ashina et al., 2016

> It *is* a biological disorder that *is* non-objective, varying in time, subjective and ambiguous
>
> Joseph Dumit, 2006 (emphasis in the original)

Migraine as discourse

Of pain, it may be said that 'the message *is* the illness'(Morris *Culture* 74; emphasis in the original). Gilmore (2012) argues that 'pain discourse does more than offer descriptive language. It shapes the subjectivities, agencies, and embodiments of those compelled to engage with it. Language about pain is material in that it has the capacity to shape knowledge about pain' (85). So, what about migraine?

Descriptions of headache have been discovered in translations of Mesopotamian texts of more than 5000 years ago (Pearce *Historical*). Several studies and articles have made a diagnosis of 'migraine' based on these and many other of such very old texts by retrospectively applying the criteria proposed by the International Headache Society (see below). Historical terms for these headaches were 'hemicrania', 'heterocrania', hemigrainea', 'migranea', 'sick-headache' and 'hemikrania sympathicotonica' (Pearce *Migraine* 109; Pearce *Latham* 271; Foxhall *Migraine* 3-4). The term 'migraine' is said to originate from 'hemicrania', a term first mentioned by Galen in the second century and re-introduced in France in the late 12th century (Lardreau 32; Foxhall *Migraine* 3). The term was, however, since then not universally used as also terms such as 'cephalalgia', 'heterocrania' and 'megrim' were in common use (33). The latter term was even used as late as in 1873 by the English doctor Edward Liveing, who wrote an influential book titled *On Megrim*. 'Hemicrania' means 'half head' and refers to the (often) half-sided occurrence of the pain. As explained above in the description of the international criteria, for making a diagnosis of migraine, however, it is not strictly necessary that the headache is one-sided (unilateral), as the pain has to have 'at least two of the following characteristics: throbbing, moderate to severe, unilateral, or worsened by activity', which means that double-sided pain can still be diagnosed as 'migraine' as long as two of the remaining characteristics are fulfilled. However, the belief that 'migraine' has to be 'unilateral' has influenced the thoughts on migraine even to the present times, as many doctors still only diagnose migraine as it is 'hemicrania', one-sided. A detailed description of the history of migraine or its misdiagnosis lies not in the scope of this thesis, but important is that, linguistically, the disease (or constellations of symptoms) received a 'name'. From then on, doctors and patients knew what they were talking about. And, to apply Wittgenstein's metaphor: They now could look at the beetles in the boxes of other persons.

Without classifications, medicine would be 'helpless', as already emphasized by Feinstein in 1970 (see above). Nevertheless, 'formal disease taxonomies are highly plastic, evolving and changing continuously' (Kelly 92). Foucault gives an overview of the history of medical classifications, mainly of those on 'madness'. One of these, that of Johnston (1644), also included cephalalgia (headache), here described as one of the 'troubles of external senses' (*History* 192). At that time, these

classifications, according to Foucault, were 'an entirely empty activity', as they 'ultimately functioned as little more than images, whose value lay in the vegetal myth that they contained within them' (194). These early classifications may be qualified as 'pre-discursive' (Foucault *Archeology* 76), and of such 'pre-discursive' classifications, it may be said that they belong to the 'semi-silence' that preceded the present discourse (25). For example, in psychiatry, diagnoses are classified according to the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) and it has been said that before this manual, as 'mental disorders were only vaguely defined, the profession could conceal its ignorance' (Bowman 280). With the manual, the ignorance has largely disappeared or at least areas of ignorance are clear, and in addition there has been an explosion of scientific research (280). The DSM has proven to be 'a powerful heuristic for psychiatric inquiry and discourse' (280), but is still a discourse with artificial diagnoses.

After some preliminary attempts to classify headache (Foxhall *Migraine* 92-93), in 1927 a categorization was proposed into 'headaches with pain one can forget, those with pain one cannot forget, and those with pain that makes one forget everything else' (Dawson of Penn 207). The first 'modern' classification of the different headache types was proposed in 1962 (Friedman et al., 1962; Solomon et al., 2008; Foxhall *Migraine* 179). The authors did not restrict headache to 'head pain from brow level up', as was common in that time (to distinguish headache from facial pain), but they included 'both painful and nonpainful discomforts of the entire head, including the face and upper nucha', in which 'nucha' means 'neck' (127). As argument for their choice, they stated that 'since so much that a man describes as may be any abnormal head sensation, it is essential, for proper treatment, to determine whether the complaint is actually one of pain' (127). They did, however, not explain what is 'nonpainful discomfort of the entire head', or how to 'determine whether the complaint is actually one of pain'. Obviously, they included every discomfort a patient could be complaining about, thereby acknowledging that 'pain' has no reference in reality, and that every complaint of the patient is to be taken seriously. In their classification, which they based on 'pain mechanisms' (which were, however, largely unknown at that time), 'for convenience short and simple names' are suggested (127). Importantly, they stated that 'essential in the study of headache, in most instances, is an appraisal of its close link to the patient's situation, activities and attitudes. Sometimes obvious, but more often subtle, headache may be the principal manifestation of temporary or sustained difficulties in life adjustment' (127). In their view, headache is more of 'non-organic' than of 'organic' nature. Their classification included 'vascular headaches of migraine type', 'muscle-contraction headache', 'combined headache', 'headache of delusional, conversion, or hypochondriacal states', among others, their ideas, however, have not withstood the test of time.

