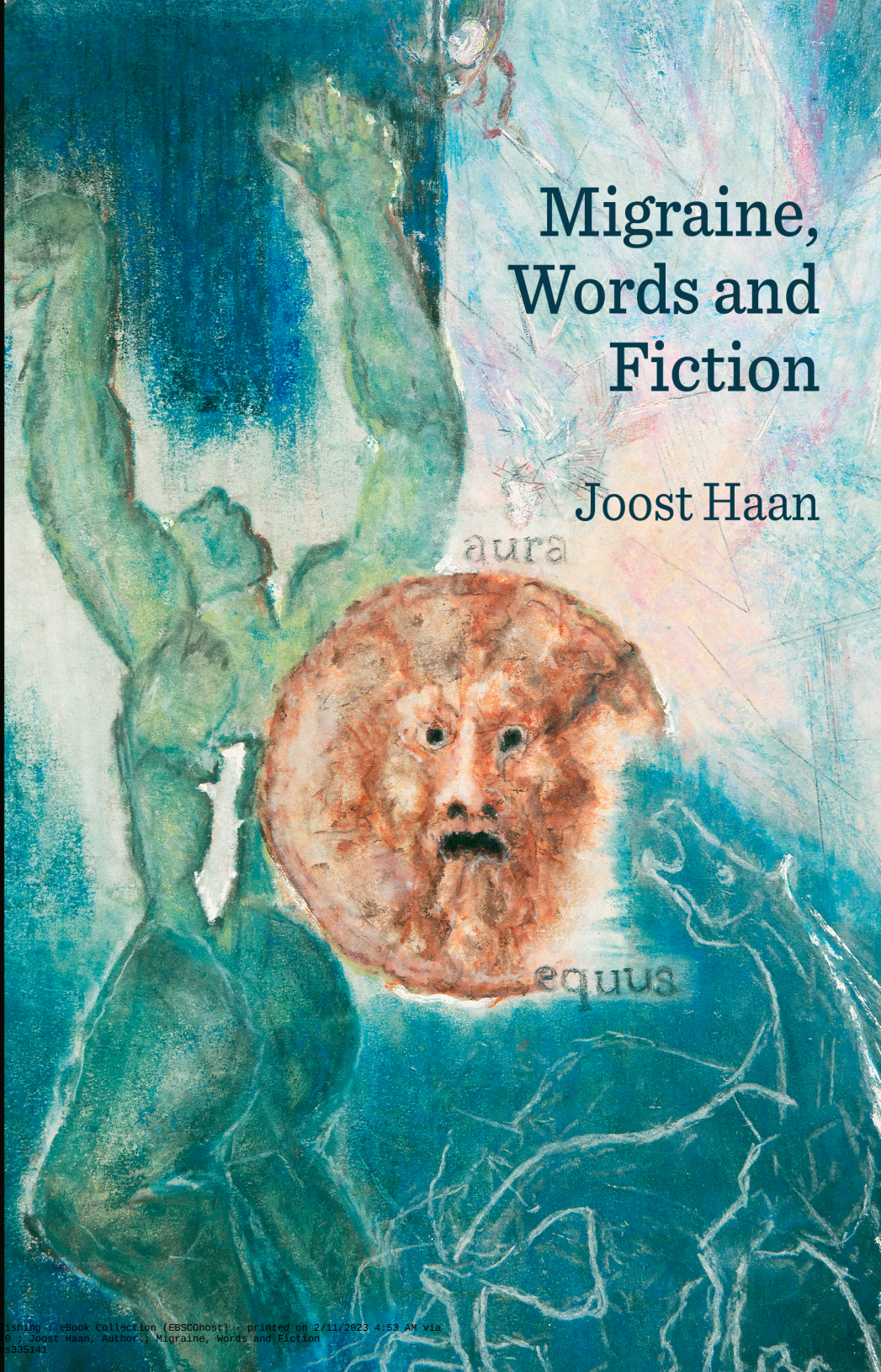
Migraine, Words and Fiction

Joost Haan



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FOREWORD

The interdisciplinary field of medicine and literary studies has in the last decades received much attention from both sides. This is – for example – illustrated by the existence of several devoted journals, such as *Literature and Medicine*, the *Journal of Medical Humanities* and *Medical Humanities*. A subspeciality of the "'medicine-literary studies field' is pain, which has also received much scholarly attention. As a result, there are several books that specifically address the association of pain-syndromes and literary studies, such as *The History of Pain* by Roselyne Rey (1993; English translation 1995), *The Culture of Pain* by David B. Morris (1991), *The Language of Pain* by David Biro (2010), *Pain. A Cultural History* by Javier Moscoso (2012), and *The Story of Pain: From Prayers to Painkillers* by Joanna Bourke (2014).

All of these texts, however, deal with chronic pain. In my opinion, a remarkable omission is that there are virtually none in international or local publications in literary studies specifically focusing on one of the most frequent forms of pain, which occurs in attacks: migraine. Chronic pain and pain that comes in attacks are different, not only in a 'medical', but also in a 'literary science' sense. Being a migraine specialist and scholar of literary studies, in this book, I intend to fill the gap of this omission.

I start this book with an answer. Its title is "Migraine, Words and Fiction", and yes, there is an important relation between these entities. In fact, (a diagnosis of) migraine does not exist without words and indeed there is a lot of fiction about migraine. I will prove these points by first exploring the relation between pain and language. Clearly, this issue finds itself on the interstice between medicine (neurology) and literary studies. In line with this, I will explore how people with pain may make their pain 'readable' and how fictional texts about pain 'perform' the pain instead of only describing it. In this book, I will first focus on pain in general, to set the stage for the relation between language and migraine. I will compare medical thoughts on pain and migraine with those provoked by literary works in their being paradigms of expression, and try to bring these together.

There is much literature on pain in medicine and also in literary studies. An analysis from both sides might improve mutual understanding, as there is indeed a need for a dialogue between these disciplines (Morris *Culture* 2). If such a dialogue becomes possible, not only may both disciplines benefit, but also practitioners, patients, readers and dedicated scholars in literary studies. For Gogel and Terry (1987) 'interpretation as a primary activity of clinical medicine [..] sometimes proposes metaphors such as the doctor as a literary critic or the patient as text' (205). After their analysis of possible models for 'the interpretive schools of thoughts', including a critical reading of the work of Brody (vide infra) and several others, they conclude that 'there is something to be found in a merger of medicine with literature or literary methodology, but there is little agreement about what that something is' (210). In fact, this 'something' is what I aim to explore in this book.

I focus on migraine because there is hardly any knowledge from the side of literary studies about this pain-syndrome that comes in attacks and has a double potential in relation to language, both destructive and creative.

Almost everyone knows what pain is. The 'almost' refers to the >99% of living beings who may feel and express pain, including fetuses, babies and demented, intellectually disabled and unconscious people. There are, however, some individuals who (apparently) are incapable of feeling pain at all. This exception is present in a very rare genetic abnormality called congenital or inborn indifference of insensitivity to pain (Van Ness Dearborn 1932; McMurray 1950; Sternbach 1963; Critchley *Divine Banquet*; Danziger et al., 2006; Levy Erez et al., 2010; Nahorski et al., 2015; Staudt et al., 2017).[1] In the general view, not feeling pain seems wonderful, but in practice the condition places a heavy burden on its sufferers. First, those who claim not to feel pain are seen as hysterics, mental defectives or psychotics (Sternbach 252). Second, not feeling pain may be dangerous, as the body does not warn for possible external dangers, which may lead to burns, unrecognized tumors, etc. In this way, not feeling pain may even be

[1] A spectacular example of this affliction is the so-called 'Human Pincushion', an American who appeared on the vaudeville stage and 'harmed' himself with knifes and needles, apparently without feeling pain. During one of his last appearances on stage he let himself be crucified as Jesus. As more than half of the audience fainted at the sight, he had to stop his performances (Critchley *Divine Banquet* 197-198). Less spectacular are the so-called 'fakirs', who also often suffered from the same condition (Kotsias 2007). The syndrome of congenital or inborn indifference or insensitivity to pain was shown to be caused by mutations in genes coding for sodium channels.

lethal. It seems, therefore, that the ability to feel pain is a necessary condition for any human being.

Thus, except for the 'congenital insensitivity', everyone probably knows the feeling of pain. Remember for example the intestinal cramps as an infant, the humiliating pain when hit on the buttocks after a mischief, the pain of the scratch on your knee after falling of your bike, the pain of gout in your great toe, the hangover, or the invalidating pain of arthrosis in the hip. Clearly, pain is ubiquitously present in all life-stages, in numerous forms, disguises and situations. But, in fact, the answer to the question how to express or represent what pain is in reality, still turns out to be extremely difficult to give. Why is this?

First, there is the complex origin of the word 'pain'. In their article "A Philological Study on Some Words Concerning Pain", Procacci and Maresca (1985) explain that the Greek words *algos*, *odynia* and *angina* were used for different kinds of pain. The word 'pain', however, was derived from *poena*, which meant 'punishment'. This association pointed at the ascription of pain and suffering to prior transgressions of sin. They also point at the complex significations of the English words 'ache' and 'pain', and the Italian and French difficulties to separate dolor, douleur and dolore. And what to think about the German word Schmerz? So, what we are talking about is a sort of Babylonian confusion of words.

Secondly, there is the question whether pain has a function. In general, acute pain is considered to initiate evasive behavior, and chronic pain is thought to induce protective inactivity favoring recovery (Pitts 275). It may be argued that the human pain system provides evolutionary advantages, as humans can memorize and thereby avoid pain before bodily harm occurs, and they can also transmit information from generation to generation by word about threats to be avoided (276). For these functions they probably needed words to express their pain.

However, thirdly, there is the difficulty patients experience when attempting to express their pain in words, as well as the difficult interpretation of these words. In this book, I will describe situations where in the compex interaction between words, referents and reality so-called signifiers and signifieds are important. If we use the word 'pain' we somehow expect it to mean something, to refer to something. Yet, what is that 'something'? If we say 'tree' pointing at a tree or 'horse' pointing at a horse, there is a word that relates to a referent. But what can be the referent of the word 'pain'? Can we point at pain? Mostly, the only thing left is a verbal expression. The

translation of the words of what pain-sufferers feel – and cannot point at – will be at least somewhat unreliable, as there is not only a difficult process of expression, but also one of translation and interpretation. For doctors diagnosing and (attempting to) cure someone, at least this unreliability of the words used for diagnosis and cure have to be overcome. I intend to do this for migraine, but there are many pitfalls on the road.

Since almost everyone knows what pain is, it seems obvious that pain is part of 'reality'. As hinted at, it may, however, be disputable what 'reality' is. Some have even claimed that all humans have their own reality and that our perception of the world is 'a fantasy that coincides with reality' (Frith 111). Without a doubt, language is extremely important here, not only to describe this imaged reality, but also – as especially postmodern thinkers have emphasized – to create reality. Stenner and Eccleston state in their article "On the Textuality of Being" (1994), 'we understand language to be more like a set of tools (for local and contingent use) than as a set of representations of some *really real reality*' (my emphasis). This raises the question the more: what about the really real reality of the paroxysmal pain of migraine? What is its relation to language? These are the questions I hope to answer in the next chapters, first by taking the text of the migraine patient as starting point and thereafter focusing on literary texts about migraine, in this way bringing medicine and literary studies together, in the hope that both fields will benefit from it.

CHAPTER 1

PAIN AND WORDS

Everyone who doubts the reality of pain should take a hammer and hit one's thumb and then answer the question again: 'Is pain a representation of really real reality?' The answer will probably 'yes' and 'don't ask me to do such a ridiculous thing again'. So, 'many pains [..] are familiar to us all' (Schott *Communicating* 209). Still, in fact, pain has no substance, it is not an object that may be touched, pointed at, objectively measured or made visible. One may argue that pain can sometimes be 'seen'. The facial expression of someone with pain, however, is not specific, as it is indistinguishable from the expression and gestures of sorrow, triumph (a footballer who has scored an important goal), or ecstasy. Besides, it has been shown that language is more important for gestures than the other way around, as even for congenitally blind subjects, hearing a particular language is sufficient to gesture like a native speaker of that language (Özçalişkan et al., 2016).

What is crucial for the understanding of pain is that no one can feel the pain of others and that 'one of its most frightening aspects is its resistance to objectivation' (Scarry *Body* 56). In other words, pain is the 'clearest and most plausible case of an object which no one but the sufferer may experience directly' (Fiser 1). Pain is always an internal sensation and, as such subject to interpretation, speculation, doubt, mythology, gossip and sometimes even to manipulations of power and ideology. In addition to this, it depends on language.

The language of pain

To illustrate the subjectivity of pain and its relation to language the philosopher Ludwig Wittgenstein presented an often-cited metaphor: the beetle in the box (see for a description Cohen's *Wittgenstein's Beetle and Other Classic Thought Experiments*). Wittgenstein proposed to imagine a situation where everyone has a box and knows that it contains a 'beetle'. By looking into their own box, everyone may perceive what a beetle looks like. No one, however, can look into anyone else's box. No one knows what form, color or shape the beetle of the other has. So, the individual

designation of ‘beetle’ may point at an object that looks like a ‘real’ beetle, but it may also point at one that resembles a coin or a cigarette. The box may even be empty, causing the owner of that box to use the word ‘beetle’ for ‘void’. Importantly, although the beetle may be represented by a coin or an absence, the word ‘beetle’ makes verbal communication possible. In the end, the content of the box does not matter, as the actual shared language is much more important (Bourke *Story* 7).

When talking about their beetle or about their pain (or e.g. about hunger, love, dizziness or fatigue), people probably talk about different things, feelings or sensations, but what they talk about becomes a common ‘reality’ and something they may communicate about because of the stereotypical way of describing the sensation. Pain has to do with individual experience, but also with intersubjective articulation. Without a doubt, pain is a private object (Fisher 1986). But, for Wittgenstein, a private language, interior and unsharable, would be completely devoid of sense (Moscoso 5). Meaning is only produced by the collective credibility of private sensations. Subjectieve meaning is anchored in homogeneous experiences (201). According to Fiser (1986), ‘patients suffering the same or similar pain syndromes show a remarkable consistency in the use of words’ (9). So, based on this consistency, for the consideration of the ‘objective reality’ of feeling pain, in this text Wittgenstein’s beetle-metaphor will be further worked out, as it is based on a consistency of words.

In her book *The Story of Pain. From Prayers to Painkillers* (2014), Joanna Bourke states that ‘assuming that pain has a definitive, ontological presence is to confuse presentations of sensation with linguistic representation’ (4). She argues that it is a mistake to view pain as an entity, although many pain-sufferers do so. Indeed, patients often talk about pain as an ‘it’; as something that attacks them from the outside. The controversy of whether pain originates on the inside or outside goes back to Hippocrates. Fourth-century BC physiologists believed disease to be the result of an imbalance between the inner and the outer, the ontologists considered disease as an outside object invading the body (Cassell 143). In the latter situation, the noun ‘pain’ came on the same linguistic level as ‘chair’, ‘thumb’, or ‘mouse’. But one could still not point at it.

Bourke calls the idea of an outside event the ‘ontological trap’ of representation (5) and advises to see pain as a ‘type of event’ rather than an object or actual entity, by stating that:

> what do I mean when I say that pain is an *event*? By designating pain as a "type of event" [..], I mean that it is one of those recurring occurrences that we regularly experience and witness that participates in the constitution of our sense of self and other. An event is designated "pain" if it is identified as such by the person claiming that kind of consciousness. Being-in-pain requires an individual to give significance to this particular 'type of' being. (5; emphasis in the original)

Thus, pain is not an object, but an experience, designated as such by an individual and leading to a constitution of our sense of self. Pain is therefore also 'a belief', which brings me back to Wittgenstein's beetle and the subject that believes that also a void can be a beetle.

There is indeed a large body of literature describing the so-called 'pain believe', a concept introduced in 1989 by Williams and Thorn (Williams and Thorn 1989; Strong et al., 1992; Williams et al., 1994). It is defined as patients' own conceptualization of what pain is and what pain means for them (Williams and Thorn 351). To measure it, a 'Pain Beliefs and Perceptions Inventory (PBAPI)' was developed to investigate four dimensions of pain beliefs: mystery, self-blame, permanence and constancy (Williams and Thorn 1989). When using the word 'beetle', everyone believes in one's own beetle. The same probably is true for 'pain'. Important, however, is that by recognizing one's own beetle or pain, one thereby accepts that others may have a beetle or pain as well. This distinguishes pain from sensations such as hunger and love, which are not necessarily experienced by everyone, but, when they are, have an external referent (food, someone to be loved), which is in contrast with pain.

When accepting the fact that one's own pain, but also that of others, is part of some sort of reality, the issue emerges of *how* pain becomes real. One mode of its becoming real concerns the diagnostic situation of someone with pain who wants to validate his or her pain as 'real' and someone who might be able to interpret these sensationa and can recognize a recognizable pattern. This is the encounter of patient and doctor. Indeed, pain is the most frequent complaint doctors are confronted with.

Patient and doctor

Here, the term 'doctor' will be used for someone who has studied medicine and takes care of patients in a diagnostic and/or therapeutic context. Such a person may also be defined according to the description of Arthur W. Frank (2016) as 'an artificial person who acts not on his or her own personal moral authority, but rather as representative of an authority that has a collective

form' (12). In this book, the term 'physician' will be avoided as much as possible, as it refers to something 'physical', and this is not always the case in pain syndromes. At this point it is also useful to note that the term 'patient' comes from the Latin word *patior*, which means 'I suffer' (Gooddy *Disorders* 663).

Many patients with pain and headache do not show perceivable 'physical' abnormalities, so for that they don't need a physician. This does, however, not make their pain less important. Pain as a complaint occurs ubiquitously. An important question is how pain 'shows' itself. Pain (and headache) are most often seen as a 'symptom' (a complaint; a subjective feeling that may be expressed, but not seen from the outside or objectively measured) and not as a 'sign' (accompanied by objective abnormalities).

For Epstein (1992) there are first symptoms or complaints – the patient's own subjective perspective of deviations from normal health, second, signs – the objective manifestations of disease located by the physician during a physical examination and third, (and historically most recent), laboratory findings (32). Of course, pain may co-occur with or be the expression of a visible or measurable lesion, such as a swollen thumb that is hit by a hammer (don't blame me), a scratch, the red toe of the patient with gout, or a brain tumor on a scan of a headache patient. In those cases, however, the diagnosis will not be 'pain', but will be based on the causative factor ('trauma', 'gout', 'tumor'), although the pain itself may be the main, and sometimes only, symptom. When a subject with pain has clearly visible physical abnormalities at examination and/or ancillary investigations (scans, blood tests), that 'sign' becomes in its turn diagnostic 'proof' of the pain and often metaphorically replaces it. In the words of Elaine Scarry, this pain is 'lifted into the visible world' (13). Then it is not said 'he or she has pain', but 'he or she has gout', or 'he or she has a brain tumor'.

A teleological confusion is nearby as illustrated by Friedrich Nietzsche in his 'pain – pin' metaphor (cited by Culler *Deconstruction* 86-87). Nietzsche describes someone who suddenly feels a pain in his foot. When looking down he/she sees a pin lying on the floor and associates the pain with the pin. This situation may cause confusion: the reversal of cause and effect. The person first experienced pain (effect) and then saw the pin as (presumed) cause. The pain was first, the pin came later. So, to make a causal relation between pain and pin, time must be reversed, which leads to the artificial association of two 'things', which 'in reality' may not be associated at all. The pin may have had nothing to do with the pain. Maybe there was another pin causing the pain, maybe the protagonist sprained his

or her ankle, maybe the pain was 'psychosomatic'. For David Biro (2010) this is an example of how we are in such a situation not engaged in science (uncovering truth), but in art and metaphor (creating truth). When experiencing pain we often look for and then find a presumed cause. Often, our metaphorical imagination reorders the temporal sequence and – according to Nietzsche – language blatantly misrepresents the facts (126). A presumed association of cause (lesion) and effect (pain) is probably the right explanation in the abovementioned examples ('trauma', 'gout', 'tumor'), although even in those cases this is not 100% sure, but this is much more problematic in many other situations where a structural cause or provocation of the pain is less obvious. Patients often tend to explain their pain by associating it with temporally related occurrences, such as stress, anxiety or the wheather, but these are almost always wrong assumptions which can, unfortunately, also lead to wrong diagnoses and treatment.[2]

Mostly, the one who has to make a diagnosis and install treatment is the doctor. There is a large body of literature describing the possible variants of the encounter of patient and doctor. For example, in his article "A Contribution to the Philosophy of Medicine. The Basic Models of the Doctor-Patient Relationship" (1956), the famous (anti-) psychiatrist Thomas S. Sasz distinguished three options: First, the variant of 'Activity-Passivity', in which the doctor 'does' something with/to the patient. Second, 'guidance-cooperation', in which the patient places the physician in a position of power but is active as well. Third, mutual participation', both parties have approximately equal power, are mutually interdependent and engage in activity that will be in some way satisfying to both (586-587). The latter seems to describe the current practice of so-called shared decision making.

Next to 'symptom' and 'sign', another important distinction is that between 'illness' and 'disease'. It appears that the use of these terms in medical and other literature is very confusing and even conflicting. Illness may be described as 'a sense of dis-ease, a sense of distress, related to a patient's perceptions and feelings' (Novack 347), and as such it is disease without objective phenomena. Some define 'disease' as something that may be objectively identified as a biological process by a laboratory test (319), but this simple definition has been criticized (Brody *Stories* 45). In his book

[2] An example of this is the use of antibiotics in patients with headache ascribed to the flu. Symptoms of the flu – by definition, as it is a viral and thus self-limiting disease – always disappear spontaneously. The amelioration is then ascribed to the antibiotics, whereas these have not contributed to the course of the disease whatsoever.

Stories of Sickness, Howard Brody defines disease (= 'sickness') as 'the notion of *being abnormal* or *functioning in an abnormal way*' (45, emphasis in the original). Defined as such, the distinction from illness becomes very difficult. He indeed argues that 'the distinction between *disease* and *illness* has been much discussed, but never resolved, within the philosophy of medicine and the medical social sciences' (61,2; emphasis in the original). S. Kay Toombs refers to Jean Paul Sartre's analysis of pain and illness and his distinction of four levels: (i) pre-reflective sensory experiencing, (ii) suffered illness, (iii) disease, and (iv) the disease state (*Temporality* 230). The first three levels refer to how the patient constitutes the illness, the last to the doctor's conceptualization. When adopting the 'simple' definition or that of Sartre, according to Novack there may be disease without illness (e.g., hypertension), and illness without disease (e.g., hypochondria) (347). The question remains what is 'objective disease'. Is it only objective after demonstrating structural damage, or can it also be objectively based on words only? One must realize that often all we have is the word of the sufferer.

Richard J. Baron takes a clear standpoint on this topic in his article "An Introduction to Medical Phenomenology: I Can't Hear You While I'm Listening". He states that most frequently illness is seen as an objective entity that is located somewhere anatomically or that perturbs a defined physiologic process. One may say that such an entity "is" the disease, thereby taking illness from the universe of experience and moving it to a location in the physical world (*Introduction* 606). This strongly resembles Bourkes description of the 'ontological trap' as mentioned above.

However, when a patient has pain ('illness'), not always a 'disease' can be made of it, as there are many situations in which a patient has pain without objective abnormalities. Then, the diagnosis depends completely on the description and behavior of the patient, on his or her words and gestures. The problems that arise in such a situation may be easily seen. The value and accuracy of the diagnosis and subsequent treatment then fully depend on the ability of the sufferers to describe their pain and on the skills of the diagnostician to appreciate and interpret the words correctly. Here, the danger of a 'double trap' lies around the corner. Words are symbolical (or metaphorical), so in the symbolization of pain (translating one's sensation into words) and the transformation of such a symbolization into a diagnosis, which is a process of 'double symbolization', much can go wrong.

Nevertheless, in many pain syndromes nothing better is available than a translation of the words used by the patient into a diagnosis. What a

diagnosis is will later be considered in depth (see section ‘The diagnostic process’), as it is one of the main themes of this book.

The word diagnosis is derived from the Greek words dia (through, between) and gignoskein (to know) (Parrino and Mitchell). Surely, a correct diagnosis has many advantages. A diagnosis may also have disadvantages, for example, when it is used as a difficult term behind which a doctor can ‘hide’ and gain or keep a status. In what follows, I will consider some (neurological) examples of such diagnoses. For instance, when a patient tells a doctor that he or she has been blind in one eye during a short period, a diagnosis of ‘amaurosis fugax’ is made. This diagnosis is a literary translation of the words of the patient (the Greek word ‘amaurosis’ means ‘blindness’ and ‘fugax’ designates the temporality of the occurrence). As another example, ‘claudicatio intermittens’ is diagnosed when a patient tells the doctor that he or she limps after walking a certain distance because of pain in the legs. The term ‘claudicatio’ is an eponym, referring to the Roman emperor Claudius, who limped since his youth (Pearce *Claudicatio*). When a patient tells the doctor about experiencing memory loss during a certain time, the diagnosis is ‘transient global amnesia’, a literal translation of the complaints in other words. That the cause of such an occurrence is largely unknown remains hidden in difficult words. In line with this, Beer has argued that one of the primary functions of technical language is to keep non-professionals out (88). Butler (1997) also refers to this ‘specialized language’. For her, it may easily lead to a misconstruction of its own theoretical construction as a valid description of social reality (145).

This diagnostic translation into (difficult) words heavily depends on metaphors. There are numerous articles on the metaphors that describe medical situations and pain. The landmark publication on disease and metaphor is Susan Sontag’s *Illness as a Metaphor* (1978), but there are many other elaborations of the use of metaphors in medicine.[3] For Schott (2004) words used in this particular context do not mean what they mean in any other context. As said, the words of a patient expressing pain must be taken seriously and carefully weighted. This raises the question whether patient and doctor speak the same language. Do they have a ‘shared’ reality

[3] Examples are: Burnside (1983), Caster and Gatens-Robinson (1983), Hodgkin (1985), Marston (1986), Mabeck and Olesen (1997), Hutchings (1998), Arroliga at al. (2002), Brody (*Stories* 2003), Kirklin (2007), Rosenman (2008), Kirmayer (*Culture* 2008), Periyakoil (2008), Plug et al. (2009), Biro 2010; Casarett et al. (2010), Frank (*Metaphors* 2011), Loftus (2011), Zeilig (2014), Bourke (*Story* 2014) and Neilson (2016).

or use the same metaphors? The 'simple' answer might be 'yes', as doctors are human beings, who also feel pain when they hit their thumbs, but the reality is much more complex.

The different processes of making a diagnosis based on words seem crucial. Many pain scales and inventories are available to 'measure' pain (Noble et al., 2005). The prototype of these pain assessment-scales is the pain inventory of Melzack and Torgerson called the McGill Pain Questionnaire – so named because both researchers worked at McGill University (Melzack and Torgerson). Their questionnaire is purely based on what the person with pain says. In the questionnaire as many dimensions as possible of the 'pain experience' are included. Here, the word 'pain' refers not only to intensity, but also to a variety of qualities (50-51). For these qualities the questionnaire scores around 100 words, dividing them into sensory, affective and subjective qualities. The words included in the list are highly metaphorical, such as 'beating', 'flickering', 'pounding', 'boring', 'drilling', etc. The authors concluded that: 1) there are many words in the English language to describe pain; 2) there is a high level of agreement that the words fall into classes and subclasses that represent particular dimensions or properties of pain; 3) substantial portions of the words have the same or approximately the same relative positions on a common intensity scale for people with widely divergent backgrounds. (53)

The questionnaire was considered useful, not only to specify pain, but also as a diagnostic tool to separate different causes of pain (Melzack *Properties*; Katz and Melzack). For Biro, the McGill Pain Questionnaire not only helps patients to describe their pain but also substantiates the reality of their pain (158).

Due to its length, applying the questionnaire is rather time-consuming and therefore not much used in daily practice, although a shorter version was developed (Melzack *Short Form*). For scientific research, however, the whole questionnaire is still widely used, also expressed by more than 100.000 'hits' on Pubmed.[4]

In daily practice, however, mostly the so called visual analogue scale (VAS) is used, which asks the patient to score the severity of pain on a scale 0 (no pain) to 10 (the worst pain that this individual may imagine) (Huskisson 1974; Hawker et al., 2011). This scale 'translates' the pain of the patient into a number and a visual image, rather than putting it into words. The

[4] Last accessed 30-1-2022

choice here is between giving pain a number (VAS) or expressing it in verbal metaphors, such as those of Melzack and Torgerson. This choice seems crucial in doctor-patient encounters, and also in the context of this book, in which I, for obvious reasons, choose the verbal ('metaphorical') version.

The migraine sufferer Siri Hustvedt expresses her concerns about the VAS as:

> I have always found it comic when a doctor asks me to rate my pain on a scale of 1 to 10. Here numbers take the place of words. Rate my pain in relation to what? The worst pain I've ever had? Do I remember the worst pain? I can't retrieve it as pain, only as an articulated memory or an empathetic relation to my past self: childbirth hurt, migraines hurt, the pain in my cracked elbow hurt. Which one was a 6, a 7? Is your 4 my 5? [..] Does a 10 actually exist, or is it a sort of ideal representation of the unbearable? (*Shaking* 181)

Indeed, such scores may have a disorienting effect on those who find themselves translated into it. So, when making a 'diagnosis' – although only based on symbols such as words – one must keep in mind the reference to a commonly perceived reality, such as in Wittgenstein's beetle in the box. A right diagnosis of pain is important but must take into account issues such as unjustified 'objectivation' or 'metaphorization' of pain and too easy interpreting its causes (pin – pain). There is, in my opinion, a necessity to see the constructs of words about pain as more than just a representation, a measurement or interpretation. Crucial is 'diagnosis'. Every diagnosis by definition is retrospective (it 'looks back' as it bases on passed events).

The diagnosis of pain with words

As said, it is difficult to define 'pain', especially so because it often has no (presumed or detectable) objective signs in 'reality'. Patients with pain syndromes lacking objective 'proof' or 'representation' of the existence of their pain (when scans, blood tests and physical examination are normal), however, might experience a pain that is just as 'real' as the pain of the patients whose pain may be 'proven' and named after the lesion causing it.

The structuralist Ferdinand De Saussure (1857-1913) specified the meaning of words in terms of 'signifiers' (words) and 'signifieds' (objects). The signifiers depend on their difference with the meaning of other words (eg. 'mouse', 'spouse' or 'house'). They may be attached to 'real' objects in reality, but occur first as images or ideas in our head when we think about a

'mouse', 'spouse' or 'house'. These images or ideas and by implication their existence in reality De Saussure called 'signifieds' (De Saussure 2011). Although the images in people's heads may be very diverse, they can still fall under one signifier. For example, our mental image of a photograph of a mouse, a real mouse or a drawing of Mickey Mouse, all can fall under the signifier 'mouse'. De Saussure reconceived the problem of reference as one of signification rather than as mimesis (xvi).

But what about the signifier 'pain'? Of this word, almost everyone has one's own 'image', idea or sensation (beetle in the box, hit with the hammer on one's thumb), but one can call it a 'signifier without signified' in the sense that it has no 'material' place in reality. Pain is not there like a cat on the mat. It is in one's head (even when it is in one's toe or thumb – or head).

That signifieds and signifiers are distinct is easily seen: the sound 'mouse' is distinct from what that sound means or indicates in 'reality'. Yet the distinction of the signifier 'pain' with the sensory phenomena that this signifier indicates is much more difficult. The main cause of this seems to be the fact that there is no object in reality (signified) that embodies (the image of) pain.

For Scarry the only state that is as anomalous as pain is the imagination (162). For her, pain is a state remarkable for being wholly without objects and its imagination is remarkable for being the only state that is wholly its objects (162). Pragmatically, 'pain' has been defined as an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage (International Association for the Study of Pain, cited by Quintner et al, 2003). The emphasis on structural damage may indeed be called 'pragmatic', but it is not the whole truth, as there is also pain without (visible) structural damage. The pin, scratch or red toe are closely attached to the sensation (and sometimes erroneously to the cause) of pain, but in fact they are not more than metonymies (tropes of contiguity in place or time) or examples of synecdoche (a part stands for the whole/ pars pro toto).

Foucault states that 'the signified is revealed only in the visible, heavy world of a signifier' (*Birth* xvi-xvii). Seen as such pain may be seen as a signifier without a signified. Nevertheless, there must be 'something' in reality that represents pain. Is this the word 'pain'? Indeed, this 'something' often mainly consists of its translation in language.

Mark D. Sullivan (1995) discusses this translation in his article "Pain in Language. From Sentience to Sapience", predominantly basing his arguments on Ludwig Wittgenstein's standpoints:

> Wittgenstein believes the pain sensation alone is not sufficient to account for our experience of pain. He argues that a language based entirely on private pain sensations could not distinguish between correct and incorrect use of pain words and would therefore be meaningless. (5)

So, pain expression must be mediated by the conceptual structure of public language, or by the use of analogy. Pain is not only constructed by language in the Saussurean sense of an idea in our head, but also by a language that communicates ideas that were already formed in our head as part of a common experience and not in need of interpretation or classification (6). The common experience may be called 'reality', or at least 'part of reality'. We all have a box and in all our boxes sits a beetle waiting for existential explanation.

The patient as text

As said, for the expression, representation and finally the diagnosis of pain often only words are available (which may be seen as a Saussurean signifier without signified). Thus, what the patient says counts and in the transference of this reality of experience, he or she must be unconditionally believed.

In a sense, a patient may be read as a text. Such readings of patients are in line with the meaning of the word 'text' as it is used in literary theory: A text is anything that may be 'read'.[5]

When a patient experiences pain there may be no structurally visible abnormalities. Nevertheless, a diagnosis must be made for the benefit of the patient. As the words become or replace the signified (the image in one's head), it may indeed be argued that, in a sense, patients with pain can be 'read' as a (fictional) text, as they are only represented by the words they utter. This has been called 'the readability metaphor'.

It has indeed been suggested that people with symptoms such as pain may be 'read as a text' (Daniel *Patient as Text* 195). The patient's words must be transcribed into a diagnosis. In translating the patient's experience into a

[5] Sutrop (1994) even claims that ' "Text" has by now so many different meanings that its use seems altogether meaningless. All is text. Text is all'. She blames Roland Barthes to be one of the roots of 'this terrible mess' (39).

clinical text, a differential diagnosis is made. A critical moment, however, appears when one tries to detach the told to the telling. Nietzsche's pin – pain metaphor lays around the corner here.

For Stephen L. Daniel (1986) a patient is analogous to a literary text which may be interpreted on four levels: (1) the literal facts of the patient's body and the literal story told by the patient, (2) the diagnostic meaning of the literal data, (3) the praxis (prognosis and therapeutic decisions) emanating from the diagnosis, and (4) the change effected by the clinical encounter in both the patient's and clinician's life-worlds. (*Patient as Text* 195)

Thus, there is the important distinction between what the patient says and what is objectively visible/measurable. In general, doctors tend to react to the objective signs and less so to the words of the patients. Daniel, however, goes as far as to argue that any reader's experience of a poem, short story, or novel is similar to the physician's encounter with a patient. In his article he emphasizes that medicine is an interpretive art and the body has become a grammar of signs in a language any observant physician could read clearly and completely (198). Important is the effort to find meaning for the clusters of literal signs and symbols (204). This is the process of differential diagnosis which favors one possible diagnosis and neglects or rules out another leading to 'the physician's imaginative preconception of what the truth about the patient might be' (205). The clinical 'truth' becomes a judgement based on words, interpretation, emotions, empathy, criteria, poetics and politics.

The idea of 'reading' (the pain of) patients as a text has been adopted by many scholars. The reader of the text (often the doctor) is interpreting, rather than studying some kind of empirically existing reality in its own right. Everything depends on interpretation, but there is a distinction between the 'knowable' and the 'interpretable'. The first 'is already there', the second is 'produced'. The 'patient as text' is not a way of revealing the truth, but one of constructing, based on a part 'truth' and a part 'interpretation'.

Nancy M. P. King and Ann Folwell Stanford (1992) comment on what they call 'a close reading of the patient' (186) and warn for 'the temptation of labeling the narrator unreliable' (1987). This seems obvious, as – in my opinion – what a patient says must always be believed. Even if the utterances seem improbable or impossible, the reasons of the patient saying those words must be taken seriously. When patients describe their symptoms, sometimes 'strange' metaphors are used. One of my patients, for example, described her headache as the feeling of a birds' nest on her head.

‘Is this possible, doctor?’, she asked. ‘Of course,’ I replied, ‘You have made it possible’. Another patient described shooting pain from the right side to the left side of her head, thereby neglecting all neurological anatomical borders. For me, the descriptions of her pain were more important than my anatomical knowledge. Indeed, these pain paroxysms were later described as ‘epicrania fugax’ (Cuadrado et al., 2016) and we have to take them seriously because there are patients who describe them as such (Haan *Bestaat het?* 2017).

In “The Interpretive Maze: Reading Doctors Reading Patients”, King and Stanford describe the so-called communication triangle of author, subject and reader (191). In their view patients can be positioned as authors, the story they tell as the subject, and the physician as reader.

Dekkers accepts the suggested metaphor of ‘the patient as text’, but only under the condition that it should also include the body as a text (280). He argues that the body also has a story to tell. In the encounter with a patient, the doctor must not only ‘read’ the words, but also the ‘bodily signs’. This seems obvious and raises the issue: What text is to be interpreted? On the other hand, George S. Rousseau (1986) finds ‘the patient as text’ a cliché. For him it is an option as long as one realizes that there are senses in which the patient clearly is *not* the text (177). As examples of such senses, he mentions empathy and compassion. For him, doctors not only are readers, but also artists (160), and thus the patient not only is a text, but also an ‘inspiration’ that goes beyond reading. Unavoidably, inspiration also implicates interpretation.