The next classification was first published in 1988 (International Classification of Headache Disorders 1988), with updates in 2004 (International Classification of Headache Disorders 2004), 2013 (International Classification of Headache Disorders 2013) and 2018 (International Classification of Headache Disorders 2018). It has been described as a major breakthrough and one of the most important developments in the headache-field of the last hundred years (Tfelt-Hansen and Koehler, 2011). It has also been called the 'bible' of headache medicine (Tinsley and Rothrock, 2018). The Danish neurologist Jes Olesen was from onset the main force behind this classification. In the Preface of the 1988 classification, it is admitted that 'mistakes have inevitably been made', but also that it is expected that 'the operational diagnostic criteria published in this book will generate increased nosographic and epidemiologic research activity in the years to come' (9). Indeed, it is recommended 'to put it [the classification] into immediate use in scientific studies' (9). Next to the scientific use, the

authors expected that 'over the course of years it will probably influence the way we diagnose patients in our daily work' (10). They added that 'only patients who really have the disease should have the diagnosis, but on the other hand, all patients who really have the disease should fulfill the diagnostic criteria' (10). This raises the question what the 'really' meaning is in 'patients who really have the disease'. How is this reality defined? It seems no more than the words of the patients translated into the criteria. And how does one define 'disease' in this context? This defining is done on the basis of the criteria that are used to give a name to a disease. In combination with the second part of the sentence ('patients who really have the disease should fulfill the diagnostic criteria'), this becomes a self-fulfilling prophesy. This was recently illustrated in an article with Olesen as co-author. The article starts with the sentences 'Headache is a symptom in the main rather a condition. Only when headache-attacks fulfill specific diagnostic criteria consistently does a primary headache disorder occur' (Mitsikostas et al., 2016). Here, the occurrence of the headache even seems to depend on the criteria.

Important here might be Foucaults question 'Who has the power to make a discourse?' (*Archeology* 42). He stresses the importance of persons with authority in the process. This authority 'delimited, designated, named, and established madness as an object' (42) and the discourse of madness was 'made possible by a group of relations established between authorities of emergence, delimitation, and specification' (44). In other words, founders of discursivity are 'individuals whose ideas become so important that it is difficult to talk about a given domain without referring back to them' (Hodges et al., 564). Obviously, Jes Olesen may be seen as the authority in the process of making the criteria of headache.

Another issue of the International Classification is that the criteria do not classify patients but attacks, as:

> there is a fundamental distinction between classification and diagnosis. Classification refers to the systematic definition of a group of related disorders or to the development of diagnostic categories. Diagnosis refers to the assignment of an individual patient to a particular diagnostic category. (Ashina et al., 2016)

This choice is motivated by the arguments that the headache of a patient may change over lifetime and that patients may suffer from different types of headache. It is, however, impossible to diagnose 'all headache episodes in every patient', also because 'most patients have too many and cannot remember them sufficiently well' (International Classification of Headache Disorders 1988; 11). Thus, the classification made headache a self-fulfilling prophesy, rendering the different headache-types into 'things' with a name. The words of the criteria introduced a 'signified' and the question is whether this is a positive or negative development.

On the topic of giving names to diseases and defining criteria, John G. Scadding already wrote in 1967 that 'when we use the name of a disease in clinical diagnosis, we are referring to the whole complex of abnormal phenomena observed in a group of individuals selected because they present some stated common abnormality' (877).

The 'name' (signifier) is given to a combination of symptoms and signs (signified) 'which have been observed so frequently and be so distinctive that they constitute a recognizable picture' (877). The consequence of giving such a 'name' is, however, that:

> diseases are regarded as having some sort of independent existence, though the sense in which they can be said to exist is left conveniently vague by referring to them in such undefined terms as “events” [..] or “entities” [..] or by regarding them as attributes of the patient [..]. There has been much discussion of the taxonomy of diseases, as if diseases were objects like animals, plants, and bacteria, which can be dissected and analysed to yield features by which they can classified. (877)

This is exactly the purpose of defining criteria, to classify the features and make an ‘object’ of it, even if there are no ‘objective’ signs. There are many syndromes that are only definable in such terms, for which no biological test exists and in which the diagnosis is the endpoint of a process that is ‘no more than the resemblance of the symptoms and signs to a previously recognized pattern’ (879).

In her article “*I am* …, *I have* …, *I suffer from* …: A Linguist Reflects on the Language of Illness and Disease” (1999), the linguist Suzanne Fleischman reflects on her own disease (called myelodysplastic syndrome or MDS). This syndrome is very rare and only defined through criteria. She concludes that ‘MDS is a diagnostic construct, a product of definition or construction, which takes on identity in the clinical world *once it has a name*. This statement suggests, in turn, that it is ultimately a construct of language’ (11; emphasis in the original). The diagnosis is ‘to contain and thereby to control’ (13).

Obviously, another of Scadding’s ‘end-point’ diagnoses or ‘names’ that are based on the recognition of a pattern is ‘migraine’, which is also one of the diseases that has taken on identity in the clinical world once it had a name. One may argue that such an endpoint is necessary to go ahead (Schulte and May 2015), but also that it works contra productive (Shevel and Shevel 2014; Lane and Davies 2015).

The authors of the preface of the classification of 1988 advised to learn the general rules of the classification by heart. In the second edition of the criteria (2004), the advice to use the criteria scientifically was even put stronger, stating that ‘no journal should publish papers related to headache that are not using this classification and the associated diagnostic criteria’ (International Classification of Headache Disorders 2004). This ‘no journal should’ unmistakably is an index to discourse.