In her article “Doctor-Patient/Reader-Writer: Learning to Find the Text” (1989), Rita Charon defines several possibilities for the patient as text: The the illness itself in which the patient is one character, the pathography in which patients record and interpret their own illness and the texts with ‘joint authorship’ in which doctor and patient co-author the story (138). The latter seems to resemble the current practice of shared decision making.

There are also scholars who warn against the tendency of too easily accepting the metaphor of reading patients as text. Rimmon-Kenan (2006) argues that patients often try to adopt the language of medicine, perhaps because it gives them the feeling of control and the illusion of being able to discuss their condition as peers (246). Here, the ‘text’ of the patient (verbal utterances, but also non-verbal signs such as grimaces, gestures, etc) is influenced by the situation (the ‘reading’) and therefore less reliable. The

words do not represent the 'embodied self' of the patient anymore, but also reflect the intention and the context.

The terms 'embodied' and 'embodiment' are used in different definitions by cognitive scientists, psychologists, workers in robotics, researchers in artificial intelligence, linguists and philosophers. The concept of 'embodiment' is called 'tricky'. In linguistics, a common definition of 'embodied' is that mind and body are inextricably linked and on equal planes (Biro 44). So, a Cartesian split between mind and body is rejected. One can see embodiment as 'being in the world' in the sense that 'I am my body', rather than 'I possess a body' (Toombs *Illness* 202). Another term is 'body without organs', introduced by Deleuze and Guatarri. Here, the lived physical body and the self which 'experiences' itself as being 'inside' the body are both consequences of reflexive, normative ways. The 'self-inside-the-body' is the body without organs (Nick J. Fox *Refracting* 352)

As possible safeguards against paternalistic misreading the patient, Hudson Jones (1994) mentions the importance of 'the patient's interpretive role' and that therefore the doctor-patient relationship reaches beyond the scope of the reader-subject-author analogy (194). It is important to seek a dialogical reading and see the patient as a person rather than as a text (197). King and Stanford also caution against 'paternalism in a modern dress' (186) 'one-sided reading' (189). They stress that a dialogic encounter between doctor and patient should avoid 'the physician's tendency to create monologic interpretations' (196). This criticism was also adopted by Gogel and Terry (1987), who see patients not as 'passive texts' (214), and stress the importance of a model that allows the patient's personal reading of his own body and condition (214). Baron in his short article "Medical Hermeneutics: Where is the "Text" we are Interpreting?" (*Hermeneutics* 1990) also emphasizes that the texts of patients are not fixed things (27). He warns for making the patient a 'source document' (28). This idea is also expressed by Shapiro (2011), who emphasizes that patients' stories can change from one telling to the next (68). The texts of patients must not be seen as 'objective truth'. Kirmayer (1992) warns against accepting language as too 'objective' and advices to realize that language itself creates meaning. Besides, he points at the possible 'destroying' effects of pain on language, a notion that lies close to the opinion expressed by Scarry in her book *The Body in Pain* (1985), and which will be discussed extensively later in this book in the context of migraine.

After 'the patient as text' a new 'textual' layer of the patient-doctor encounter emerges, that of the medical record. In their article "The Voices of the

Medical Record", Poirier and Brauner describe how a patient is not only turned into a 'text', but also into a medical record, a 'managerial, historic, and legal document', which they also describe as 'somewhat schizophrenic' (29). The content of the medical record must reflect its writers' medical interpretation and should be understandable for the reader. The record may contain the discourse of one doctor 'talking' to himself, or the contributions of several different doctors. Poirier and Brauner compare this with the 'heteroglossia' of Mikhail Bakhtin, mentioned earlier, which are fragments of texts that 'circulate' around the principal one and relate to various other texts, forming a 'social phenomenon'. Thus, the medical record creates a complex world, as novels do.

From the ideas of the abovementioned scholars it may at least be concluded that illness has acquired 'an unprecedented textuality' (Morris *How to Read* 140), and that this is especially true for patients with pain, as they often have only words to make their suffering part of reality. As a 'text', they need the best 'reader' they can get. A doctor must fulfill this task, being a 'professional reader of pain' (139).

But, considering the fact that the 'reality' of describing and reading pain is a problem by itself, as there is always a distance between author and narrator, the important question that now emerges is how to measure pain, as its expression mainly depends on words. How to detect the presence of pain? How to make sure that the pain can be read in the right way? The sufferer translates his or her sensation of pain – or other sensations, such as 'hunger' or 'love' (if he or she knows them) – into words and the listener firstly must believe the utterances and secondly interpret them. There is, however, an important difference between the sensation of pain and that of love and hunger, as explained by Scarry (*Body* 5). Whereas love (someone or something to be loved) and hunger (food) refer to objects in the external world, pain is not '*of* or *for* anything' (5; emphasis in the original). Pain has no referential content (no signified), and therefore 'resists objectification (in language)' (5; my addition between parentheses). Morris quotes the novelist (and doctor) Richard Selzer, who once argued that the language of medicine cannot quite pin down the object it seeks, no doubt because it is not an object (*Culture* 218). So, a process of interpretation (and exclusion) is necessary to make a diagnosis of pain.

The diagnostic process

Let me now look at forms of texts connected to the diagnostic process, which in most cases start with an encounter between patient and doctor. This

encounter is often called ‘asymmetrical’, as knowledge and emotions of both parties are not on the same level (Meeuwesen et al., 1991). The doctor who takes a clinical history may be compared with a historian (Riese 437). The encounter may lead, as Rimoldi states in his article “Diagnosing the Diagnostic Process”, to the conclusion that the diagnostic process is a problem-solving situation with doctors as active searchers and selectors of information in the hope this will enunciate a diagnosis, a diagnostic impression or no diagnosis whatsoever (271).

The medical curriculum trains students to perform the ‘life’ encounter with a patient in a systematic way, depending on the circumstances in which the patient is seen. Obviously, a patient with an acute illness in the emergency room has to be handled differently (more quickly and pragmatically) than a patient with an ‘elective’ complaint, such as chronic pain, who is visiting the out-patient clinic. As headache-patients are mostly seen in the latter situation, I will focus on that type of encounter. In medicine (and neurology), a disease is generally called ‘chronic’ when it lasts for more than 3 months, but for pain, even lasting more than 6 months (Lavie-Ajayi et al., 193) has been mentioned. Both periods are arbitrary and the origins of these are hard to trace.

The established approach to a patient with chronic pain consists of first taking a ‘history’, by asking about the current complaint, previous illnesses, medication and intoxications (alcohol, smoking, caffeine, drugs). This task is not easy in the case op pain. This ‘history’ may be considered unreliable, as the patients have to describe (their complaints) from memory, but nevertheless they must be believed unconditionally. It can be easily understood that this method will not lead to very reliable descriptions in patients who are mute, severely demented, aphasic, oligophrenic, unwilling, foreign or comatose (Schott *Communicating* 211). However, also in ‘normal’ patients (a contradictio in terminis), history taking often is difficult.

After questioning the patient, a physical and neurological examination is performed by the doctor, which may be rather threatening. For Leder (1984), in the physical examination the patient experiences her/his body as a scientific object beneath the dispassionate gaze and the palpating fingers of the doctor (*Medicine* 33). Toombs (1987) says of this situation that the patient perceives himself to be an object of investigation, rather than a suffering subject (232).

Taking these descriptions together, it becomes clear that a neurological examination (often necessary when the patient has pain and of crucial importance when the patient suffers from headache), contains elements that emphasize this 'objectification of the body', including fundoscopy (literally looking into the patient by looking at the retina with a special lens) and the investigation of reflexes (the patient is not only objectified, but also turned into a mechanical puppet).

As the neurologist William Gooddy describes,

> a patient must conform with a large number of test patterns, whether it be in his eye movements, his response to having the soles of his feet stroked, his explanations of the certain sounds spoken to him, his ability to recall the names of kings and queens, his attitude to politics, newspapers, radio and television, and his judgement of the safety or desirability of remaining alive. If he falters in responding to a bright light flashed in his eyes, if he cannot distinguish a penny from a shilling, if he does not quite know the similarity between a house-fly and a tree, if he no longer wishes to drive lorry-loads of waste paper five days a week for the next forty years, he may be subjected to the most rigorous correctives, which include powerful persuasion, the strongest available and sometimes dangerous drugs, a collection of tests which require the penetration of his deepest interior, and the direct attack upon his most vital and valuable organs, some parts of which may actually be removed and studied elsewhere. (*Disorders* 664)

The 'gaze' of a doctor on the patient during the physical examination may be compared with that described by Michel Foucault in *The Birth of the Clinic. An Archeology of Medical Perception* (1994) as 'the eye that knows and decides, the eye that governs' (89). He describes the clinic as the first attempt to order a science on the exercise and decisions of the gaze (89). The gaze is used to regroup and to classify patients by species or families (89).

In the chapter "Seeing and Knowing", Foucault further reflects on the importance of the 'clinical' gaze. In his opinion, the gaze refrains from intervening, is silent and gestureless and has 'the paradoxical ability to *hear a language* as soon as it *perceives a spectacle*' (108; emphasis in the original). So, the gaze seems part of reading the patient as a text, as described above. Foucault distinguishes a hearing gaze and a speaking gaze, between which a balance must be sought. He points at the distanciating effects of the gaze and at the artificiality of the diagnoses thus made. The gaze classifies, includes and excludes. When dealing with patients with pain, the 'gaze' is predominantly used to exclude pathological signs, as the diagnosis of pain-syndromes mainly depends on symptoms that are

invisible. Of course, the gaze still is important by looking at and interpreting non-verbal signs such as grimaces, gestures, clothing, etc.

The 'gaze' on pain was eponymously worked out by Sontag in her short essay *Regarding the Pain of Others* (2003). In this text, she focuses on photographs depicting and/or representing pain. The advantage of a photograph is that it combines objectivity with 'a point of view' (23), which is total subjectivity. But, she admits, for the identification or misidentification of the photograph words are necessary. No picture can gain 'meaning' without words. For her, sentiment is more likely to crystallize around a photograph than around a verbal slogan (76). The description of a photo in words resembles the so-called 'ekphrasis', the 'verbal representation of visual representation (Mitchell 152). For him, on the one hand 'words can "cite", but never "sight"' (152), on the other hand writers can make us see (152). He states that language can stand in for depiction and depiction can stand in for language (160).

Maybe Sontag is right in her conclusion that sentiments are more likely to crystallize around a photograph than around a verbal slogan, but I would argue that the words of pain also are 'ekphrastic': they produce an image and (should be) sufficient to 'mobilize' the sentiments of the listener and 'viewer', although – in a sense – the doctor will also 'read' the patient as a kind of painting. The main shift, however, is from one sense to another, from hearing and saying to seeing and saying. Deborah Padfield elaborates this in her article "Representing the Pain of Others" (2011). She starts with emphasizing the danger of using words without checking the picture they generate in the minds of others (242). One of the dangers of language – she argues – is that often people assume they understand each other when at times they are speaking of very different experiences (241). This danger is particularly immanent in the health setting.

Brody (1994) describes the encounter of patient and doctor as the 'deeply rooted 'need to know' versus an equally deep 'need to be known' (*Broken* 81). The power disparity between the parties (82) is difficult to overcome as no patient would favor 'the help of relatively powerless physicians' (82). According to Mintz (1992), medical language frequently creates a distance between doctors and patients, enhanced by special forms and metaphors. For him, by means of the words the patient is dehumanized. Dekkers (1998) adds to this discussion that doctor's and patient's narratives are often seen in opposition to each other (288). In his opinion, the clinical encounter may even be seen as a meeting of two worlds. Patients and doctors are in two quite different 'realities' (289). Here, the obvious task of both parties is to

search for a shared reality. Charon (2006) does not have much confidence in the doctor – patient encounter either. For her, doctors use to talk in technical jargon, usurp authority, withhold critical information, deceive patients about their medical conditions, ignore what patients brought to the conversations and control what would be talked about and how (*Self-Telling* 193).

Maybe the disadvantages of 'the patient as text' and the hierarchy in the patient-doctor encounter disappear when techniques from literary studies are used and the patient is seen as a 'literary text'. In this way, some more distance might arise, but on the other hand, the positions of both 'parties' may become more equal, more as 'author' and 'reader', as I shall argue hereafter.

The patient as literary text

The thought of reading a patient as 'literary' text might seem strange at first sight. Illness and disease are serious matters, which differ considerably from fiction. Nevertheless, imagine a patient telling a doctor about his or her complaints. The patient searches for words to describe something that is real to him or her, and sometimes even 'looks in the sky' for the words. The challenge for the patient is to describe an internal perceived 'reality', for which words and images are the only available symbols. In fact, patients hereby 'create' an extension of their reality, thereby creating a new world on a new ontological level. Without any doubt this resembles the creation of a fictional text. This 'fiction-like text' must be appreciated and interpreted by doctors. For Rousseau (1986), 'doctors *must* imagine a fictive world, in addition to a real one, if they are to perform their work' (160; emphasis in the original). He further asks 'in what *precise* sense [..] is medical diagnosis based on imagination?' (160; emphasis in the original). For him, a possible answer is that literature helps the doctor to read, explicate and interpret, as well as to control language (161). This explanation, however, seems not to go far enough. Literature is not only an aid for a doctor, but also a substantial and intrinsic part of the encounter with the patient. Analyzing texts produced by patients is the daily work of doctors. So, they must be sure to be good at it.

Texts may be analyzed in many different ways. The formalists, for example, saw a literary work as an assemblage of 'devices', which they interpreted as interrelated elements or 'functions' within a total textual system (Eagleton 3). For them, literary language deformed ordinary language, often leading to an 'estranging' and 'defamiliarizing' effect. They saw literary language

as a set of deviations from a norm, a kind of linguistic violence (4). Formalists focused on the study of texts without taking into account any outside influence. Consequently, as Eagleton argues, their standpoint leaves the definition of literature up to how somebody decides to read, not of the nature of what is written (7). This makes the formalists' way of interpreting text less suitable for the patient – doctor encounter, in my opinion. The structuralists, on the other hand, emphasized the relation between 'signified' and 'signifier', as described above in the paragraph about Ferdinand De Saussure. The resulting 'pain as a signifier without signified', seems not the ideal starting point for the patient – doctor communication either, especially so in the search for a common 'reality'. Important for the post-structuralists (e.g. Michel Foucault) was the notion of 'discourse', defined as a group of statements which provide a language about a particular topic at a particular historical moment' (Hall, 29). Although of great importance to the present book (and further worked out in chapter 3), discourse analysis seems more suitable for more general, historical and cultural issues than for the analysis of two persons talking to one another (although at the background of the language of both the speaker and the listener certain discourses certainly are active). The 'reception theory' emphasizes the role of the reader in determining the meaning of a text. Eagleton even states that without a reader there would be no literary text at all (64). Within reception theory, reading is more important than writing. There is an 'implied reader'; a certain kind of reader is already included within the very act of writing itself (73). The latter situation, with the writer taking the possible reception of the reader into account, resembles that of patient and doctor, as there is the effort of the patient ('writer') to try to 'persuade' the doctor ('reader'), by means of his or her 'rhetoric', or call it 'performance'.

In her article "Illness as Argumentation: A Prolegomenon to the Rhetorical Study of Contestable Complaints", Judy Z. Segal describes the rhetoric of the doctor-patient interview by referring to Aristoteles:

> The second rhetorical concept is *pisteis*, Aristotle's catalogue of persuasive appeals, including the following: *ethos*, the appeal from the character of the speaker; *pathos*, the appeal to the audience's emotions; and *logos*, as Aristotle says, 'the arguments themselves' – both are inductive (largely, arguments from example) and deductive (arguments by reasoning from general principles). (231; emphasis in the original)

She emphasizes that one should be cautious with illness theories that are based on 'types of patients', and advises to direct attention to what patients say, thereby especially taken *pisteis* into account and to see illness as a conclusion drawn from a series of arguments that may be judged on their

merits, without moralizing element, for example, of perceptions of personal weakness, over-sensitivity, neuroticism, delusion, dissimulation or fraud (237). It has been argued that even in Aristotle's day, the term 'rhetoric' had acquired unsavory connotations (London 291). Anyhow, where diagnostic doubt exists, it should not come to rest on the shoulders of the patients. What Aristotle calls an 'argument from past facts' is that a patient who expresses pain should be believed (Segal 237).

For the philosopher Hans-Georg Gadamer (1979), Aristotle took distance from a too much 'technical' reading of words (80). Aristotle argued that there is an asymmetry between language (which is finite) and the world (which is infinite) and therefore one will eventually run out of words and therefore need to economize, by extending the meaning of a particular word to cover additional objects. Gadamer's ideas, inspired by those of Aristotle, might be used for an analysis of the clinical encounter between patient and doctor to be considered as a 'literary' act, which may be analyzed on several specific 'literary' levels.

First, the situation resembles that of a 'drama' where two protagonists are in a dialogue. Strictly spoken, it is indeed an artificial situation where both parties are 'not themselves' and 'play a role'. For Moscoso (2012), pain mobilizes all the elements of theatrical representation. 'The experience of harm has its actors, plot, stage, costumes, props, scenography, and, of course, its audience' (6). Indeed, doctors often are in disguise and 'uniformed' (in a white coat) and speak in a different way as they would speak when at home with their family or friends. Patients often are a little bit nervous, also because they are interrogated with peculiar and sometimes profoundly personal questions (e.g. about smoking, drinking, previous diseases, social circumstances, sex-life). The doctor chooses 'professional' questions, the patient gives 'persuasive' answers to optimally persuade the 'one-person audience' about the truth of his or her symptoms. The general sources of reasoning of this situation may be considered as Aristotelean *topoi*, which can be translated as 'stereotype' (7). The 'rhetoric' potential of the patient - doctor encounter is very important. Most patients present their complaints as clear and immanent as possible to a doctor, to enhance the possibility to be taken seriously, be understood correctly and receive a satisfying diagnosis. Patients use words to be believed and to be taken seriously. In sharp contrast with this are patients who e.g. visit a doctor to be tested for approval to regain their driving license after a neurological disease. These patients, in my experience, use 'rhetoric' to prove that they are relatively 'healthy' and have no limitations in their functioning whatsoever. These opposites show that the 'rhetoric' of a patient depends on the final goal to

be achieved. It is 'teleologically' determined. The rhetoric is changed by the context, and it may be said that 'even the most transparent, immediate and visible of emotions, pain, disappeared in the midst of rhetoric artifice' (35). So, here we have indeed a dramatic interaction that serves to theatrically produce a 'truth' or at least a shared ontological level, that unfortunately is often not the same for the different actors in the drama.

Second, there is the 'story' of the patient. This 'narrative' component of the patient – doctor encounter has been discussed in many articles, and even has gained a separate place in medicine, called 'narrative medicine' described as the study of the whole spectrum of associations between medical topics and literary texts (Charon 1989; 2001; 2006). The spectrum contains patients writing about their illnesses, doctors writing about their patients, students learning to write patient stories (Kaptein et al.) and so-called 'bibliotherapy', which is the therapeutic effect of books (Jack and Ronan). The prototypes of the 'narrative' or 'story' of the patient were presented by Frank (*Reclaiming* 5) and discussed in detail by Brody in his *Stories of Sickness* (2003). In their theory, three types of stories may be distinguished: Quest (search for healing), restitution (returning to the healthy state) and chaos (which is more like an 'antinarrative', as the sufferer has no control or oversight). I will come back to this later.

A third option to view the patient – doctor encounter is to see it as a lyrical situation as in a poem.[6] Here, the 'author' (speaker, focalisator, patient) utters his or her text, but the 'reader' (doctor) is *in concreto* not present and even of no importance. The text is autonomous, it is a 'closed' entity and can only be 'overheard' by a listener who may be considered an outsider. Or – according to Frank – it is a privacy temporarily made visible to the listener (*Foucauldian* 339). In his opinion, most first-person writing about illness is already more lyric than narrative (340).

One of the most important works of Aristotle, *Poetics*, includes this 'overhearing' without personal involvement as a way to unveil the world. The 'reader' or 'listener' gains knowledge of the 'truth', but does not influence it. Here, we are dealing with 'how language works', what it does

[6] The term 'lyrical' has different meanings (Culler *Literary Theory* 73-82). It can be used to describe expressions of deep emotion and enthusiasm in a spoken or written text, performance, or any other depiction. In relation to a poem it is used in the sense of a 'lyrical text', in which a subject expresses him or herself, without speaking to someone in particular. In this situation, the 'reader' can be described as being 'eavesdropping'. The 'speaker' keeps a monologue.

to the reader, but without any influence of the reader on the 'work'. In Aristotle' theory, theatrical texts 'work' best when they involve the principle of concentration ('unity of time, place and action') and that of 'verisimilitude' (an author should present what is probable and credible). Maybe this can also be applied to 'non-theatrical texts'.

The so-called 'Aristotelean turn' contrasts with the 'Platonic' turn. In his 'dialogues' Plato does not take part of the encounter himself. He describes 'from a distance' a conversation between Socrates and another person (e.g., Adeimantus, Glaucon), therefore they are not called 'Platonic', but 'Socratic dialogues' (Erich Frank 41). The 'dialogue' is rather peculiar as one of the participants talks and is only interrupted by short utterances of the other, with words as 'yes', 'naturally', 'quite true', 'certainly not' or 'unquestionably'. Due to this 'one-way discourse', the 'dialogues' may be called 'quasi-dialogues' or even 'monologues'. It has been suggested that Plato chose this form to 'mask his own view', probably because at that time taking a certain philosophical/political position was (as Socrates had witnessed) not without danger (Krentz 34). Nevertheless, these 'dialogues' have been described to represent the 'double aspect of the dialogue – as work of philosophy and as artwork' (Hathaway 195). The dialogues have also been compared with 'dramas' (Krentz 33). As 'one-way dialogue', however, they cannot serve as a model for a patient – doctor encounter. It may be argued that the 'ideal' communication between patient and doctor consists of several different parts: first, the patient holds a Platonic monologue and the doctor only says 'yes', 'naturally', 'quite true', 'certainly not' or 'unquestionably', or only asks some simple questions. Then an Aristotelean dialogue develops between two equally important speakers, which is finally followed by the monologue of the doctor during which the patient only utters 'yes', 'naturally', 'quite true', 'certainly not' or 'unquestionably'. As for the two 'one-way' parts, such an encounter may be called a 'double' or 'mirroring' dialogue in the sense of Plato. Maybe the patient-part is 'artwork' and that of the doctor 'philosophy'.

In contrast to the Platonean part, the 'Aristotelean turn' is defined by Brody as 'more accepting of the role of narrative' (*Stories* 188). It offers the opportunity to systematically analyze the patient – doctor encounter as if it was a literary text. Aristoteles' distinction of three aspects of such an encounter (*ethos*, the argument of the speaker; *pathos*, the appeal to emotions; *logos*, the argument itself) are already described, but another of his categorizations is of more importance here. Aristotle distinguishes as 'three branches of knowledge' *techne*, *episteme* and *phronesis*. The first, *techne*, involves making, producing objects, technology (Frank *Asking* 221).

Episteme is concerned with universal laws, it 'teaches the laws that govern what is crafted' (221). *Phronesis*, on the other hand, is the opposite of acting on technology and universal laws (scripts and protocols). It depends on experience and is also called 'practical wisdom', or 'the habit of practical reasoning' (Gadamer 81). It is 'the application of more or less vague ideals of virtues and attitudes to the concrete demands of the situation' (82) and is an ability to apply general or universal knowledge to particular situations (Gatens-Robinson 174). As patients are often approached as a 'puzzle' (169), an 'ill-structured problem' (170), or by 'pattern recognition' (171), maybe a turn to the practical wisdom of *phronesis* and being less 'mathematical' ('puzzle', 'structure', 'pattern') may help to overcome the one-sided commitment.

Fredrik Svenaeus (2000) emphasizes that the meeting of patient and doctor must be a dialogue. As the clinical encounter is characterized by an 'asymmetrical estrangement', the goal must be that the meeting leads to 'a shared language' (179). To reach this goal, Gadamer's 'merging' or 'fusing' of horizons ('Horizontverschmelzung') is crucial. In this concept, the process of an exchange of ideas (between two persons, but also between a reader and a text) is described. When two persons exchange their ideas and opinions in a conversation, they will start with different prejudices and biases, and before having read the text, the reader has a 'pre-notion' of what it will be about. During the conversation, or while reading or re-reading, by receiving new information, a fusion of the visions of writer and reader will take place and will consequently lead to approaching of the horizons. Both parties will understand the text from their points of view, with their own 'prejudgments'. Typically, the reading and re-reading of the respective 'texts' lead to new understandings and fusing of horizons of meaning, and so become part of a new 'super-horizon'.

In a subsequent article (2003), Svenaeus works out the idea of applying Gadamer's philosophy to the clinical encounter by focusing on *phronesis*, placing it central in 'Gadamerian hermeneutics of medicine'. Central is the *phronimos* (wise man), who 'knows the right and good thing to do in *this* specific situation' (418; emphasis in the original). The main theme in Svenaeus' article is a reaction to another article called "Why the Practice of Medicine is not a Phronetic Activity", published by Duff Waring in 2000. Waring contends that 'Aristotle did not regard the application of medical reasoning to clinical cases as a form of *phronesis*' (139; emphasis in the original). For him, Aristotle regarded the practice of medicine 'as a unique kind of *techne* that could be analogized to *phronesis*' (139-140; emphasis in the original). One of his arguments is that Aristotle 'cites health as

something which the physician aims to produce' (141), and one of the characteristics of *techne* is that it includes knowledge of steps that bring something into being. In his opinion, craft knowledge of production (*techne*) is not included in practical wisdom about good conduct (*phronesis*). Svenaeus (2003) agrees with Waring that for Aristotle, medical activity belongs to the realm of *poiesis*, rather than *praxis.* There are indeed important differences between *poiesis* and *praxis*. Whereas *poiesis* connotes 'making' and 'aims at an end distinct from the act of making', *praxis* connotes 'doing'. Consequently, doctors have developed *techne* rather than *phronesis*. Svenaeus, however, gives two counterarguments to this opinion. First, Aristotle associated *phronesis* less with medicine than with politics, due to the structure of the Greek society. Second, for him, according to Aristotle, 'health is not something that the doctor can bring about by himself, but something that can only be brought about by the doctor helping nature heal *itself*' (410; emphasis in the original). He concludes that for Aristotle medical skill is a *techne* that is very similar to *phronesis* (411). He then goes one step further in arguing that medical practice never 'makes' anything in the sense of *techne*, but rather helps to re-establish a healthy balance which has been lost. He thus concludes that medical practice is closer to *phronesis* than to *techne* (420-421).

So, to summarize, the most important points of the previous sections are that the patient may often be seen and read as a text, and even as a literary text. Important in the encounter of patient and doctor is the hermeneutic merging of horizons, in which – from the side of the 'reader' (doctor) – *phronesis* rather than *techne* is required. The next question is which methods the 'reader' (doctor) has at his or her disposal in the encounter with the 'text' (patient). In other words, how to analyse words of pain?

Many texts have been published about the relation between pain and the words used to express them. For example, much attention has been paid to how words are used to describe pain in different cultures, such as a comparison of pain descriptions in Jewish, Italian, Irish and 'Old American' (Zborowski 1952), Italian and Irish (Zola 1966), English, Thai and Japanese (Fabrega and Tyma 1976), and separate analyses of words used to express pain in Thai (Diller 1980), Indian (Pugh 1991) and Swedish (Gaston-Johansson and Allwood 1988). Other studies addressed gender differences in the language to describe pain (Strong et al. 2009). Agnew and Merksey (1976) sought – and found – differences in the language used by patients with 'psychiatric' and 'organic' pain. These topics (different cultures, different genders, different presumed causes of pain), however, are not the

topic of this book. Here, the language that makes an understanding of the 'reality' of pain possible will be sought.

As early as 1887, an anonymous author asked what pain is, immediately giving an answer to his/her own question: 'No one knows' (Lancet 333). Almost 50 years later, the British neurologist MacDonald Critchley contemplated on 'Some Aspects of Pain' and concluded that the effects of pain are 'inconstant, unreliable, and non-specific', before turning to fiction to illustrate the truth of his statement. Somewhat more recently, Rashi Fein (1982) wondered what is wrong with the language of medicine and after her analysis emphasized that to express pain words are important and powerful. Ehlich (1985) distinguished three types of expressing pain: crying and groaning, pain interjections and pain descriptions (180). For him, the expressions in the latter category are closest to the traditional categories of linguistic analysis (183). Ehlich turns to Wittgenstein's assumption that all language use is to be seen as an instance of making assertions (185), but concludes that the underdevelopment of the semantic field of expression for pain forces to speak with unclear metaphors (185).

In the next chapters I will mainly focus on the use of these metaphors in migraine, a very specific pain-variant with many remarkable aspects. I will first work-out the thoughts on 'real' migraine and thereafter on its 'fictional' form.

CHAPTER 2

MIGRAINE AND WORDS

After outlining in chapter 1 the medical and literary diagnostic aspects of pain in general, thereby mainly focusing on the pros and cons of the process of how to read a patient with pain as a kind of text, I will now turn to the case of headache. First, I will discuss headache in general and after that turn to a specific form of headache: migraine. As can be read in the Preface, this form of pain has not very often been specifically addressed to in the majority of scientific literary publications and books about pain, but in my opinion nevertheless constitutes special aspects of the relation pain – language – reality. In most instances, migraine will turn out to be the 'prototype' of a logocentric type of pain.

First, I return to Ludwig Wittgenstein's metaphor of comparing pain with a 'beetle in the box'. This comparison may be easily translated to headache, reading 'pain' (or 'brain') for 'beetle' and 'skull' for 'box'. Indeed, no-one can look into the skull or thoughts of another being. No-one can feel the someone else's headache. Up there, on the top of their bodies, all humans have a 'box' containing a private 'beetle', a place where pain is individually and metaphorically perceived. The beetles of all of us, however, must have something in common.

Like many other kinds of pain, headache as a symptom is not very specific, as it may arise in many situations and be caused by many conditions. For example, headache may occur during a flu, a hangover or sinusitis. It may also occur after hitting one's head, a cerebral hemorrhage or be part of a chronic condition such as tension type headache, cluster headache, or migraine.[7] Joanna Bourke expresses this non-specifity in her seminal work *The Story of Pain* (2014) when she writes that headache patients were probably the most stigmatized of all people-in-pain. She points at the fact that the anguish of those sufferers did not fit many of the neat conceptualizations

[7] As described in chapter 1, a disease is called 'chronic' when it lasts for more than 3 months and for pain one counts sometimes even more than 6 months (Lavie-Ajayi et al., 193).

of “real” pain, thus baffling, frustrating, and irritating caregivers. Their pain behavior was irksome because of the absence of any objective signs (42).

Thus, like ‘pain’, ‘headache’ is a very broad term and – especially when it occurs in a chronic way – its sufferers are often not taken seriously (Borsook and Dodick 2015). In contrast with that, almost all headache sufferers think that their pain exceeds that of symptomatology alone and points at a serious disease, for example a brain tumor. So, there are connotations of headache with something serious, whereas in most cases this (fortunately) is not true.

The experience of having a headache and being told that ‘nothing is wrong’ is described by Yuval Noah Harari in *Homo Deus*:

> Thus, suppose I feel a sharp pain in my head and go to the doctor. The doctor checks me thoroughly, but finds nothing wrong. So he sends me for a blood test, urine test, DNA test, X-ray, electrocardiogram, fMRI and a plethora of other procedures. When the results come in she announces that I am perfectly healthy, and I can go home. Yet I still feel a sharp pain in my head. Even though every objective test has found nothing wrong with me, and even though nobody except me feels the pain, for me the pain is 100 per cent real. (167-168)

In other words: after describing a symptom as headache, virtually all sufferers consider it a word / signifier of which the (serious, objectively present) signified has to be decoded. As stated above for ‘pain in general’, however, the signifier headache often is also without signified, but it still is an image or idea in our head that is 100 percent real.

The description of a headache by its sufferer is often problematic. A frequently cited description is that of Virginia Woolf in her short essay *On Being Ill* (2002): ‘Let a sufferer try to describe a pain in his head to a doctor and language at once runs dry’ (7). This citation is often used to illustrate the destructive powers of headache on language, but this explanation may be challenged as I will discuss in chapter 4. Woolf explains the meaning of her words in the subsequent sentences: ‘There is nothing ready made for him’ and consequently ‘he is forced to coin words himself, and, taking his pain in one hand, and a lump of pure sound in the other [..], so to crush them together that a brand new word in the end drops out’ (7). So, the sufferer will try to choose or invent the right words to describe the headache. There must, however, also be a reader of those words, who may only interpret the (words of) pain when comparing these with his or her own suffering (or beetle in the box). This situation can be described as by Armstrong (1984), in that its subjective nature is such that it is only through personal experience

of pain that a doctor may have insight into the meaning of the descriptions given by patients (742). Of course, this does not mean that doctors may only understand the diseases of their patients after having suffered from those diseases themselves, but in the case of pain (such as headache) it might help.

To 'measure' the severity of headache, next to words and metaphors, in daily practice, often the VAS scale is used (Huskisson 1974; Hawker et al., 2011) (see chapter 1). This scale requires the patient to translate the pain to a number and represent it on a visual scale. It may be easily seen that the reliability of this 'representation' will be rather low, as the process contains several translating and possibly deforming steps: from individually perceived headache to a number, then to a visual scale, then to an interpretation by a caregiver in words and finally from these words into a 'diagnosis'.

Another method is the McGill pain questionnaire, also described in chapter 1, of which Robert Kugelmann (2003) has put that:

> the relation of pain to language, the major human sign system, is complex. Severe pain reduces one to moans, groans and screams; pain is often verbally inexpressible and, as a result, a common pain assessment tool is a series of schematic drawings of faces, from grimace to happy face, with which a patient can indicate pain level. At the same time, pain overflows speech with a florid growth of metonymical and metaphorical terms, captured, for example, on the McGill Pain Questionnaire. (*Symptom* 37)

The 'verbal' McGill Pain Questionnaire is, however, despite all its subtleties and metaphors, probably not suited to fully describe the experience of headache. To overcome this problem, Hunter (1983) proposed a 'Headache Scale' based on the McGill questionnaire, but her selections of verbal signifiers turned out to be insufficient to distinguish between the different forms/causes of headache.

In their article "Language of the Patient with a Raging Headache", Friedman et al (1979) analyze the steps of the patient – doctor communication. They state that:

> first there is the patient's perception of headache and then the patient's selection of a set of verbal symbols (words) which he or she judges as having some relationship to the subjective state, then there is the uttering of the words selected, then there is the perception of the doctor of the patient's statement (the selected words), then there is the translation of the (selected) statement of the patient by the doctor. (401)

Although all of these steps are of great importance, the second (selection of verbal symbols by the patient) and the last step (translation by the physician) are crucial. Indeed, as the authors emphasize, in the communicative process between patient and physician, words are symbols and subjective states are referents (401). Here, they seem to be talking about signifiers and signifieds (referents). It may thus be concluded that in a translation of what a patient feels or says, the verbal expression (symbol) and thus the comprehension of or diagnosis by 'third' parties, such as a doctor, will be – at least – somewhat unreliable, as there is no circumscript 'referent' or 'signified'.

Havi Carel (2011) adds another aspect, by writing about his head with a headache that it:

> remains attached to me and becomes increasingly conspicuous, increasingly disabling. The claim here is not that the body is a tool, but that a similar process of becoming conspicuous characterizes both forms of malfunction. But the body is different from a tool in important respects. Its dysfunction is so important, so intimately linked to our well-being because it *is* us. (40; emphasis in the original)

What is important here is that the notion of 'us' (or 'me', my 'self') is mainly seated in the head, which emphasizes the importance of the head and that of head-ache. It is difficult to separate the 'us' with headache from its emotions, which emphasizes the importance of making a headache diagnosis more 'objective'. For this, in the first place, most patients and many doctors search for 'objective proof', for a visible and touchable cause of the pain. Often, only headache with such an objective sign is 'believed' and taken seriously. Therefore, in the next section I will first describe this association of headache and objective signs, such as a cerebral scan.

Headache and objective 'sign'

As said, most headache sufferers are at times convinced that they have a serious intracranial disease. Stoddard Holmes and Chambers (2005) translate this fear: Not only is pain literally always in one's head, but it is also almost always experienced within an imaginative as well as a material context (134), the 'material context' being the fear of a tumor or hemorrhage. In clinical practice, the fear of the patient to have a serious structural lesion in the head often makes the doctor to order a 'scan' (CT or

MRI).[8] In doing so, the doctor does not only distrust his own clinical interpretation, but also the scientific investigations of this situation, as virtually no patient with headache and a normal neurological examination has a relevant abnormality on a scan. Besides, most importantly, this doctor does not trust the words of the patient.

For Leder, in case of headache the two-dimensional artificial depictions of the skull reduce the importance of words (*Medicine* 36) and for Albert Howard Carter mimesis in modern medicine is increasingly technological: physicians turn more and more to technicians and machines for development of information (144). Through the production of these artifacts, not only the patient, but also the visual representation (CT or MRI) will be read as a text. Indeed, for Heelan, there is an analogy between reading a text and 'reading' an instrument (189). For him, the consequence of this reading is that 'once an instrument is *standardized, the instrument itself, being an embodiment of the theory, can define the perceptual profiles and essence of a scientific entity*' (192; emphasis in the original). In other words, the text (in this case the cerebral CT or MRI) becomes a representation of the headache of the sufferer. This mechanism resembles the Saussurean relation between signified and signifier, but even more the theory of Peirce. His three types of signs are the icon, the index and the symbol. 'Icon' means that the relation between sign and meaning is 'motivated' on resemblance (e.g. a picture of a person that looks like that person). In this sense, a CT or MRI may be seen as an icon as they resemble the 'real' brain of a subject. The index is motivated by contiguity (e.g. as smoke is associated with fire). The 'smoke and fire' metaphor may be used for a CT and MRI also, as these scans show a representation, but not the (functional) contents of the brain of which headache is one example. The symbol – finally – is not motivated, but its meaning is arbitrary, it depends on an agreement. In case of a CT or MRI, the scans are symbolic as it is universally agreed to see these two-dimensional black-and-white pictures as a depiction of a human structure, or even (mistakenly) as a human function, such as a headache. For doctors, the visual image of the inside of the head of a headache patient often plays a more important role in the diagnosis than the verbal representation of the pain. It is as if technology makes the body 'readable', and as if the job to make a diagnosis is 'delegated' to the machine that makes the picture, or to the reader of that picture (mostly the radiologist). For example, often only after obtaining a 'normal' scan do the

[8] A CT, or computed tomography, is a depiction in slices making use of X-rays. A MRI, or magnetic resonance imaging, makes use of a magnetic field to do the same, and in general is more precise.

words of the patient become important to make a diagnosis. A head-scan showing abnormalities renders the words of the patient less important, as then the diagnosis will be 'tumor', or 'hemorrhage', or something else that is presumed to cause the headache (but never a 'void').