Thus, these criteria became the ‘truth’ of headache diagnosis. Indeed, the terminology of the criteria ‘gradually took root in the daily conversation and writing of the headache specialists (Solomon et al., 2008), without the possibility to escape. Although they were created to separate recognizable and ‘pure’ groups of patients for scientific investigations, they became also increasingly used to diagnose patients in daily practice. Thousands of scientific studies were based on the basis of these criteria, mainly published in devoted journals such as *Cephalalgia*, *Headache* and *The Journal of Headache and Pain* (Robert et al., 2010; Robert et al., 2016). In these publications, it sufficed to mention that the diagnoses were ‘made according to the criteria of the International Headache Society’ when describing the patient groups included. Indeed, as Lane and Davies (2015) write, ‘it would now be impossible to publish a paper on headache without referencing the ICHD-3 beta or reiterating the ICHD-3 beta criteria for the headache entity under consideration’ (1339). In the studies, a control of whether the diagnoses of the individual patients were correct was, however, never performed (and also was impossible from the point of view of the reviewers and the publishers of the articles). Medication trials and clinical and genetic studies were based on the semiology of the criteria; drugs were allowed to the market and only reimbursed by insurance companies when used for the ‘right’

diagnosis according to the criteria and studied in the 'right' trials. The sparse criticism arguing that there is no real scientific basis for the classification at all has largely been ignored (Shevel and Shevel 2014; Lane and Davies 2015). Nevertheless, the arguments of Shevel and Shevel that the required number of attacks, duration of headache, unilaterality, pulsating quality, severity of pain and aggravation by activity are insufficiently supported by scientific and clinical observations (not to speak of its self-fulfilling prophesy) seems sound. They were right in stating that the criteria were mainly based on opinions. Likewise, Lane and Davies argue that 'the ICHD-3 beta criteria have assumed a status that is not justified by evidence' (1339). It may be said that although the criteria are not the 'truth' they have produced the 'reality' of the headache patient. No doctor, scientist or patient can ignore the discourse produced by these criteria, based on opinions and in- and exclusions. In 2014, Olesen admitted that there are 'some problem areas' in the classification, but in the meantime also emphasized that there are 'no competing classifications' (Olesen *Problem Areas* 1193). Indeed, this is a dominant discourse. A paradigm shift as proposed by Shevel and Shevel in 2014 seems to be without a chance. Nevertheless, as described above for fibromyalgia, also migraine may be seen as a construct that 'sought to define a discernable reality outside the play of language'. Perhaps in the future, migraine will be diagnosed on more objective facts than words alone (for example genetic investigations).

According to Foucault, the discourse of medicine depends largely on the 'gaze', by which one selects what is considered to be relevant. For him, 'the clinical gaze has the paradoxical ability to *hear a language* as soon as it *perceives a spectacle'* (*Birth* 108). This 'new alliance between words and things, enabling one *to see* and *to say*' (*Birth* xii; emphasis in the original), consists in migraine mainly of the saying, and much less on the seeing. It is the words of the patient that are interpreted, after being selected by the diagnostician. Of course, the 'seeing' can play a (small) additional role, as for example also grimaces, gestures and choice of clothes contribute to the interpretation. Selection and interpretation of various signs thus make a separation between 'migraine' or 'non-migraine'. Ideally, 'the language used to discuss migraine should be scientifically accurate, reduce stigma, avoid bias and misperception' (Young et al. 2012, 2). Unfortunately, this is hardly the case. In addition, language has also the power to shape reality. In its extreme, 'there is a fatal tendency to be satisfied with words instead of trying to understand things' (Schopenhauer cited by Mintz 224) and 'we set up a word at the point where our ignorance begins' (Nietzsche cited by Mintz 224). The main problem is that language is necessary to give meaning to signifiers without reference in 'reality', such as the use of the word 'pain'. Language is necessary to understand reality, but also creates reality.

An important aspect of a discourse was that it may give 'labels'. It may give a thing a 'name', which then may 'obscure' the choices and interpretations that has led to that 'name' or 'label'. Staiano (1982) gives an example of such a situation:

> In Belize, the disease/illness label 'malaria' is employed by medical practitioners, ethnomedical healers, and lay persons alike. This utilization of a single term to refer to a specific set of signs and symptoms appears to represent a case of the *articulation of codes* and it does, in a limited sense, facilitate communication. However, examination of the full sign exposes the superficial nature of the equivalence. (340; emphasis in the original)

When in this example 'malaria' is replaced by 'migraine', the statement is also true. The term 'migraine' is used as well to describe a specific set of signs and symptoms, and likewise in migraine

the label reflects a wide range of possibilities. Important is not only what is included in the label, but also what it excludes (and why).

Another example of the use of such 'labels' is given by Foucault in his books *Archeology of Knowledge* and *History of Madness*. He describes how the medical discourse of classification determined the thoughts and practices on madness. Remarkably, most of his arguments are again also true for migraine. As in the example above (where 'malaria' was replaced by 'migraine'), in the following text, 'madness' may be replaced by 'migraine', and it remains as true as the original:

> The unity of discourses on madness would not be based upon the existence of the object 'madness', or the constitution of a single horizon of objectivity; it would be the interplay of the rules that make possible the appearance of objects during a given period of time: objects that are shaped by measures of discrimination and repression, objects that are differentiated in daily practice, in law, in religious casuistry, in medical diagnosis, objects that are manifested in pathological descriptions, objects that are circumscribed by medical codes, practices, treatment, and care. (33)