According to James G. Brueggemann in his article "Poetry and Medicine" (1985) the technological aspect of the health care system have impaired communication between patient and physician and a demand for 'tests' is substituted (371). Physicians become technocrats and patients shoppers. It has even been said that for doctors who read a CT scan the imagination and the power to heal is reduced (Bowman 279). An example is the situation in which the physician need not even be in the room when information is gathered about the patient. The result of this all is that the 'Foucauldian gaze' not only refers to patients, but even more so to their technological representation, mistaken as signified.

Samuel A. Banks (1992) describes this shift from patient to technology as:

> Much is lost in the telling. In the anomie and routine of these massive crisis houses, the narrators are usually distracted, interrupted, often unheard. Without an attentive audience – clear evidence of understanding – the tale is told in fragments that quickly dissolve in the swirl of physical examinations, laboratory tests, record keeping, and treatment procedures. (26)

Here, the 'massive crisis houses' are hospitals and medical centers, and the 'narrators' – of course – the patients. Unfortunately, their 'tales' or texts get lost. Indeed, scans are often seen to represent a patient, sometimes even leading to a diagnosis of so-called 'scan-negative headache' (a description used for a patient with headache and a 'normal' scan). Such a description may be seen as bypassing the words and feelings of the person with pain. Patients with headache and no abnormalities at examination or morphological alterations on a scan have a double problem as there is the possibility 'that *their illness* will never be given the status of a disease where the cause and the treatment are already known'[9] (Moscoso 166; emphasis in the original). David Biro rightfully points at the fact that there is no definite way to verify someone else's pain, no foolproof, sophisticated test like an MRI or a PET scan, so in the end, 'all we have is the word of the sufferer' (133). Indeed, a diagnosis of 'scan-negative headache' must be seen as an error, as it combines and thereby confuses subjective signs ('headache') with technology ('scan'), neglects the personal suffering of the patient and suggests some sort of devaluation of the pain. Such a scan may even 'permit

[9] See chapter 1 for the distinction between illness and disease.

already overworked doctors to rely increasingly less on their intuitive skills' (Rousseau 160). There is a widespread belief amongst the lay population that the accuracy of such technology is impeccable and thus represents existential truth. In reality or call it daily practice, however, a CT or MRI mostly gains importance by its *not-showing* abnormalities. The diagnosis must come from the words of the patient. Nevertheless, as said, almost every patient with headache wants 'a scan', but the value of this investigation in the diagnostic process virtually always is overrated. Besides, even if there is a visible lesion on the scan, the patient does not feel the lesion as such. As the philosopher S. Kay Toombs has put it: 'Even if the lesion is visualized on a CAT [=CT] scan and pointed out to him, it remains ineffable. He experiences only its effects. The nervous system itself remains a hidden and threatening presence' (*Illness* 220). It is, remarkably, not unusual that a patient reacts disappointed when a scan is normal and does not show an abnormality causing the headache. Patients, apparently, rather prefer a 'signified' (in the form of an object in reality and not only as an image in their head) over the uncertainty of only having a signifier (a word, something that names it).

In her article "Living to the Imagined Body: How the Diagnostic Image Confronts the Lived Body" (2013) Devan Stahl describes an opposite experience. She visits a doctor for numbness in her legs and he shows her the MRI of her brain:

> It's MS!' he declared, almost triumphantly. I was stunned; whatever he saw on those images was lost on me. 'How can you be sure?' I asked. Rather than help me interpret the pictures, the doctor became offended, assuring me that he was a specialist and knew what he was looking for. (53)

Next to the bluntness of this doctor, the showing of images with or without abnormalities to a patient participates in medicine's cold culture of abstraction, objectivation and mandated normativity (53). Stahl even states that it is questionable what kind of 'truth' this image represents (54). As already mentioned, the Foucauldian 'gaze' from doctor to patient now gets a supplementary meaning: that of the 'gaze' of the doctor (sometimes shared with the patient and more often with colleagues) at the visual representation of the patient. This represented image is unfortunately easily confused with the truth of the body. According to Stahl, 'patients seek medical care to be made whole, only to have themselves fragmented and objectified by the physician' (55).

For Elaine Scarry in *The Body in Pain* (1985), 'to have pain is a *certainty*; to hear about pain is *doubt*' (13; emphasis in the original). This doubt

produces a practice in which only 'the felt-attributes of pain [are] to be lifted into the visible world but now attached to *a referent other than the human body*' (13; emphasis in the original). So, objective 'proof' of pain has become extremely important for patient and doctor. This is true for a visual abnormality on a referent such as a scan, but there must also be something for a scan without abnormalities.

Bourke (2014) calls pain that is thought to be represented by a scan an 'extreme reductionism' (10). The persons-in-pain are replaced by a courtroom scene 'in which brain scans are projected against a screen' (157). In daily practice, sometimes doctors see scans even before seeing the patient or without seeing the patient at all. Johanna Shapiro (2011) calls the wide use of MRI and CT 'technical manipulations of the Foucauldian clinical gaze' (68). One can see and therefore think that one knows, but the challenge is to not see and then create an idea about reality. In this line, Bleakley and Bligh (2009) argue in their article "Who can Resist Foucault" (2009) that scans bring together the visible and the invisible (376). Indeed, 'people can suffer, yet be lesion-free' (Bourke *Story* 14), but what is better for the patient: a scan with or without a lesion? I know the answer (and have to explain this almost daily to my patients).

With the currently available diagnostic possibilities (scans), migraine is by definition a 'scan-negative headache' as according to the current criteria, when structural lesions or other causative factors for the headache are present (the headache must not be 'better accounted for by another ICHD-3 diagnosis'), another diagnosis must be made (International Classification of Headache Disorders 2018). This does not mean that always a scan has to be performed. A normal neurological examination suffices. Being 'scan-negative', in migraine the gaze is of minor importance, and words play a crucial role. Anyone will acknowledge that the pain of migraine exists, but how does it become part of reality? This is the question that I will address in the following paragraphs, in which I will also emphasize the unique characteristics of migraine in the context of chronic pain.

Migraine: Headache without a 'sign'

Next to a wealth of medical texts, there are also many scholarly texts from disciplines such as philosophy, anthropology and literary studies that deal with pain-related issues. This attention from various angles probably is the result of the ubiquitous presence of pain, of its existential importance, but maybe also of its mysteriousness and elusiveness. The latter is especially the case in pain-syndromes without objective 'proof' of its cause, when

scans, blood tests and physical examination are normal. As I have mentioned already, for the diagnoses of these syndromes only words are available, so in a sense the sufferers may indeed be 'read' as a text and their bodies may be considered to be 're-embodied in language' and also be 'read'. The attachment of their pain with reality is grounded in a common experience.

Much has already been written about pain-syndromes without objective proof of their causes and their relation to language. There are many seminal texts, next to the scholarly literature introduced in the previous pages, that analyze pain from various perspectives. Scarry's *The Body in Pain* (1985) is seen as a landmark-publication, in which she mainly describes how pain destroys language, a topic that will be specifically addressed later in this book (chapter 4). Remarkably, Scarry does not mention migraine at all in her book. The most important successor-texts of Scarry's work are: *The History of Pain* by Roselyne Rey (1993; English translation 1995), *The Culture of Pain* by David B. Morris (1991), *The Language of Pain* by Biro (2010), *Pain. A Cultural History* by Javier Moscoso (2012), and *The Story of Pain. From Prayers to Painkillers* by Bourke (2014). Worth mentioning here is Susan Sontag's short text, *Regarding the Pain of Others* (2003), in which she (literally) focuses on visual depictions of pain. What these books have in common is their thoughtful analysis of (certain aspects of) pain. They all, however, only focus on chronic pain. Paroxysmal pain, such as migraine, is hardly mentioned at all, with one exception: the book of Biro. Here, I aim to use these seminal texts to place migraine in the perspective of the spectrum of pain-disorders and I will argue why migraine is special. For this, I will shortly describe the books mentioned above separately.

Rey mentions migraine twice, first in a summing-up of various types of pain (3) and later to illustrate the work of Aretaeus of Cappadocia (who lived in Rome during the 1st century AD), and whom she calls 'an exceptional clinician' (28). This Aretaeus wrote that:

> if the headache is incidental and only lasts a short while, even if this amounts to several days, we term it "cephalgia"; if, on the other hand, the disorder persists a long time and recurs periodically at close intervals, and if it is also increasingly painful and more and more difficult to cure, we call it "cephalea". (29)

Nowadays, this distinction between cephalgia and cephalea is not made anymore, but it still reminds us of the distinction between migraine and 'non-migraine headache', of which tension-type headache is an important example (see chapter 3). Remarkably, elsewhere in his writings Aretaeus

called headache 'migraine' when the pain was affecting only one side of the head (Koehler and van der Wiel).[10] He also described that those attacks could include sensitivity to light and vomiting, and remarked about the sufferers that their 'life is, in short, like a form of torture for them' (Aretaeus quoted in Rey 29).

Morris mentions migraine three times, first to contrast it with causalgia (pain which gets worse at light touch[11]) (16), second to refer to a statement of an American general about AIDS ('our relative unconcern about the vastly more common affliction of migraine') (66), and third to describe what the American writer and neurologist Oliver Sacks has said about migraine ('the prototype of a psychophysiological reaction') (277).[12]

Javier Moscoso only mentions of migraine that it once was considered to be an expression of hypochondria (184).

Bourke also only sporadically mentions migraine, but does describe the different metaphors of headache in certain cultures, as 'for example, the Sakhalin Ainu of Japan complain of "bear headaches" that resemble the heavy steps of a bear; "musk deer headaches", like the lighter galloping of running deer; and "woodpecker headaches", as if pounding into the bark of a tree' (68).

Biro, a practicing doctor who has also a PhD in literature, takes 'the inexpressibility of pain' as starting point for his book to explore the relations between pain and language (14). For him, 'pain has the elusive quality of an absence, an absence not only of words to describe it (that is, a linguistic

[10] This is not correct as many migraine patients have bilateral pain, which is acknowledged by the criteria (see chapter 3).

[11] Pain that gets worse at light touch may also be called 'allodynia', which has been described to occur during and outside migraine attacks.

[12] The British neurologist Oliver Sacks (1933-2015) is probably one of the best-known neurologists worldwide. He became particularly famous for books like *The Man who Mistook his Wife for a Hat* (1985), *Awakenings* (1973) and *Musicophilia* (2007), and for the film version of *Awakenings*. He also participated in television documentaries (*The Mind Traveller, Tales of Music and the Brain*) and one of his publications has been adapted into a play (*A Kind of Alaska*). A complete overview of his work may be found on his website (http://www.oliversacks.com/). Being read by million persons without a medical background across the globe (his books are translated in over 25 languages), Sacks' texts probably serve as only or main source of information on neurological diseases for many, including migraine as he has written a lot about this topic. His first published book even was a monograph on migraine (Sacks 1970; Haan et al., *Sacks*).

absence) but also of ways to think about it (a conceptual one)' (15). According to him, talking about pain is 'to fill a void' (73). For the filling of this void mainly metaphors are used, of which he gives numerous examples. He uses a fictional patient with migraine ('Rachel') to illustrate his descriptions of the metaphors used in pain. For example:

> for all these differences, Rachel uses the same kind of metaphor as the boy with appendicitis to describe her pain. "My migraines," she tells her doctor, "are not like other headaches. The pounding kind, for example, that feels like a hammer is coming down on your skull. Or when my sinuses act up and my head feels like it's being squeezed in a vice. The migraines are in a class by themselves. The pain is explosive and ripping, like there is a volcano inside my head that gradually builds up, simmers for a while, and then *bam*. You can't hear anything because the sound is so loud. You can't see anything because the light is so intense. And I'm exploding with it, disintegrating into millions of pieces. Which is fine, because I'd rather be dead than have it keep on going." (80; emphasis in the original)

Later, she calls her migraine 'an active volcano' (82), probably referring to its paroxysmal aspect, as migraine may be silent, but also erupt. Biro's book and his descriptions of the use of metaphors in migraine will frequently come back in the following paragraphs and chapters.

From my analyses of these seminal works on pain, it may be concluded that chronic pain has had much attention in the 'humanities'[13], but that paroxysmal pain such as migraine, has had not (with Biro's book as an exception). As paroxysmal pain has specific additional aspects, it is – in my opinion – of importance to consider it as something special and analyze these aspects separately. Whereas many perspectives described in the seminal works on (chronic) pain mentioned may be used to analyze the paroxysmal pain of migraine, also 'new' tools and insight must be applied.

Hereafter, I will outline the similarities and differences between migraine and non-paroxysmal chronic pain, not only clinically, but also with respect to their literary diagnostic aspects and relation with 'reality'. First, it must be emphasized that the diagnosis of migraine is a construct, based on artificial criteria. Therefore, in the next part I will work out the question 'How does migraine exist?' by placing the constructed diagnosis of migraine in the perspective of a discourse or call it the reading of migraine as text in the context of other texts. In this chapter, however, for practical reasons, I will use the word 'migraine' for a clinical diagnosis of migraine

[13] See for a definition of 'Medical Humanities' Shapiro et al., 2009.

according to the current internationally agreed criteria, see chapter 3 (International Classification of Headache Disorders 2018). These criteria define the duration of a migraine attack between 4 and 72 hours, next to phenotypic features in certain combinations, such as unilateral pain, severe pain, throbbing pain and pain that worsens on activity, and accompanying symptoms, such as nausea, photophobia, phonophobia and osmophobia.[14] For the migraine aura separate criteria are used.[15] I will first place migraine in the context of other pain-syndromes, and thereafter describe why migraine is special.

Migraine in context

To justify my choice of migraine as a distinct topic to study the reality of pain/headache in the borderland of literary science and neurology, I first have to put migraine in the context of these separate disciplines. For this, I will use some of the issues raised in chapter 1 and apply these to migraine. The topics include: 'Migraine: illness or disease?', 'Migraine: patient and doctor', 'The migraine patient as text', and 'The migraine patient as literary text'.

Migraine: illness or disease? The difference between 'illness' and 'disease' has been outlined in chapter 1. To summarize, in the simple definition, 'illness' is more a 'state of being', whereas 'disease' (or 'sickness' according to Brody *Stories*) has objective signs. As migraine is an example of a pain syndrome for which no biological tests exists it is seen more as an 'illness' than as a 'disease'. Indeed, migraine is the prototype of a 'scan negative headache'. As is often the case with pain, migraine lacks a 'signified' (object in reality/ referent/ image in our head), and thus may be an example of an illness that is not taken serious because it 'cannot be directly related to an anatomic or pathophysiologic derangement' (Baron *Introduction* 607).

Siri Hustvedt (2010) writes about her own migraine-experience that: 'a disease [..] has more there there, more *being* than an illness' (16; emphasis in the original). Her migraine 'was never referred to as a *disease*' (16; emphasis in the original). She concludes that diseases are ontologically more robust than just an illness (16). In line with this, since 2016 the

[14] The terms photophobia, phonophobia and osmophobia respectively describe the tendency of patients to avoid light, sound and smell during an attack of migraine.
[15] An aura is defined as a functional bodily disturbance, mostly of vision, which lasts at least 5 minutes and not longer than one hour.

American Headache Society has accepted and described migraine as a 'neurological disease' and on the website of the British National Migraine Centre also the word 'disease' is used.

A diagnosis of migraine is made on the basis of symptoms and not on that of signs; the diagnosis depends on the words and descriptions of the patient. For Hustvedt 'along with imaging studies, more dynamic narrative strategies should be used if we hope to understand the metamorphoses, mimesis, and powerful emotions that all play a part in this mysterious disease' (*Wept* 305).

In a questionnaire study of Lucas et al. (2004) among migraine patients, 55% of 71 respondents who never consulted a doctor for their headache declared that they had decided not to do so, as they thought that 'migraine is not a real disease' (273). In a similar line, Young et al. (2012) used the so-called 'Delphi technique' (which implies finding a consensus in subsequent steps) to answer the question whether migraine is an illness, disease, syndrome, condition, disorder, or susceptibility. Participants were systematically interrogated following a predefined scheme. The investigators chose to study a group of 'interested individuals' (including a headache specialist, epidemiologist, neuroscientist and three migraine patients) in different rounds. Consensus was not reached, but for migraine 'disease' was the most preferred term and 'illness' the least. It is, however, very likely that the selection of participants considerably influenced the outcome of this study.

An essential aspect of migraine in this matter, which is in contrast with other types of chronic pain, is that the patient with migraine is not always 'ill' or 'sick', but sometimes also 'healthy'. So, the question 'illness or disease' is confounded or confused by the paroxysmal nature of migraine. A consequence of attacks (defined as a certain occurrence with a beginning and an end) is that a state of being 'sick' alternates with that of being 'normal'. When migraine is seen as an 'illness', is it then a new illness over and over again? Is a person with migraine 'the same person whether sick or well'? (Brody *Philosophy* 247), or does this sickness make one 'a different person while remaining the same person' (Brody *Stories* 2)? Does this then mean that a migraine patient switches from being one person to another over and over again? This resembles some sort of doctor Jekyll and mister Hyde situation. Is there a 'duality of sickness', not only between but also within subjects? To paraphrase Susan Sontag in her famous book *Illness as a Metaphor*, where she talks about 'the dual citizenship in the kingdom of the well and in the kingdom of the sick' (*Illness* 7), one may ask the question

whether patients with migraine are ‘well’ between attacks and ‘sick’ during attacks and as such constantly traveling from one kingdom to another? Are they traveling between different ontological levels? Or are they constantly in the kingdom of the sick, although they are ‘well’ sometimes? Or in reverse: constantly in the kingdom of the well, but sometimes sick? Could it be that a third ‘kingdom’ exists, that of ‘less sick’ or ‘moderately well’? Important here is that there is also a quantitative aspect. Is someone who has two migraine attacks per year sick? Is someone who has two attacks per week sick? Is the one healthy and the other sick, or are we talking about sick and sicker? And then, when is someone ‘better’?

I have no immediate answers to these questions, but for me it is clear that the ‘on-off’ state of the migraine patient resembles a binary opposition, that of ‘well’ and ‘sick’. As in any binary opposition, however, the question emerges which of the two is the hierarchically dominant. Translated to migraine this would mean that one needs objective proof for entering both kingdoms, that of the ‘sick’ and of the ‘well’, but as I have already argued, this objective proof does not exist (yet). When interviewing migraine patients, they favor to see their migraine as ‘successive crises and not as a pathogen process’ (Radat et al., 394). Why separate crises? A comparison may be made with Friedrich Nietzsche’s ‘pin-pain’ parable. The ‘cause’ or ‘provocative factor’ of individual migraine attacks is almost always unclear, but, nevertheless, virtually all patients look for and ‘invent’ a cause, as they ‘can’t suffer without knowing why’ (Biro 121). So, their situation may be described as ‘pain – pin – no pain – pain – pin – no pain etc).

In this context, it may be questioned whether migraine is chronic pain at all. Acute pain is often seen as a ‘message of actual tissue damage’, whereas chronic pain is ‘usually a pain signal without damage’ (Neilson 4), but this may be doubted, as for example, it has been proven that in chronic pain-syndromes such as migraine so-called sensitization occurs: a progressive damage to the nervous system leading to a lower threshold to experience more pain. Chronic pain is often associated with depression, anxiety, frustration and anger and it may have a debilitating effect on the patients’ sense of self and their social relations (Lavie-Ajayi et al., 193). Migraine, however, still escapes the classical definitions of chronic, as it is both acute and chronic. It is defined by its recurrences and may also be described as a ‘chronic disease with paroxysmal (acute) presentation’. This phrase is reminiscent of the words of Neilson (2016): ‘for most patients, pain is transient, lasting as long as the causal illness does. Then pain disappears. For other patients, pain transforms into a chronic problem that usurps identity’ (3). I am afraid that for migraine the latter is the case, because

between attacks – when free of pain – many migraine patients are bothered by the fear of pain, the fear of the next attack (Hursey and Jack 1992; Asmundson et al., 1999; Freitag 2007; Rutberg and Öhrling 2012; Black et al., 2015), and do not feel well at all. This fear even has received its own term, being described as 'cephalalgiaphobia' (Peres et al., 2007; Giannini et al., 2013). It probably is another example of 'phobia of illness' which may also occur in patients with asthma, vestibular disease, hypoglycemic episodes, strokes and heart attacks (Noyes et al., 2004). As a variant of this, Biro describes how Rachel, his (virtual) patient with migraine finds her visual auras almost as painful as the actual migraine, as 'the anticipation of what will come is so unbearable that she prays for the headache to start' (104).

In summary of this paragraph, it is not important to determine whether migraine is an illness or a disease, but the notion of whether it is chronic, acute or both is so important that it will be central to my book (see chapter 3).

Migraine: patient and doctor. Doctors have been called 'gatekeepers for the kingdom of the sick' (Segal 231). Yet, what gates of which kingdom are they keeping and how do they do this in the case of migraine? Consider a patient with migraine who visits a doctor. At the time of the appointment, the patient will probably have no headache, as the keeping of such an appointment is impossible during a migraine attack. First, the patient will be interrogated about occurrences in the past (previous attacks) and then be neurologically investigated. The physical examination and (eventual) scan will probably be normal. So, the words of the patient become of utmost importance, a process that has been compared with a jigsaw puzzle (Blau *History* 1251), here being a complex and verbal one. On top of this the doctor must realize that patients often try to adopt the language of medicine to gain a feeling of control and the illusion of being able to discuss their condition with their doctors as pears (Rimmon-Kenan 246)

Indeed, words and their 'Vorverständnis' are important but must still be used and interpreted with caution. It is true that many patients with headache search the internet and as a result of that use medical terms to describe their complaints. Some even come up with a diagnosis presumed to fulfill the current criteria.

And then there is also the role of memory which migraine patients need to describe past pain.

Joan Kahn (1978) describes that:

> first of all, there is the fallibility of the human memory: people often fail to recall exactly when they started to feel their pain and nausea, or whether it preceded or followed their anxiety attacks. Secondly, even those significations which the patient would swear he recalled with great clarity, frequently become 'lost' to the doctor as a result of any of the numerous *random* factors that can diminish the optimal transmission and reception of verbal messages. (84; emphasis in the original)

She is right and, in this context, important questions emerge. Does a 'pain-memory' exist and if so, how reliable is it?

It has often been said that it is very difficult to imagine pain. Maybe this is caused by the fact that pain (and also that of migraine) is a signifier without a signified. One cannot close one's eyes and imagine or see an object called 'pain'. One cannot point at it. Nevertheless, the reminiscence of pain plays an important role in the patient-doctor encounter and is of crucial importance for the diagnosis of migraine. Memories, however, are often unreliable. The story persons remember is often not identical to the symptoms they had experienced, and there is growing evidence that pain may not be remembered accurately (Babel 865). This topic is especially problematic in the case of paroxysmal pain such as migraine, as patients almost always visit the doctor when they do not have pain.

Hunter and colleagues (1979) studied the memory for headache in neurosurgical patients using the McGill pain questionnaire. They found in these patients a remarkable ability to remember the intensity and quality of their pain but could not rule out that they 'were recalling *words* that they had chosen at the assessment, rather than the pain experience itself' (43; emphasis in the original). Babel (2015) investigated the memory of pain in patients with migraine compared with patients with 'non-migraine headaches'. He concluded that headaches in both groups were found to be remembered accurately, but that 'both negative and positive affect were overestimated' (870). It appeared that migraine patients 'reported more intense and more unpleasant headaches' compared with other headache-types (872). The question is what this says about the memory for migraine pain.

It may thus be asked what one remembers: the pain or the words that represent it? Of course, important for paroxysmal pain such as migraine is that it comes and goes. As Fiser (1986) puts it pain alters and fades, and we have no external marks by which to identify it. We may sit and wonder if

this pain is the same as it was before, or different. We may not know, and no one may be able to tell us' (3). So, taken together, probably not only pain depends on words, but also the memory of pain and in migraine this may be called 'tricky'. It may, however, even be wondered what came first: the pain or the words.

Fiser puts the memory of pain in the context of multiple experiences of pain. She emphasizes that it is impossible to compare one's own pain with that of others (conform the beetle in the box), but when someone has multiple periods of pain, a comparison between the separate episodes might be possible. She comes to this conclusion after she had two knee-operations herself and thus was able to compare the pain caused by the one with that of the other. Translated to migraine, this would allow the patient to compare the severity of the pain of the different attacks. The pain does not necessarily become more 'real' in this way but may be seen in the context of repetition. For Kirmayer the apprehension, belief or conviction that it will persist indefinitely adds to the suffering of pain (*Culture* 330). For migraine the situation is different. It will not persist indefinitely, but return indefinitely, which makes a big difference, as this pain has its effects, even when not present, mostly so in the form of the already mentioned fear for the next attack (Black et al., 2015). What is finally made available to the doctor (through the patient's narrative) constitutes remembered significations. All a doctor can use to diagnose migraine is this signification expressed in language, words and linguistic signs, and sometimes some 'paralinguistic' signs (called 'nonverbal phonology'), such as 'kinesic signs' (e.g. facial expressions), 'proxemic signs' (how a patient orients himself in space), 'fashion signs' (clothing, sunglasses), or 'chemical signs' (odors)'. For example, sometimes the partner of a migraine patient claims to be able to smell that an attack is coming, ongoing or ending.

Being a life-long chronic, but at the same time paroxysmal, disease, migraine has specific narrative aspects. In fact, for migraine, the narrative 'is' the diagnosis. Patients tell the story of their whole life and the short stories of the individual attacks, and for both they do this mostly from memory. As Biro puts it, they use 'a narrative that replaces the blankness and invisibility of pain' (91). Chronic pain can mark a radical redirection of the trajectory of the life story (Brody *Stories* 2). In migraine, this happens over and over again.

Stories have beginnings, middles, and endings. Each story assumes that something existed before the events of the started-off story, and 'the "beginning" of the story must make implicit reference to those prior events'

(Brody *Stories* 32). The literary critic J. Hillis Miller wrote that all stories contain in themselves 'the seeds of their eternal rebirth or their eternal recurrence' (cited by Brody 37). This description may be applied to migraine. There is a start, a middle and an end and that end precipitates the start of the following attack. Indeed, the beginning of a story always has sufficient antecedents, causally or probabilistically speaking, and the ending is always sufficient for further consequences. Translating this to migraine, the 'story' is indeed what defines its reality. And as additional conceptual metaphor there is Wittgenstein's 'beetle', which adds a concept of pain to the individual stories of individual patients, as the diagnosis of pain but also of its recurrence is determined by the uniformity of the stories told by millions of migraine sufferers worldwide. Their descriptions establish the 'reality' of migraine pain. The 'sign' of migraine not only consists of the words used or the stories told, but also of its ubiquitous and stereotypic representation.[16] In a sense, the story of a migraine patient may be seen as 'intertextual', as part of its importance lies in the fact that it resembles the texts of other patients.

The narrative of a migraine patient may thus be seen as what Loftus (2011) calls an 'expanded metaphor' (226) and this metaphor is stereotypic and global. Indeed, enhancing a diagnosis of migraine (headache or aura) is the use of *specific* metaphors for every sensation that has no 'objective' representation in reality. So, as for example fatigue or dizziness, migraine is a metaphorical disease. Being chronic (but intermittent), migraine is often associated with metaphors of 'temporality' (Haan, *Metaphor*).

Again, it must be remembered that migraine is a disease without objective 'signs', a signifier (arbitrary word) without signified (object in reality). In his article "What's in a Word: The Distancing Function of Language in Medicine", David Mintz (1992) discusses another disease without signified: schizophrenia. His text may literally be applied to migraine and to that order I added comparisons between brackets:

[16] The same is true for the aura of migraine. Around 20% of migraine patients experience certain visual or sensory sensations shortly before the headache of their attacks occurs. To describe this experience patients also use words, but in this case not to describe pain. Auras mostly affect vision, but sometimes also smell, hearing, motor function or tactile sensations. These hallucinations belong to another ontology and are – by definition – inaccessible for 'outsiders'. Nevertheless, drawings of migraine patients of their (visual) auras are very similar and may even be used for scientific calculations in space and time (Schott 2007; Hansen et al., 2013).

> Western language, and, in particular the language of disease, is replete with examples of objectifying linguistic features. We say "he *has* arthritis," [migraine] not "he is arthritizing," [migraining] thus defining the disease as an entity separate from the person's daily life and activities. The former expression addresses primarily the joints [head], the latter has to do with the whole person. An even more distancing usage would be: "He *is* a schizophrenic," [he is a migraineur] where the individual loses his identity as a person and is identified as a disease. This kind of language has profound consequences for the way in which we view our patients. A person who *is* schizophrenic [a migraineur] is schizophrenic forever [a migraineur forever]. Because the illness is so entangled in the identity of the patients, they cannot be cured. The "asymptomatic" patient is sent home in a state of "remission", and the stigma of schizophrenia [migraine] hangs forever over his head. A diagnosis which might do less violence to the person of the patient might be to say: "He is schizophrening" [migraining]. In this case, the activity of the disease can be halted without it seeming that the whole identity of the patient has been interrupted. In all these cases, language serves a distancing function by painting diseases as discrete, self-sufficient objects and then assuming the person to be a passive substrate of the disease. (226; emphasis in the original)

Someone may be 'a schizophrenic', just as one may have a 'CT-negative-headache' or be 'a migraineur'. According to Mintz (229), doctors often use a form of 'distancing language', such as 'the cancer in room 104' or 'parkie' for a Parkinson patient. 'Schizophrenic' or 'migraineur' may be seen as similar distancing and denigrating terms, 'objectifying [the sufferer] as a disease' (229). Not surprisingly, the term 'migraineur' was unanimously rejected by the panel of several 'interested individuals' in the Delphi study already mentioned (Young et al., 2012). It is a term that stigmatizes (Young 320; Young et al., 2013), and should be avoided (see also chapter 3 on this topic).

In line with this controversy surrounding migraine terminology, many contemporary scientific articles and textbook chapters about migraine start with 'migraine *is* a neurovascular disorder' (my emphasis). With this statement a summary is given of an enormous amount of scientific research that has investigated the role of nervous tissue and blood vessels in a migraine attack. The 'is a' resembles the 'as if' comparison used in many metaphors. Nevertheless, migraine cannot be seen similar to a neuron or a blood vessel. Likewise, it may be said that:

> though neurological metaphors have assisted with the accumulation of scientific knowledge, their enshrinement as the means of understanding pain has had a terrible cost. We think of pain in terms of nerves, but nerves are

> not experience and nerves are not necessarily emotion. Nerves are not pain. (Neilson 6)

Of course, nerves are necessary for pain perception, but we must not make the Cartesian error to confuse nerve action potentials with pain experiences (Merskey *Taxonomy* 301). A distinction has been made between xenochthonous (exogenous) and autochthonous (endogenous) causes of disease (Copeland 528). In the case of migraine, an endogenous (genetic) cause seems very likely, but in addition, provoking factors may also play a role. Many patients indeed blame external factors (such as weather, stress, fatigue), but the importance of these is strongly overemphasized and often bases on to the pin – pain illusion. Migraine mainly is 'pain from the inside'. Outside factors such as food, beverages, the weather or stress are often seen as 'cause', but these play a minor role, as migraine is predominantly genetic. This means that the susceptibility to get attacks was 'always there'.

And then there is the phenomenon that migraine patients are pain-free between attacks. When explaining the occurrence of attacks by endogenous or external factors, or a combination of both, however, also this absence of pain between the attacks must be explained. Semiotically, the absence of a 'sign' may also be seen as as a 'sign'. Indeed, having no headache is part of the vocabulary of migraine as much as having headache.

The abovementioned considerations lead to some preliminary conclusions. First, it is important to consider migraine as a disease with attacks and pain-free periods between the attacks as its expression and its 'signs'. Second, there is the important but unreliable role of memory. Third, migraine is a 'scan negative headache', which means that other 'signs', such as words are necessary for its diagnostic reality. This emphasis on words leads to the next topics: The migraine patient as text and as literary text.

The migraine patient as text. The question here is: How to 'read' a patient with migraine? As elaborated on in chapter 1, patients may be read as a text, but this concept has received much criticism, especially because it is considered too 'simple'. Of utmost importance for the present discussion about migraine is the criticism of Richard J. Baron (1990), who emphasized that the expectation that 'there is a text somewhere to be found' runs the risk of 'conceptualizing patients as more static than they are' (25), adding that 'patients are *not* static things in the way that the Folio Edition of Shakespeare is' (27; emphasis in the original). The text of patients indeed is not static, and migraine is an excellent example of this. A migraine patient has (at least) two texts to be read (one about the attacks and the other about

the period between the attacks). As explained by a former chairman of the Dutch society of headache patients: 'When you see them, they do not have it. When they have it, you don't see them'. This means that migraine patients are different narrators and different texts at different times of their disease. Doctors in general see migraine patients only when they are 'well' and this may lead to a lack of understanding, as many doctors have 'a tendency [..] to focus on the body only when ill' (Leder *Medicine* 35). This pronouncement reminds me of a migraine study I was involved in many years ago. The study was about attack-treatment and the patients had to come to the hospital during an attack. This was my first opportunity to actually see patients during a migraine attack. What I remember clearly is the difference between those patients and the ones that had been visiting my outpatient clinic. During their attack they looked, behaved and spoke differently. There was, however, also a big difference between the patients with attacks in the study. For example, one patient was brought to the hospital by her husband, looking very pale and vomiting constantly. At my question how severe the attack was, she said 'O, doctor. This is a very mild attack'. Sometime later, another patient walked into the hospital reporting to have the most severe attack ever, but nothing abnormal could be seen at the outside. Of course, also the agony of the latter patient was 'real'. All patients who express pain must be unconditionally believed. In this respect I fully agree with Stone and Evans (2011) that 'psychogenic headache' does not exist.

So, patients in and out of attacks may be read as different texts in the context of the 'readability metaphor'. Maybe there are even more different texts. Whereas migraine is a life-long disease, there may also be long periods without attacks during their lifetime. Migraine attacks may start at any age (mostly around the time of the menarche in girls, but also around puberty in boys), and in most patients stop after the age of 60 years (Haan et al., *Elderly*). Thus, for an individual patient there is the story of the period without attacks (before the start and after the cessation) and that of the on-off periods when the migraine is 'active'. When realizing this, it may be questioned where the words of migraine patients initially come from. What do they describe? What do they remember? To answer these questions, Wittgenstein's ideas about the origin of the words on pain may be important. His starting question is: 'how does a human being learn the meaning of the names of sensations – of the word 'pain' for example?' (cited by Bourke *Story* 6). Wittgenstein used an example in which 'a child has hurt himself and he cries; and then adults talk to him and teach him exclamations and, later, sentences. They teach the child new pain-behavior' (6). In order to have meaning, Wittgenstein concluded, words for feeling-states like pain

must be inter-subjective ('beetle') and able, therefore, to be learned. In other words, the naming of a 'pain-event' may never be wholly private (6). On the one hand, Wittgenstein is right in saying that words on pain are not 'wholly private' (the beetle is private, but the recognition of the presence of a beetle is not). On the other hand, the role of 'child', 'adults' and 'teaching' in the learning of the pain behavior of migraine patients is questionable, as many migraine patients do not have their first attack before puberty and some patients even get their first attack and 'migraine experience' after they are more than 50 years of age (Haan et al., *Elderly*). Thus, the pain-text in those individuals cannot have been 'learned' as a child, but probably was – as Wittgenstein seems to argue – already 'inscribed' in language. So, could it be that the ways of expressing pain in words and gestures, and thus also that of migraine, probably were already 'pre-programmed'? This question raises several interesting research topics. First, it may probably only be concluded that the words used to express pain (migraine) are already 'inscribed in language' after studying pain- (migraine-) patients who were raised in isolation, without contact with others (and specifically without other migraine patients). Only then the 'pure' and unbiased expression of pain (migraine) in words would become clear. Such a Kaspar Hauser situation is, however, unthinkable. I would estimate that the language of such a control group would differ much from that of 'educated' persons. Second, evaluating differences between the verbal expression of patients who get migraine at a young age versus those who get it later could also shed light on the Wittgensteinean 'inscription of pain in language'. Scientific studies of this kind have, however, not been performed yet and therefore we have to do with texts and maybe even literary texts.