Mental illness is not an objective fact, and the same is true for migraine. They both became constructed as an object within a discursive formation. Among the aspects Foucault considers important for a discourse he mentions 'the determination of relations that make it possible to characterize a group (these may be numerical or logical relations; functional, causal, or analogical relations; or it may be the relation of the "signifier" (*significant*) to the "signified" (*signifié*)' (11; emphasis in the original). Of the process of producing a discourse Foucault writes: 'take notion of the tradition: it is intended to give a special temporal status to a group of phenomena that are both successive and identical (or at least similar)' (21). How to associate this with the discursive choices made in migraine? These choices are mainly based on the identical descriptions of the pain and visual symptoms (auras) described. This recognition of the uniformity of the verbal descriptions determine their 'reality'. Foucault recognized such mechanisms in discourse, describing history as 'a slow accumulation of the past' (141). Historical statements must be treated 'in accordance with what they have in common' and 'the extent of their repetition in time and place' is considered highly important (141). This conception resembles the abovementioned ideas of Scadding (1967) about the 'common abnormality' (877) and 'previously recognized pattern' (879), which are important in naming a disease.

Foucault advises to see through the discourse by questioning ready-made syntheses, groupings normally accepted before examination and links, the validity of which is recognized from the outset (14). He does not show us how insightful or wise texts are but how far the discourses of doctors, scientists, novelists, and others create the things they claim only to analyze (Culler *Literary Theory* 13). In other words, we must be extremely critical, as 'reflexive categories, principles of classification, normative rules, institutional types: they, in turn, are facts of discourse that deserve to be analyzed beside others' (22). It appears, however, very difficult to 'leave' the discourse. It is not possible without 'extreme artificiality' (23), and only possible if one subjects 'the groupings of history' to interrogation (26), as is done by Shevel and Shevel (2014) and Lane and Davies (2015).

Patrick Heelan (1983) goes a step further. He emphasizes that 'what a measurement process provides is a "text"; [..] this is an artifact, like a text, that a trained scientist can "read"' (188). He uses the word 'text' between quotation marks in a different sense as the same word without those marks.

The word ‘text’ with quotation marks refers to ‘text-like structures in the World’ (184), and without marks refers to what is the usual meaning of the word. Anyhow, important is that ‘“text” may have a meaning apart from any implication that Nature has in mind, though not apart from the cultural circumstances in which the “text” is produced’ (188). In other words, such a ‘text’ depends on an artificial agreement and not on Nature. Consequently, ‘each practical empirical procedure is a humanly planned process in which nature is made to “write” in conventional symbols a “text” from which scientific information is “read” by the experienced scientist using the resources of scientific language within this is then expressed’ (188). Reading this ‘text’ is only possible when one knows the language. ‘The transparency and clarity of such “texts” vary’ (192). In the first place a text is an artifact constructed (by writing) according to the paradigms and rules of language for a particular semantic domain’ (193). In the case of migraine this domain is that of doctors; the language is ‘theory laden’. In order to be able to read, one has to know the language. The consequence is that there is a distinction between those who know and those who don’t know the language.

> I promise nothing complete; because any human thing to be complete, must for that very reason infalliably be faulty … My object here is simply to project the draught of a systematization of cetology
>
> Hermann Melville,
> cited by Carol A. Bowman, 1992

> The authority of language misleads once terms are received as ‘physical truths’
>
> Gillian Beer, 1990

Consequences of the discourse of migraine

The main consequence of the headache classification and criteria has already been mentioned and may be summarized as: ‘It is the theory which decides what we can observe’ (Albert Einstein, cited in Staiano *Definition* 113). In the search for and creation of a signified, the signifier ‘migraine’ became reality and transformed ‘a patient’s *illness* into a *disease*, a recognizable entity in the Western classificatory system’ (Churchill and Churchill 76). This may be called a positive consequence as it allowed for better communication between patients and doctors and between scientific investigators. Due to the criteria worldwide, the same rules were applied to these patients with headache. The separation of a well-defined ‘pure’ diagnosis made treatment trials possible in homogenous groups of patients.

There are, however, also negative consequences to this diagnostic system. A diagnosis made by means of criteria leads to exclusion. According to Foucault, ‘what we are dealing with is a modification in the principle of exclusion and the principle of the possibility of choices; a modification that is due to an insertion in a new discursive constellation’ (*Archeology* 67). Scadding (1967) writes about this topic: ‘a patient is unequivocally placed in a diagnostic category by the discovery of its defining characteristics and excluded from it by proof that this is absent’ (878). The result of the discourse of migraine is that every patient who tells a story that does not completely ‘fit’ into the