The migraine patient as literary text. Hartman Landon has compared types of pain with a sequential rhythm (such as migraine) with poetry, as it 'has meter and shapes time into a rhythm of stressed and unstressed moments' (75). Migraine has also been compared with 'a drama in three acts', based on its premonitory symptoms or aura, the headache phase, and the 'hangover' after the attack (Blau *Diagnosing* 21). As described in the section 'the patient as literary text', the encounter of patient and doctor may be analyzed as fiction and described in literary terms. Perhaps such an analysis is even more applicable to most encounters of migraine patients with their doctors, as they have – at the time of the encounter – very often no pain at all. These patients have to 'look into the sky' for words to describe their remembrance of past pain. They have to create a new world on another ontological level in their words on pain. This dramatic situation is mainly created by the rhetoric 'need' of the patient to describe from memory their suffering and anguish. Most important here is not the previous pain (which

can never be felt or alleviated anymore), but the thoughts of future pains, leading to a fear of pain (Black et al., 2015). Applying Aristotle's thoughts and theories, especially those about *logos* (the argument itself), on headache and migraine may be fruitful. In such a rhetoric situation Aristotle emphasized the importance of the 'argument from past facts' to produce 'verisimilitude'. As said, for the patient-doctor encounter, aspects such as *ethos* (the argument of the speaker), *pathos* (the appeal to emotions) and *logos* (the argument itself) are important. The categorization of Aristoteles of 'three branches of knowledge', however, also seems more applicable here. *Techne*, the structural representation of the pain (neurological examination, CT or MRI scan) leads to a 'negative' sign in the case of migraine ('scan negative headache'); *episteme*, the universal laws, may be translated as the criteria for making the diagnosis of migraine, the stereotype, ubiquitous and universal beetle (see chapter 3); most importantly here, however, is *phronesis*, the opposite of acting on technology and universal laws (such as scripts and protocols). This 'practical wisdom' is of utmost importance to make the dramatic encounter result in Gadamer's 'merging of horizons' ('Horizontverschmelzung'), and to see all patients with migraine as unique, individual cases which must be 'read', 're-read' and understood in one's own horizon.

The practice of diagnosis may thus be compared with the Aristotelean '*poiesis*', as this term encompasses that literature and art not only create a representative (and interpretative) surface, but also 'reveal' (parts of) reality. In other words, pain is not created, it was always there and 'real', a fact that we can all confirm from experience (e.g. a hit with a hammer). What differs between (the words) of individual patients is less important. More important is what they share. The stereotype part of their words, stories and narratives forms the reality of their pain. Thus '*diagnosis*' and '*poiesis*' may be seen as related practices referring to reality but creating different ontological levels.

In the case of migraine, the reality of the patient even consists of several separate realities, but as Noble-price winner J.M. Coetzee has written in his novel *Waiting for the Barbarians* (2007): 'Pain is truth; all else is subject to doubt' (10). As such, in my further argument the relation between pain, truth and doubt will be worked out, focused on the relation between words and migraine. My next (sub-)question will be what the word / diagnosis 'migraine' means in truth and in doubt. Then I will ask what this diagnosis (migraine) does with words and subsequently what the importance is of time in this process. These questions will be the topics of the next three chapters.

CHAPTER 3

MIGRAINE'S EXISTENCE IN DISCOURSE

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.[17] 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 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,

[17] '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.

several choices must be made. Thus, meaning is produced rather than acquired (Moscoso 2).

There are 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). He calls the absence of criteria in contemporary medicine 'particularly lamentable' as many decisions 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 an 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.

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. 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':

> 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).

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.

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 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. For 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 this, diagnoses 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. As Fleischman puts it 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' (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. For Kathryn Vance Staiano (1982), as symptoms only gain meaning through transformation by the physician, 'emphasis is on the "correctness" of the physician's interpretation' (332). And in this interpretation, unfortunately, much can go wrong. The consequences of such an 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, I will give some examples of such medical discourses, that highlight three aspects of the force of discourse.

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)[18]. 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

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

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 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)[19]

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'

[19] 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'.

(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)

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).

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 '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 book, 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.

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[20] 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

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

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). 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), now known as one of the so-called 'CGRP-antagonists'. 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.[21]

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 (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).

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

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.

CHAPTER 4

DOES MIGRAINE DESTROY LANGUAGE?

Some scholars have argued that pain destroys words. The major propagator of this thought is Elaine Scarry, a professor of English at the university of Pennsylvania. Her book *The Body in Pain. The Making and Unmaking of the World* (1985) has become a classic on this topic and was even called 'canonical' and 'seminal'. Scarry describes the effects of pain on the 'unmaking' of the world, with as starting points that physical pain has no voice (3) and that there is an inexpressibility of physical pain (3). For her, 'physical pain does not simply resist language but actively destroys it, bringing out an immediate reversion to a state anterior of language, to the sounds and cries a human being makes before language is learned' (4). In her opinion, there is 'ordinarily no language for pain' (13) and 'before destroying language, it [pain] first monopolizes language, becoming its only subject' (54). In addition, for her, physical pain is 'consistent in its assault on language, so the verbal strategies for overcoming that assault are very small in number' (13). In other words, 'the person in pain is ordinarily bereft of the resources of speech' (6), because 'intense pain is language-destroying' (35). In her book, she mainly focuses on the effects of the pain of physical torture on speech, but her thoughts on pain have also been read in a much broader sense by many scholars.[22] In the discussion of either having pain (for instance in the case of someone being tortured) or producing it (as a torturer), in this book, I will for obvious reasons focus on the 'having' instead of the 'producing' of pain, as it is not known who or what 'produces' the pain of migraine.

The concept of a destroying effect of pain on language has been accepted, or at least strongly considered, by many other scholars. Kugelmann, for example, accepts that 'pain afflicts and can disable any activity, including walking, grasping, swallowing, remembering, and thinking' (*Vernacular* 308), and elsewhere adds that pain 'reduces one to moans, groans and screams; pain is often verbally inexpressible' (*Symptom* 37). The

[22] Scarry's words have – for example – influenced the thoughts of Morris (*The Culture of Pain*), Biro (*The Language of Pain*) and Thernstrom (*The Pain Chronicles*).

inexpressibility of pain is the starting point for David Biro's book *The Language of Pain* (14). In his opinion, 'pain has the elusive quality of an absence, an absence not only of words to describe it (that is, a linguistic absence) but also of ways to think about it (a conceptual one)' (15). He summarizes that 'there are no words when one is in severe pain' (20). David B. Morris emphasizes that 'pain passes much of its time in utter inhuman silence' (*Culture* 3) and that 'pain is a radical assault on language and breaks down understanding' (73). Elsewhere, he states that 'silence is a common response to a pain no one can see or verify' (*How to Read* 153) and also points at the undoing of creative functions by chronic pain (153). Mariet A. Vrancken (1989) associates the destruction of language with its unsharability, a point that was also suggested by Scarry. Vrancken argues that 'what pain achieves, it achieves in part through its unsharability, and it ensures this unsharability through its resistance to language' (441). Indeed, whereas the idea of a beetle can be shared, the beetle itself cannot. In his article "The Language of Pain," Ehlich (1985) makes a distinction between 'three types of expressing pain: 1) crying and groaning; 2) pain interjections; and 3) pain descriptions' (180). What he means with categories 1) and 3) will be clear. Category 2) includes linguistic expressions such as 'ow', 'ouch', 'au', or 'ai' (181). These pain interjections form a part of language and can be communicative just like 'oh' or 'hm''. He calls the use of these interjections 'inverbations', suggesting that these kind of expressions of pain are more verbally controlled than the cries and groans of the first category. Javier Moscoso (2012) says it much simpler: 'At the end of the process [of pain], screams replace words' (186).

A slightly other standpoint in this matter is taken by Fredrik Svenaeus (2014), who argues that 'pain can surely stop me from doing what I want to do or becoming who I want to be' (*Hermeneutics* 411), but emphasizes that this destroying effect of pain 'is only *one* of the potential relationships between pain and mental suffering' (411; emphasis in the original). There are other things than pain that can make a person suffer. He adds that he does not want to introduce 'some kind of dualist philosophy' (411), where pain (body) is seen separate from mind (e.g. words or language). In his opinion, 'medicine has been too preoccupied with the *causes* of pain and other bodily symptoms and too ignorant of the way the symptoms attain *meaning* for the person suffering from them' (411-412; emphasis in the original). So, translating this to Scarry's emphasis on the destroying of words by pain, he considers her standpoint too simple. The interaction between the bodily sensation of pain and the mental action of language is much more complex than the 'one way' destructive one. So, possibly, pain can destroy language in its semantic sense in certain circumstances, but it

probably does not destroy the sense of meaning and it even also can have other effects on it, including the production of meaning. There may even be a creative vision on what accompanies the experience of pain (Engdahl Coates 243). It seems that illness can thwart creativity (243) and that pain 'enables one to "toy" with language and even to "coin" new words' (244).

Indeed, there has been more critique on, than agreement with, Scarry's statement that pain destroys words. Joanna Bourke, for example, criticizes Scarry for referring to pain as an entity, as 'something that is outside language, absolutely private and untransmittable' (*What is Pain?* 159). According to her, Scarry gives pain an 'independent life' (159), which Bourke even calls 'an extreme version of reification' (159). In Bourke's opinion, pain is an event and not a thing. Whereas a thing can destroy, an event cannot. For her, 'Scarry has fallen into the trap of treating metaphoric ways of conceiving of suffering (pain bites and stabs; it dominates and subdues; it is monstrous) as descriptions of an actual entity' (160). Pain is not an object that can destroy, but an event that can also have positive consequences.

Still, Scarry finds support from others. For instance, Arthur W. Frank has worked out the effects of illness (including pain) on language in his book *The Wounded Storyteller* (1995). He describes how a sick person's search words to describe their illness and compares those persons with 'narrative wreckages' (53). In another publication, he even states that 'pain is the black hole into which language seems to disappear' (*Metaphors* 184). At first sight, he seems to agree with Scarry that pain can destroy language, but on the other hand, he argues that there is more. He states that 'the ill body is certainly not mute – it speaks eloquently in pains and symptoms – but it is inarticulate' (*Storyteller* 2). For him, ill people need to tell their stories. The creation of stories forms the main part of Frank's theory in which he distinguishes three kinds of illness narratives. In the 'restitution narrative', the sick person tells the story of how he or she became healthy again. The 'quest narrative' describes the search for health. The sufferer accepts the illness but seeks to use it (115). The 'chaos narrative', however, imagines life never getting better (97). The latter category can be described as 'chaotic in their absence of narrative order' (97). Elsewhere, Frank further elaborates on this topic and writes of chaos narratives that 'the losses, the pain, the incoherence of suffering become so overwhelming that language cannot resocialize what has happened', even to the point that 'the "pure" chaotic voice is a hole in the narrative' (*Reclaimin*g 7). It is a 'return to the condition of being mute', and its authentic speech is 'the scream, and beyond that, only silence' (9). For Frank, pain provides a specific example, as:

> pain makes the body thematic. The body in pain cannot relegate its embodiment to the background. Pain fragments the body as "it" hurts "me." One part is thus separated from the whole. Pain makes also apparent the limits of language: the experience of pain exceeds attempts to express it. (9)

So, it seems that chaos narratives go beyond the limits of the expressible, and in this sense indeed can have an influence on the use of words. Here, Frank seems to agree with Scarry. On the other hand the restitution and quest narratives do the opposite; they create stories and meaning.

In his lengthy article "Elaine Scarry and the Dream of Pain" (2001), Geoffrey Galt Harpham expresses his criticism on Scarry's *The Body in Pain*. For him, her book is 'scarcely academic at all' (205). He illustrates this by pointing at the fact that 'a glance at the index to *The Body in Pain* reveals no reference to De Man, Foucault, Derrida, Barthes, Jameson, Benjamin, or Kristeva; their places are taken by von Clausewitz, Amnesty International, the Greek Colonel's Regime, and the Nuclear Test ban Treaty' (206). It can be discussed whether this remark must be seen as an expression of the at that time dominant discourse in the humanities, which can in its turn be criticized as being a discourse in itself, or as an argument that Scarry was an independent thinker who used original sources. Anyhow, Harpham proceeds by mentioning that linguistic reference 'although never the subject of explicit theorization, is the single most important principle in Scarry's thinking' (211). For him, *The Body in Pain* seems actually more vitally concerned with language (211) than rooted in the reality of the body, but 'Scarry never defines reference, or provides a criterion for deciding whether language is or is not referential' (214). He compares *The Body in Pain* with the complexity of an M.C. Escher composition, as the text 'constitutes a vast, obsessive-compulsive nesting of stipulations concerning the interior structures of things: torture, war, injury, imagination, creation, and artifacts' (219). His conclusion is that Scarry's work 'is in fact, best considered not as a succession of arguments but as an ongoing creation, an artifact to gaze at, to admire even to the point of stupefaction, without regard for its utility' (228-229). Such admiration is clearly a matter of irony here, and it comes as no surpise that Harpham does not agree with Scarry's arguments about the destroying effects of pain on language, especially so because he finds her definition of 'language' insufficient.

A more productive position is taken by Butler (1997). She acknowledges that pain can be a threat to language and can shatter language, but also that language can 'wield *its own* violence' (6; emphasis in the original). She points at the fact that there is a 'specific kind of injury that language itself

performs' (6). The thought that words can damage is one of the pillars of her book *Excitable Speech: A Politics of the Performative*. I will discuss the performative use of language by patients, but also in works of fiction, in Part II of this book.

Thus, to summarize the above, some agree with Scarry that pain may destroy words, some take an intermediate position and some strongly disagree, as pain may also create. It has even been argued that in their turn words produce pain. In the next paragraphs, I will work out these separate standpoints in association with migraine.

Pain can create

My hypothesis is that pain not only destroys, but may also create. One example to support this hypothesis is formed by the symphonic works of the Swedish composer Allan Pettersson (1911-1980), who suffered from severe rheumatoid arthritis. His music seems to be pain turned into music. Another example is the Mexican painter Frida Kahlo (1907-1954), who had lifelong chronic pain due to poliomyelitis, a severe accident, numerous spinal surgeries and a limb amputation and who turned her agony into a number of well-received paintings (Courtney et al., 2016).

In this book, however, I do not deal with music or painting, but with words. The main reason for this is that words are of utmost importance in the patient-doctor encounter (as can be read in chapters 1 and 2), are crucial to make a diagnosis and to 'perform'. Pain may destroy words, but possibly also create language, for example by the creation of a narrative by the patient in pain, expressed by Rey as 'pain always has a specific language' (4). For Siri Hustvedt, 'every illness has an alien quality, a feeling of invasion and loss of control that is evident in the language that we use about it' (*Shaking* 6). In her case, headache did not make language dry but created a quality. Indeed, Scarry herself does not only refer to the destructive power of pain on language, but also states that 'physical pain has no voice, but when it at last finds a voice, it begins to tell a story' (*Body* 3). In the second part of her book she describes the 'making' of the world in opposite to the 'unmaking' worked out in the first part. Comparable with Frank's creative restitution and quest narratives, which are in opposite to the chaos narratives that mute, she also sees some creative function of pain. So, it can be argued that pain destroys language, but at the same time leads to an increase in creativity. Here, Woolf's "On Being Ill" cited above is also of importance. After writing that pain makes language run dry, she describes the other side: that pain may create. After crushing the words of pain together, 'a brand-

new word in the end drops out' (7) and in 'illness words seem to possess a mystic quality' (21). In line with Svenaeus and Frank, cited above, Kirmayer (1992), for example, states that 'through the pain and suffering that foreshadow its own mortality, the body drives us to seek meaning' (325). Morris sees pain as something 'that ennobles even as it destroys' (*How to Read* 199) and quotes the surgeon/writer Richard Selzer who has written that 'pain invents its own language' (222). So, it seems that in many instances, words are created by pain instead of being destroyed by it.

In line with this, there are numerous remarkable examples of how pain indeed creates instead of destroys words. It is often said that the creation of language by subjects in pain mainly consists of the creation of metaphors. This is – for example – discussed by Kirmayer (1992) in his article "The Body's Insistence on Meaning: Metaphor as Presentation and Representation in Illness Experience." He states that 'just as bodily changes are felt immediately in the metaphoric process of thought, so the interactional nature of metaphor ensures that thoughts may be felt immediately in the body' (336). Important for pain is that 'we never see reality directly but only though the formative influence of our social conceptions of reality' (341). So, metaphors are grounded in bodily experiences and social interactions. In the chapter "Metaphor and Worldmaking" of his book *The Language of Pain* Biro also emphasizes that the production of metaphors is essential for the expression of pain. He states that 'metaphor exchanges absence for presence' (68). Indeed, the filling of voids is the primary motivation of metaphors (73). Biro even goes as far to state that 'pain is an all-consuming interior experience that threatens to destroy everything except itself *and can only be described through metaphor*' (75; emphasis in the original).

An example of how pain creates instead of destroys words is given in the article "Thinking Through Pain" by Martha Stoddard Holmes (written with the help of Todd Chambers). She describes how pain claimed a new place in her life (127). She had to be treated with surgeries and chemotherapy for a painful disease (which she does not specify further) and describes the effects of the pain on her language. Having first relied on the 'memorable ideas and prose' of Scarry (129), she starts to 'argue' with her. While doing so, Scarry's idea that pain destroys words becomes increasingly strange to her, lying in bed 'literally surrounded by words' (130), such as books, folders and her notebook. Her body in pain appears to be 'not a site of language erosion but language generation' (131). She demonstrates this by writing her article and several other texts on pain, and by pointing at the fact that there is a 'substantial history of human efforts to remember pain, literally to re-embody it through poetry and narrative and art' (136).

Mark D. Sullivan (1995) describes how Wittgenstein also refuted the destructive power of pain on language. Important is that Wittgenstein emphasized that pain is not absolutely private (5; see chapter 1). Its 'sharability' (conform the beetle in the box) is what it is all about. Sullivan stresses that 'Wittgenstein believes that the pain sensation is not sufficient to account for our experience of pain' (5). A language based on private pain – without the possibility to share the experience – would be meaningless. Pain is learned and defined in terms of outer circumstances and context (6), it is defined 'more in terms of its relations than its inherent qualities' (7). This resembles the abovementioned 'bodily experiences and social interactions' of Kirmayer. So, pain cannot destroy words, as the words (of pain) are used universally and based on a 'publicly negotiated concept of pain' (8). Sullivan also quotes Martin Heidegger, who has said that 'humans live in the house of language' and adds his own version after his analysis of Wittgenstein's thoughts: 'Human pain lives in the house of language' (9). He concludes from his analysis that 'pain generally drives us to language' (10). As such it creates.

Moscoso (2012) comes to an almost identical conclusion after comparing the ideas of Scarry with those of Wittgenstein. Whereas, in his opinion, Scarry was 'convinced that pain was "originally an interior and unsharable experience",' for Wittgenstein 'the mere possibility of a private language, and by extension a private experience, interior and unsharable, would be completely devoid of sense' (4-5). Besides, pain is not only known, but also learned through the mediated experience of others (5). According to Wittgenstein, 'you learn the concept 'pain' when you learn language' (5). Pain therefore does not destroy language, it creates language, even from childhood on. And in its turn language also creates (the conceptualization of) pain. After a comparable analysis of the thoughts of Scarry and Wittgenstein, Biro concludes that we 'must break with the illusions of the private world and focus instead on the private and sharable one' (54). A language for pain must be generated to make pain sharable (56). This language can only consist of metaphors, the 'as if' that also represents Wittgenstein's beetle in the box, but 'the thing in the box has no place in the language game at all; not even as a *something*: for the box might even be empty' (74; emphasis in the original). So, pain creates, the concept of pain can be shared, the box does nothing else than create sharability; or it connotes the created sharability of pain. The shared is the signified. Maybe this shared signified can be found in autobiographic accounts of sickness and pain. herefore, the next paragraph is about ego-documents.