criteria is not 'allowed' a diagnosis of migraine. So, what about a patient who has had only 4 attacks and not 5 (which is a requirement for the diagnosis)? What about a patient whose attacks last shorter than 4 hours or (even worse) longer than 72? For these patients, lacking one criterion, the criteria offer an 'escape' in the form of a diagnosis of 'probable migraine', but when more than one of the features of their symptoms do not 'fit', patients virtually always end with the diagnosis 'tension type headache'. This has been called a 'waste basket diagnosis' as this diagnosis is mainly based on the absence of recognizable symptoms (no nausea, no photophobia, etc). It has also been called 'featureless headache' (Jensen 340). Whereas migraine is a diagnosis of inclusion as a set of features is required (attacks, pulsating, nausea, phonophobia and photophobia), tension type is a diagnosis of exclusion. It is a 'left-over', characterized by 'unverified and inadequately validated hypotheses and a paucity of established facts' (McTavish 231), but what this author forgets is that of migraine it may be said as well that there is a paucity of established facts, and that 'tension-type headache' has nothing to do with muscles in the majority of patients. The distinction between migraine and tension-type headache creates a 'gap' between a diagnosis with which one is taken seriously and for which dedicated medication is available (migraine) and one with a name that incorrectly suggests its cause, is completely unexplained, for which there is no specific treatment and which is therefore often frustrating (tension-type headache). So, receiving a diagnosis of migraine seems to be a 'favor' in contrast with being categorized as a 'tension-type headache' patient (Prakash 2016). This ranking resembles the so-called 'prestige hierarchy' of diseases described by Album and Westin (2008). They analyzed the perception of doctors and medical students about the 'importance' of diseases compared to one another. The resulting listing of 'disease prestige' (with myocardial infarction[29] at the top and fibromyalgia at the bottom), by the way does not mention migraine or tension-type headache at all (the first pain syndrome is sciatica – pain in a leg – at position 25; remarkably, severe neurological diseases such as multiple sclerosis and apoplexy are even lower on the list). The distinction between migraine and tension-type-headache is also reflected in 'pain stigma' as described by Goldberg (2017). Stigmatization 'occurs where an in-group marks an out-group as different on the basis of a shared demographic characteristic, and attributes deviance to members of the out-group as a result of that characteristic' (238). Here, the artificially defined 'characteristic' of migraine creates tension-type-headache as an 'out-group'. Chronic pain may lead to 'pain-shaming' (238) and my guess is that this occurs more frequently in patients with tension-type-headache than in those with migraine.

McTavish (2004) writes about headaches that 'their one virtue is that the majority are transient. Indeed, most are only moderately painful, short-lived and occasional. Their variety, in fact, has meant that with the possible exception of migraine, a headache has never been considered to be a disease in itself: it has always been a symptom, a clue only, a sign of some deeper dysfunction' (3). Here, he seems to follow the 'disease hierarchy' described above. He also includes the treatment of headache in his argumentation, stating that 'fortunately, because most headaches were "ordinary," the failure to understand their causes was of no great moment: they disappeared soon enough, and even sooner upon taking aspirin' (164). In other words, on the one hand there is 'migraine', a headache that must be categorized as a disease and on the other hand some lesser headaches, that are to be seen as 'ordinary'. The most frequently occurring headache in the population, however, is one of these so-called 'ordinary' headaches, tension type headache, which also may lead to considerable suffering and for which no specific and effective treatment is possible (Fumal and Schoenen 2008).

[29] A 'myocardial infarction' is also known as a 'heart-attack'.

Clear proof for the disparity between migraine and tension-type headache was found in a study of funding of headache research in the year 2004 (Olesen et al., 2007). They found that all funding (nearly 315 million euro) went to migraine research and virtually none to tension-type headache. This might be seen as a consequence of the discourse.

It is said that, 'diagnoses are useful conceptual tools that enable physicians to make certain interferences and predictions, based on current medical thinking' (Album and Westin 2008), but in the case of headache such a categorization also creates a hierarchy: the distinction between migraine and 'non-migraine' headaches. This problem was recognized by Blau as early as in 1993, when he wrote 'patients consult clinicians for help and understanding, not for classification or fulfilling criteria' (*Diagnosing* 21), and he added: '(1) How do we diagnose? (2) With what degree of certainty can different patients be diagnosed correctly? (3) What are the pitfalls in the interpretation of diagnostic criteria? (4) What do we do if we cannot make a diagnosis? (5) What is the realistic value of the diagnostic criteria?' (21). Nevertheless, based on the artificial and discursive separation of 'migraine' from the large group of other headaches, drugs were developed that were 'specific' for 'migraine'. This led, for example, to the development of sumatriptan (and later of other so-called 'triptans'), which was 'predicated on findings in brain chemistry, genetics, and other basic sciences' (McTavish 170). In the introduction of the revised International Classification of Headache Disorders, published in 2004, it is stated that 'when you look for patients who will respond to a triptan, you must diagnose your patient according to the diagnostic criteria for migraine with aura and migraine without aura of this classification' (13). In 2008, Olesen expressed this in other words, arguing that sumatriptan has a highly specific mode of action and 'this proves that clinical diagnosis according to ICHD [the criteria] has been able to identify a group of patients who share a reasonably uniform response to pharmacological intervention and presumably then share a common pathophysiological pathway' (Olesen *International Classification* 692). Of course, the efficacy of this medication is an advantage for those patients who get the label 'migraine', but what about the other headaches, and how specific are these 'triptans'? From subsequent scientific observations, it became clear that triptans are not at all specific for migraine. For example, the non-migraine headaches that occur between attacks in many migraine patients also could be effectively treated with sumatriptan (Cady et al., 2000; Lipton et al. *Sumatriptan* 2000). Likewise, migraine-like headaches associated with carbon monoxide exposure (Lipton et al. *Carbon* 1997), acute headache after a cerebral hemorrhage (Rosenberg and Silberstein 2005), and headache occurring after sexual activity (Frese et al., 2006) responded to the drug. Sumatriptan is also an established treatment for cluster-headache, a rare syndrome with severe, short-lasting headache attacks around one eye with redness of the eye and tearing. The drug was even claimed to be effective in hangover headache. The look for 'patients who will respond to a triptan' (International Classification of Headache Disorders 2004) thus must take into account that many non-migraine headaches react to the drug as well. Efficacy of this drug cannot be used to 'prove' a certain diagnosis or establish the 'reality' of migraine.

In practice, it appeared that another consequence of the criteria was the further splitting-up of the groups of patients fulfilling the criteria for one of the headache-types into subgroups, thereby creating even more artificial distinctions. Pain itself seems to carry its own dishonor (Bourke *Story* 41), but there seems also to be a discrimination between different forms of pain. According to Morris:

> Like most classifications, of course, the contrast between acute pain and chronic pain contains ambiguous, twilight areas. Inevitably, specialists propose technical adjustments designed to wipe out twilight, with the result that new categories spring to life: subacute, ongoing acute, chronic benign neoplastic, and so on. Our categories for thinking about pain still remain less flexible than pain itself. (*Culture* 70)

Of course, the first 'function' of the criteria is a separation of patients (with headache) and 'normal persons' (without headache). In the case of headache, however, the difference between 'normal' (no headache) and 'abnormal' (headache) is a quantitative one as virtually every human being will now and then experience a headache, for example after a hit on the head, during a flu or when having a hangover. Also, in patients with spontaneous headaches, some of which resemble migraine-attacks, the distinction of a migraine versus a 'not-migraine' diagnosis is quantitatively determined by the criteria. For a diagnosis of migraine, at least 5 attacks fulfilling the remaining criteria are needed. One may ask whether a person with one headache attack per year which fulfills the criteria for migraine is sick. Does this person have a disease? The same questions may be asked about someone who has six attacks per month. The answer to the question will probably 'no' in the first patient and 'yes' in the second. This implies that there must be some 'cut-off point' between the no and the yes. The criteria place the cut-off point at 5 attacks during lifetime, but it is the question how 'realistic' this is. As expressed by Foucault:

> there is a strange ambiguity here, since in its signifying function the symptom refers both to the relation between phenomena themselves – or what constitutes their totality and the form of their coexistence – and to the absolute difference that separates health from disease; it signifies, therefore, by tautology, the totality of what it is and, by its emergence, the exclusion of what it is not. (*Birth* 92)

So, the question emerges, what is normal and what is not? Or, who is sick and who is not? Or, who is sometimes sick and sometimes not?

Further, within the group of patients fulfilling the criteria of migraine a distinction is made between migraine with aura and migraine without aura. This distinction is not based on the headache, which is essentially the same in both groups, but based on the occurrence of visual, motor or sensory symptoms that occur before the headache. The old term for migraine with aura was 'classical migraine' and that for migraine without aura 'common migraine' (Sacks). It has been debated whether migraine with aura ('classical') and without aura ('common') must be seen as two separate diseases, or whether they both form part of the migraine spectrum (Russell et al., 2002; Manzoni and Torelli 2008). In the light of the present discussion, it may be argued that also a separation of these two probably is a discourse, as most patients who receive a diagnosis of 'migraine without aura' will now and then have an attack with aura, and vice-versa (patients with migraine with aura can have attacks without aura).

A further distinction made is that between 'episodic' and 'chronic' migraine. In the episodic form, patients must have migraine headache on less than 15 days per month and in the chronic form patients have headache on more than 15 days per month, with on at least 8 days accompanying symptoms typical for migraine (nausea, sensitivity for light, sound or smell). These entities were not included in the criteria published in 1988 but were introduced in those of 2004 (International Classification of Headache Disorders 2004; Medrea and Christie 2018). It has been said that this

distinction in the classification system has 'served to shift many patients with chronic tension-type headache (CTTH) or concomitant CTTH and episodic migraine to this new category' (Tinsley and Rothrock, 2018). In the first place, however, the word 'chronic' seems to be wrong, as migraine is a life-long disease and therefore 'chronic' by definition, even when it occurs in an 'episodic' pattern. This semantic problem was already acknowledged by the Headache Classification Committee, chaired by Olesen, stating that 'all the primary headaches are chronic in the sense that they present for many years' (*New Appendix* 743). Furthermore, the value of the quantitative distinction fixed at more or less 15 days per month may be questioned (Burshtein et al., 54). Why give a separate diagnosis based on the number of days per month? A remarkable illustration of this quantitative (and discursive) distinction can be found in two articles in one volume of the prestigious journal *Lancet Neurology.* They were both published by the same research groups, describing the results of two trials with a newly developed drug (TEV-48125). One trial was performed in 'high-frequency episodic migraine' (Bigal et al., 2015a) and the other in 'chronic migraine' (Bigal et al., 2015b). There was only a quantitative difference between the migraine patients in the two studies: in the first study patients had migraine headaches 8-14 days per month and in the other more than 15. Not surprisingly, the results of the trials were similar. It may be debated whether making such a quantitative difference is reflecting 'reality' (Bursthein et al., 2015). Remarkably, although the distinction between episodic and chronic migraine was made in 2004, Guerrero-Peral and colleagues (2014) found a description of chronic migraine already in a medieval text. Is this a justification of the distinction between the two entities, or another example of how discourses work?

It seems that Foucault was right by asking

> how a General Grammar defines a domain of *validity* for itself (according to what criteria one may discuss the truth or falsehood of a proposition); how it constitutes a domain of *normativity* for itself (according to what criteria one may exclude certain statements as being irrelevant to the discourse, or as inessential and marginal, or as non-scientific); how it constitutes a domain of *actuality* for itself (comprising acquired solutions, defining present problems, situating concepts and affirmations that have fallen into disuse). (*Archeology* 61; emphasis in the original)

The 'less than – more than 15 days' separation of episodic versus chronic migraine indeed seems to be posed as a having validity, normativity and actuality. That the separation is very artificial is no issue. It is very likely that not only pure medical arguments played a role in the making of the distinction. Defining chronic migraine as a separate entity was probably also motivated by political and social issues, specifically by a desire to stress the severity of migraine and its impact on society, next to that on the individual sufferers. Positioning 'chronic' migraine as a very severe disease led to more attention from society, and to more funding of research.[30]

A further splitting-up of migraine may be called a 'discourse within the discourse'. For example, so called 'vestibular migraine' was first introduced in 1999 as a special type of migraine, associating migraine headache with dizziness (Dieterich and Brandt). From 2001 on, a large body of literature was published, the majority of which came from one German research group (Lempert 2013). In 2012, diagnostic criteria for vestibular migraine were proposed, with Olesen as one of the co-authors

[30] It has been suggested that in contast to episodic migraine in chronic migraine the plasticity of the brain alters, but this is not proven.

(Lempert et al., 2012). It is no surprise that these criteria could be 'validated' by the same research group (Radtke et al., 2011). Recently, the discourse was 'completed' by the discovery of descriptions of vestibular migraine in antiquity, by one of the original 'inventors' of the entity (Huppert and Brandt 2016). It is, however, still a debate whether vestibular migraine exists or not. In fact, dizziness is a very aspecific complaint, which may be caused by several diseases, such as low and high blood pressure, side-effects of medication, anemia and vestibular disorders.

In contrast, not every (medical) linguistic communication, however, becomes a 'discourse'. For example, Furman and colleagues proposed in 2005 'a new disorder', which they gave the acronym MARD, which stands for 'migraine – anxiety related dizziness'. In their article they proposed definitions of 'disorder, syndrome, defining symptoms, and associated symptoms' (1), and included a hypothesis on the pathophysiology of MARD and its clinical implications (4-5). The concept and the acronym have, however, not 'survived'. A search on PubMed (the most important medical database) revealed 1 'hit' when combining the keywords 'MARD - migraine', or 'MARD – anxiety' (accessed 24-3-2020): that of the authors themselves. It is intriguing why one questionable concept (vestibular migraine) is widely accepted while another concept (MARD) is not. Besides, it is not only intriguing, but also inexplicable, and to some extent even worrisome.

The distinction between migraine and other types of headache by discourse evidently has practical consequences. One of these is described by Bourke as 'pain events are inherently social and, therefore, integral to the *creation* of communities' (Story 46; emphasis in the original). She points at the process that 'bonds of sociability are strengthened through suffering' (48). Translated to headache, this means that patients with one type of headache probably tend to seek contact with other patients with the same type in patient societies, internet fora, etc. For migraine, this sense of unity may be strengthened by a unique noun given to them. As a migraine patient one is welcomed in such societies; as a non-migraine patient one has to seek 'refuge' elsewhere. Lian and Grue (2017) discuss a similar mechanism in the case of 'myalgic encephalomyelitis', a diagnosis given to medically unexplained long-term exhaustion and energy failure. Like in migraine, the diagnosis is 'primarily based on assessing symptom descriptions against diagnostic criteria' (173). Online communities play an important role in the discursive generation of this disease, which in the medical field is thought to have a psychogenic cause, an assumption that is denied by the sufferers. So, next to forming a social bond through suffering, patients with myalgic encephalomyelitis also use the formation of a society 'to combat what they see as errant or destructive medical power' (174) and in this way 'seek to challenge the worldview of others, perhaps particularly doctors' (174). Such 'combat' and 'challenge' are probably not necessary in the case of migraine, although it is not very long ago that patients with headache and migraine were not taken seriously at all. Anyhow, parallel to the medical diagnostic discourse of migraine, a patient-driven discourse exists on internet.

A further point of importance is the discourse of the 'labeling' of the patients. Migraine patients are often called 'migraineurs', which is a term used to contrast them with patients with another headache-type such as tension-type headache or cluster headache for which no separate term exists (tensionneurs? Clusterics?). The 'migraineur' seems to reflect the tendency of doctors to transform in a way the patient into a diagnosis (Jutel 4). The term is a synecdoche in which a part of the patients (their having migraine) stands in place of the patient as a whole. Furthermore, patients themselves may 'integrate diagnosis into the self, becoming, in some cases, the disease (I *am* diabetic / depressed / schizophrenic)' (4; emphasis in the original). Bowman calls this the '"I am" construction',

which is opposite to the '"I have" construction' (9). The next step is that patients use this 'misplaced concreteness' to excuse themselves for certain actions. 'It's not me, but my ADHD' (Waugh 18), or 'what a Touretter does, [..] is reveal a Tourettized world, a world jumping with tics waiting to happen' (Fleissner 390). What the common 'migraineur' does is not clear. Most of them probably wait for the next attack, and in the meantime try to be a 'migraineur' as little as possible.

Using the so called 'Delphi technique', Young et al. (2011) asked a 'purposive sample of 15 panelists [..] all of whom represent various constituencies that have a stake in a discussion about migraine' [..] 'what to call the individual with migraine' (3). The group remained divided regarding the preferred term. Many found the term migraineur 'appropriate in an academic context' (4), others thought that the term 'conflates the person with the disease' (4). Panelists were also worried about the connotation of the language choice (7). Indeed, the term 'migraine' has a long history of being associated with personality and behavior. Lord Dawson of Penn, for example, stated that 'the victims of these headaches are often well educated and capable people in whom achievement counts for much, with the pride and hidden vanity that accompany its pursuit' (608). He adds that 'they strive for superiority; they try to avoid inferiority, and, if they fail, seek to disguise the fact from themselves by psychological pretext' (608). When reading these descriptions, one may imagine that having migraine is a reason to be proud, but 'many Americans did not welcome a psychological diagnosis, even when the migraine personality flattered them by being associated with high intelligence and creativity' (McTavish 169).

Foxhall mentions the origin of the term 'migraineur'. She describes that the term seems to date from 1936, when in an article on "Allergy as a Factor in Headache," an intensive dietary regimen for 'the true migraineur' was outlined (189). The use of the term has been subject to discussion. First, it can be said that 'to talk of someone as a migraineur implies that they are defined by their migraine' (xiii). The term becomes their identity. After being criticized for using the term also for female migraine patients and the proposition to use the term 'migraineuse' (Jonas 1180), Leviton refers to a medical dictionary, the French language and 'clinical colleagues who attend international headache conferences' and states that these sources 'assure us that migraineur is the only noun used to describe a person of either gender who has a migraine' (1180). Schiller (1989), however, remarks that 'you will find *migraineur* in no French dictionary: it is an English invention' (1168; emphasis in the original). The word may be traced to an English newspaper from 1971. Besides, a French word ending with –eur refers to a doer, which would make a migraineur as someone who is 'doing migraine'. Whatever the truth about the terminology, giving a label to a patient also has certain consequences. As argued, the diagnosis 'migraine' may be seen as the discursive production of a signified. The term 'migraineur' doubles this and may thus be seen as a doubling of the discourse. First there is the discourse of migraine and second the discourse of having migraine and being labeled as someone with migraine. It is doubtful whether this is an advantage or not. I agree with Young (2017) that the term migraineur is 'a stigma to be avoided' (Young 320).

Conclusion

The main motivation of this chapter was to show how the disease migraine is created and exists through (medical) discourse. The criteria of the International Headache Society have made migraine

into a ‘thing’, a signified, and even an ‘object’ (Schulte and May 1337). The discourse of the diagnosis of migraine resembles that of ‘madness’, as described by Foucault in his books *Archeology of Knowledge* and *History of Madness*. As that of madness, the discourse of migraine created a separate entity within the whole spectrum of normality to disease. Migraine may only be artificially distinguished from ‘normal’, from other headaches and even from variations within its ‘own’ entity.

Artificial criteria are used to make distinct headache diagnoses. The purpose of the separation of ‘migraine’ from other headache types seems purely medical (not ideological), but as the separately defined headache entities are in ‘reality’ not that distinct, the distinction by criteria leads to a process of in- and exclusion. The headache diagnoses only exist due to the internationally accepted agreements of the dominant discourse offered by the International Headache Society. In fact, there is no place for alternatives, as even the inventors of the criteria admit themselves. However, the reality of someone with ‘migraine’ might not differ very much from that of someone with ‘tension-type headache’. There is much overlap between the various headache types, not only clinically, but also with regard to treatment. Also, different headache types often co-occur. The criteria, however, have categorized, split and unfortunately also stigmatized headache and its sufferers. It even seems that being diagnosed as a ‘migraine’ patient is a favor in contrast with getting a diagnosis of ‘tension-type headache’ (Prakash 2016). Migraine gets more attention in the form of scientific research and funding, and therefore a better chance of treatment.

The question whether this discourse and its consequences form a serious problem which should be resolved, remains unanswered. As possible answers, there can be a ‘no’ and a ‘yes’. The ‘no’ expresses that this is not serious as ‘it is only through diagnostic criteria in classification systems that scientific and clinical communication is possible at all’ (Göbel 770). At first sight, this seems valuable, as diseases are really theoretical constructs developed in order to explain something about the patient’s illness. For the diagnosis of pain-syndromes, such as headache, it seems important to make ‘rules’ (criteria). These are needed for decisions about diagnosis and treatment, but it is always important to realize that these remain artificial. But on the other hand, ‘yes’, the consequences of the criteria are serious and should be challenged. There are too many choices, interpretations and exclusions, and too many (non-migraine) patients suffering from this.

There is a difference between a headache diagnosis produced by discourse and so called ‘external reality’. The distinction of various types of headache obviously is of utmost importance, as causes, provoking factors, treatment and therapy may differ between the various types. Nevertheless, the borders between one type and another stay artificial and based on agreements. Overlap of different headache-types occur frequently. The borders are not as fixed or clear as suggested by the criteria. And, importantly, a headache is not a ‘thing’ but a complaint of a human being who has to translate an untranslatable sensation into words to be heard and helped. Headache patients are individuals who need a ‘tailored’ approach and who must not only be classified, as ‘against the medical standardization of disease, the personal story claims its own unique way of being ill’ (Frank *Stories of Illness* 341). As such, the ‘discourse’ of migraine and of other headache types seems to fail.

Nevertheless, we have to do with it as long as there is no robust identification available of migraine and other headache-types based on genes or other biomarkers (Winther Schytz and Olesen 2016; Tinsley and Rothrock 2018). Only then a transition of symptomatic to etiologic classification would be possible. In the meantime, we must rely on words and the metaphors they produce. It may be said

that it ‘does not matter what we call migraine as long as all of us agree on what is called migraine’ (Schulte and May 1337). We must, however, always keep in mind the discursive (and therefore sometimes deforming) interpretation of the word. The criteria have built a new entity and in its definition ‘lies its creation – and demarcation from other objects’ (1337). Their significance lies ‘not in the fact that they offer a most detailed and accurate image of reality’ (1337), but in the scientific consensus to use the word ‘migraine’ in this particular way.

In this chapter, I have described how words are used to ‘create’ the diagnosis of migraine. In sharp contrast with this, in the next chapter, I will elaborate on how pain, headache and migraine also seem to destroy words and language; calling it ‘contra-discursive’. It will be a journey from the artificial construction of a disease to the ‘bare’ destructive reality of pain.