Ego-documents of pain and literature

There are numerous ego-documents at the border of fiction and reality that illustrate the creative power of pain. These autobiographies of illness can be called 'pathographies', with their tendency for 'part self-discovery and part self-creation' (McKim 102). The urge for the sufferers to write their texts often seems to stem from their need to come to terms with a traumatic (painful) experience, which often involves the need to project the trauma outwards (99). So, writing about their agony includes the need to share this with others. About this outward projection Frank has remarked that some authors of illness narratives have even claimed 'to have been more alive through their sufferings' (*Reclaiming* 13). Furthermore, this 'being alive' must be seen in the context of others. So, next to the tendency to 'describe their own deconstruction' (13), these patients seem to be 'more alive', and as such seem to combine the destruction caused by their disease with the creation of words.

By the way, the separation of 'fiction' and 'reality' in the context of ego-documents can be challenged, as it can never be trusted that what is narrated by an 'ego' really happened. It is clear that in first-person ego-documents the borders of truth and fiction are blurred and therefore notoriously uncertain. Why do patients write about their own illness? Do they want to regain control over their life? Do they seek attention for their illness and a correct diagnosis? Do they seek the potential to share? Other beetles? Probably it is a combination of these. Not far from autobiography there is the so-called autofiction in which author, protagonist and narrator are the same.

Virtually all (pain) disorders can inspire the creation of literary texts. For example, the simple and innocent disorder sciatica (pain in the leg) was used by the German author and Nobel laureate Hermann Hesse as inspiration for his novel Kurgast (Briët et al., 2012). Likewise, Hermann Melville, the author of Moby Dick, used his backache and sciatica in several of his novels (Smith 1985). Drew Leder (2016) describes how his lower leg pain resulted in an oscillation between nonreferential sensation and complex interpretation. For him, 'pain is not only destructive but productive on the meaning level' (457). In his opinion, 'pain is productive/destructive. These go hand in hand, though one or the other may have the upper hand at a given time or for a given person' (458).

Another remarkable example of how pain can create is the novel *In the Land of Pain* by the French writer Alphonse Daudet (originally published in

French as *La Doulou* in 1930), in which he describes the excruciating pain caused by the venereal disease syphilis. The book has been called 'none else than a *pain diary*' (Dieguez and Bogousslavsky 18; emphasis in the original), and 'one of the most valuable literary documents on the personal experience of disease and pain' (18). Daudet seems to treat pain as the central character (31). He admits that pain destroys language, as it is 'sheer torture … there are no words to express it, only howls of pain could do so' (Daudet 15), and calls pain 'the suffering of the inexpressible' (Dieguez and Bogousslavsky 39). On the other hand, the text contains numerous original and creative metaphors to describe pain, such as 'on the sole of the foot, an incision, a thin one, hair-thin; a penknife stabbing away beneath the big toenail; the torture of "the boot"; rats gnawing at the toes with very sharp teeth' (Daudet 21); or 'spasms in the right foot, with pains shooting all the way up my sides. I feel like a one-man band' (26). He continues with 'tonight, pain in the form of an impish little bird hopping hither and thither, pursued by the stab of my needle [..]. The injection misses its target, then misses again, and the pain is sharper every time' (28). Daudet also writes of 'muscles crushed by a waggon' (29), and pain as the stinging and stabbing of wasps (31). For him, pain leads to moral and intellectual growth (43), thereby pointing at its creative aspects. Indeed, a contemporary of Daudet remarked that he was 'the poet who turned pain into poetry' (39).

Another example of the creative function of pain caused by the same affliction is the French writer Guy de Maupassant who created, inspired by the pain of syphilitic tabes dorsalis, his short autobiographic novel *The Horla* (1887), which can be seen as an example of 'autofiction'. In the novel, de Maupassant describes the hallucinations and pains of the protagonist caused by the infection. It has been called 'a document of a haunted man', and 'a piece of fantastica' (Critchley *Banquet* 212). De Maupassant also describes headache as that 'hideous evil, which tortures as no torments have ever been able to torture, which grinds the head into atoms, and which makes one go mad' (212-213). 'Evil', 'torture', atoms', 'mad', de Maupassant illustrates that pain creates metaphors. This torture is not that of Scarry that destroys, but one that creates. Apparently, the disease of the writer did not only cause deterioration and distress, but also led to the creation of this piece of literature.

After concluding that pain in general can destroy, but also create, as shown in the literary examples / ego-documents above, I will now turn to the special case of headache/migraine, the central topic of this book.

Does migraine destroy or create? Or both?

Svenaeus (2014) uses the example of headache to describe the destructive force of pain on words when he states that, 'when I have a headache or become short of breath or nauseated, my whole field of perception changes and affects the way things attain meaning for me in the world. In physical suffering, the world is typically narrowed down' (*Hermeneutics* 409). A historical example is given by Moscoso (2012), describing the work of the physician Étienne-Jean Georget (1795-1828) who sees 'periodic migraine' as an expression of 'hypochondria' (184). Georget cites the words of one of his patients who describes the destroying effect of headache on language: 'above all my head aches; it takes a great effort to get my ideas together, they seem to pass by quickly; they cross one another' (184).

The destroying effect of headache has been described by many others. For example, Ira Sukrungruang (2014) in his article "A Meditation on Pain" describes that on headache days 'doors are closed to the world' (63), and on 'those days we walk silently, speak in whispers' (63-64). He keeps his pain a secret as 'to give voice to it is to acknowledge its existence' (68). For him 'headache was an unwanted guest' and 'a serial killer with an ice pick' (60). He realizes that the 'headache became personified. This pain took a pronoun' (60). The creative 'translation' of headache in metaphors is obvious. For Svenaeus, 'the structure of the world around us changes in physical suffering' (*Hermeneutics* 409). Thus, new ways of perceiving headache indeed have led to original metaphors and creativity. Moscoso (2012) turns again to Georget to describe how in the case of headache expressions can become metaphorical, as:

> when the cephalgia becomes unbearable, when the brain no longer has intellectual and moral existence, suffering is communicated through complex expressions: some feel that they have an anvil crushing their heads, others feel they are being beaten by hammer blows, others that their brains are boiling, as if they were touching scalding oil. The sensations are not described with the proper terms of popular psychology, but rather through a twisted correspondence to imaginary worlds. (185-186)

This 'twisted correspondence to imaginary worlds' strongly suggest the parallel worlds a migraine sufferer lives in or experiences.

Giving an example from another 'art', Morris mentions how the painter Georgia O'Keeffe was inspired by her headache to paint (*How to Read* 196), and even calls her headache 'a possible source of beauty' (*Culture* 197). Her headache can be seen as something 'that ennobles even as it destroys' (*How*

to Read 199). Also, it has been argued that the Italian painter Giorgio de Chirico (1888-1978) painted some of his paintings under the influence of his migraine (Piechowski-Jozwiak and Bogousslavsky 2013). Of Pablo Picasso it was first argued that migraine was an inspiration for some of his cubist paintings (Ferrari and Haan, 2000), but later this opinion was retracted (Haan and Ferrari, 2011). As said, however, this book does not deal with the association between visual representations and pain, but with the relation of pain with words.

In the article "Making Poetry of Pain: The Headache Poems of Jane Cave Winscom" by A. Elizabeth McKim (2005), the creative function of headache is part of the title. The author analyzes how the poetess Winscom (1754-1813) expressed her headache in poetry. Winscom first remarks that the pain leaves her 'in silent anguish' on her bed (94) and that it makes her 'speechless in the face of pain' (102). McKim translates this into 'the absolute power of pain to silence the sufferer' (93). However, 'the poems demonstrate Winscom's narrative composition of a self who has overcome this enforced silence to speak about the experience of head pain' (93-94). By writing her poems and creating a large number of (original) pain-metaphors, Winscom succeeded in 'the construction of a self who is able, somehow, to express the inexpressible' (106). She successfully articulated the invisibility of head pain and contradicted the silencing of the sufferer. Of course, it is unlikely that she wrote her poems during the headache attacks. She probably used her memory of the pain to create her poems. By writing her poems in the present tense, however, she strongly attaches the pain to the creating.

The actual having of migraine, on the other hand, often has direct destructive powers on language (Schwedt et al., 2019). This can be due to the pain, but also due to the aura. Up to one third of migraine patients suffer from at least some attacks with aura, the prodromes of the headache, that most frequently consist of visual or sensory disturbances. Disturbances of speech, in the form of aphasia[23], dysarthria[24] and as a component of confusion, however, may occur also (Bruyn 1968, Ardilla and Sanchez,

[23] The term aphasia is used for an inability to comprehend and/or formulate language due to a dysfunction in certain brain regions (the so-called speech areas of Broca and Wernicke). The words of the patient can become incomprehensible and/or the patient cannot understand what is said to him or her.

[24] Dysarthria can be described as spluttering over words with a thick tongue. Often, bystanders think that the patient is drunk. So, whereas aphasia affects the contents of speech, dysarthria affects its form. Both, however, can affect language considerably.

1988; Kelman 2004; Petrusic et al., 2013). Aphasia can also be the result of a large number of other brain diseases, for example a stroke or a tumor. The aphasia of migraine, however, is described as being different from that of other causes, as many patients with aphasia as a part of a migraine attack describe that they knew perfectly well what to say but were unable, due to some sort of block, to express verbally what they thought of (Bruyn 63). A consequence of this is that the migraine aura *temporarily* destroys language in these cases. In addition, inability to write ('agraphia'), read ('alexia') and difficulty in writing text messages ('dystextia') have also been described as part of the migraine aura (Bigley and Sharp, 1983; Fleischman et al., 1983; Evers et al., 1996; Whitfield and Jayathissa 2011).

How aphasia caused by migraine destroys language and creativity has been described by Dreifuss in his article "Observations on Aphasia in a Polyglot Poet" (1961). During his migraine attacks, the poet described lost his comprehension of the English language but could still curse in German. During one of the attacks, he was also unable to understand the meaning of words and his sentence formulation was faulty. The author of the article calls the disturbance of language by migraine 'apoesia' and stresses that 'migraine, though generally considered to be a benign reversible phenomenon, is followed by evidence of residual defects' (96).

In general, after the aura, in most instances the headache phase of the migraine attack starts. During that phase, the patient does not only experience severe headache, but also a combination of several accompanying symptoms, such as nausea, and sensitivity to smell, light and sound. The latter is called phonophobia, and it has been emphasized that this can also destroy language, as due to extreme sensitivity to sound, 'speaking becomes unbearable in the midst of an episode' (McKim 102). And then there is the pain of the attack, described as one of the most severe one can imagine. This pain certainly can destroy language, in the first place because the patient seeks isolation and keeps quiet.

On the other hand, Kirmayer (1992) illustrates how migraine can also produce meaning: 'When a patient with a life-long history of migraine headaches spontaneously remarks, "My head is made of glass," she is simultaneously revealing something about her body image, her model of migraine, and the way she wishes to be handled by the physician' (*Insistence* 340). Whatever the intended meaning, the metaphor of a 'head made of glass' can be considered creative. Likewise, in the headache poems of Jane Cave Winscom (see above) there are plenty of similar metaphors, such as: 'But pain within my frame its scepter rears!' (94), or 'Through ev'ry particle

the torture flies' (94). In her case the headache seems to destroy speech, but not the ability to write down these words, and to create her poem. Her poems are an illustration of the idea of Svenaeus, that pain 'gives room for positive transformation' (*Hermeneutics* 416).

In the chapter "The Inscrutability of Pain" of his book *The Citadel of Senses*, MacDonald Critchley (1986) argues that 'the head pains in migraine offer an opportunity for mulling over the nature and meaning of painful experiences in general' (*Citadel* 180). He sees the head as '*locus minoris resistentiae*' ('weak spot') in headache patients, and refers to Nietzsche, who has said that 'all pain is per se, and especially when in excess, destructive [..]. Mere pain can destroy life' (181). But on this point MacDonald Critchley makes an exception for migraine, as it also 'may fulfill some purpose or bring about some cryptic benefit to the victim' (181). He describes the benefits of a migraine attack as: 'when stress of an emotional, mental, or physical kind reaches a critical level, an attack of migraine might intervene and bring a temporary halt to such a potentially nocuous influence' (181). Here, migraine resembles a cathartic experience.

Foxhall (2019) gives another example with remarkable aspects. She describes how the Scottish poet William Dunbar wrote in the 16th century a poem called "On His Heid-Ake" on the morning after a migraine attack (*Migraine* 33-34). Dunbar writes that:

> So much that I cannot write today
> So painfully the migraine does disable me
> Piercing my brow just like an arrow
> That I can scarcely look at the light

That this is an attack of (pre-IHS) migraine is likely. The pain is disabling, probably one-sided ('brow', not brows) and with photophobia. Remarkable is that the author writes that he 'cannot write today', though he is clearly writing words, probably with hindsight. Yet even in his painful and disabled state, he produces a metaphor: the piercing just like an arrow. So, although his migraine seems to destroy words ('cannot write today'), it also seems to create ('like an arrow').

Roland Barthes (1915-1980), a French linguist, philosopher, semiotican, structuralist and post-structuralist, suffered from migraine. He described the effects of his affliction in detail in his auto-biographic book *Roland Barthes by Roland Barthes* (1977). In the book Barthes (or the 'I' called 'Roland Barthes') interrogates himself as a text (and in that sense he is a 'patient as text', but maybe also a 'text as patient'). He often talks about himself as 'he'

instead of 'I', possibly because he fears 'the labyrinth of levels in which anyone who speaks about himself gets lost' (119-120). He states that he 'had no other solution than to *rewrite myself*' (142; emphasis in the original), and this rewriting also includes his thoughts on migraine:

> *Mon corps n' existe* … ~ My body exists …[25]
>
> My body exists for myself only in two general forms: migraine and sensuality. These states are not unheard of, but on the contrary quite temperate, accessible, remediable, as if in either one it had been decided to reduce the glorious or accursed images of the body. Migraine is merely the very first degree of physical pain, and sensuality is for the most part considered only as a kind of reject-version of active pleasure.
>
> In other words, my body is not a hero. The light, diffused character of pain or of pleasure (migraine too *caresses* some of my days) keeps the body from constituting itself as an alien, hallucinated site, seat of intense transgressions; migraine (as I am rather carelessly calling a simple headache) and sensual pleasure are merely coenesthesias, whose function is to individuate my own body, without it being able to glorify itself with any danger: my body is theatrical to itself only to a mild degree. (60; emphasis in the original)

It seems that Barthes needs his bodily pain to be himself. In these paragraphs, migraine is not presented as something that destroys, but something that produces individuality and a feeling of 'self'. This is the 'self' that will be explored further in Part II of this book.

Barthes continues with 'The plural body. "Which body? We have several." I have a digestive body, I have a nauseated body, a third body which is migrainous, and so on' (60). Earlier in the text he writes about his youth and seems to take distance, as he here uses the third person singular: 'He is troubled by any *image* of himself, suffers when he is named' (43; emphasis in the original). So, whereas at first the self-image is problematic, it later becomes 'temperate, accessible, remediable' partly due to migraine. He seems to confirm this with the words 'repetition that comes from the body is good, is right' (71). The autobiography contains a list of things the author likes and dislikes, but migraine is not among the around 30 things he (likes or) dislikes (116-117). Indeed, his migraine offers more advantages, as:

> this unsuitable word [migraine] (for it is not only half of my head which gives me pain) is a socially accurate one: mythological attribute of bourgeois

[25] This is in the original translation, though the French states: 'My body does not exist…'

> woman and of the man of letters, the migraine is a class phenomenon: who ever heard of the proletarian or the small businessman with migraines? The social division occurs within my body: my body itself is social. (124)

Here, one can think of the stigmatization of migraine, as well as that of the disease hierarchy. Although the prejudice can be criticized (there are many 'proletarians' and 'small businessmen' with migraine), Barthes writes about migraine in a 'positive' way, and not as something that destroys.

Then Barthes philosophizes about the reason for suffering from migraine. He wonders why he is more migrainous when being in the country, when resting, or in the open air, than in the city. 'What am I repressing? My mourning for the city? The recurrence of my Bayonnais past? The boredom of childhood?' (124). He considers that migraine can be a perversion, that he is the victim of a partial desire, that he is fetishizing a specific point of his body: '*the inside of my head*' (124-125; emphasis in the original). Could migraine reflect an ambivalent relation with his work, in the form of 'a way of dividing myself, of desiring my work and at the same time of being afraid of it?' In other words, could migraine be a protection mechanism for him? Then he comes to a sort of conclusion:

> So different from Michelet's migraines, "amalgams of bewilderment and nausea," my migraines are matte. To have a (never very strong) headache is for me a way of rendering my body opaque, stubborn, thick, *fallen*, which is to say, ultimately (back to the major theme) *neutral*. Absence of migraine, the insignificant vigilance of the body, coenesthesia degree zero – I should read these in short as the *theater* of health; in order to assure myself that my body is not healthy in a hysterical fashion, I should occasionally need to take away its *signs* of transparence and experience it as a kind of glaucous organ, rather than a triumphant figure. Hence migraine would be a psychosomatic (and no longer a neurotic) affliction by which I should agree to enter – though *just a little way* (for the migraine is a tenuous thing) – into man's mortal disease: insolvency of symbolization. (125; emphasis in the original)[26]

Here, Barthes gives his migraine an important meaning. The headache seems to be important for his 'embodiment', and absence of migraine confirms for him that it is not psychosomatic (as it then would not disappear). It even seems that the on-off character of migraine proves for him that he is not neurotic, but a mortal man of flesh and blood. And,

[26] 'Glaucous' means a pale grey or bluish-green appearance of the surface.

importantly, he proves that migraine can create, here expressed in beautiful words and sentences.

Another case is the American writer Siri Hustvedt, who is also a migraine patient. She describes her disease in great detail in her autobiographic book *The Shaking Woman* (2010). The starting point of that text is an attack of shaking all over her body during a public speech she gave in the memory of her deceased father. After that first severe attack, she got several more, mostly when speaking before an audience. Her search for an explanation for these abnormal occurrences resembles the so-called 'quest narrative' as described by Frank in *The Wounded Storyteller* (1995). Hustvedt's quest includes a detailed description of her migraine and its possible relation with the attacks of trembling.

It appears that she has had migraine since childhood (5), including two very long episodes of 'intractable migraine', each lasting a year and leading to long hospital stays (9). She describes her experiences in the hospital as:

> those strange drugged days, punctuated by the visits of young men in white coats who would held up pencils for me to identify, asked me the day and the year and the name of the president, pricked me with little needles – Can you feel this? – and the rare wave through the door from the Headache Czar himself, Dr. C., a man who mostly ignored me and seemed irritated that I didn't cooperate and get well, have stayed with me as a time of all black comedies. Nobody really knew what was wrong with me. My doctor gave it a name – *vascular migraine syndrome* – but why I had become a vomiting, miserable, flattened, frightened ENORMOUS headache, a Humpty Dumpty after his fall, no one could say. (4-5; emphasis in the original)

The 'vomiting, miserable, flattened, frightened' seems to be in the 'destroy' category. Nevertheless, Hustvedt gradually turns out to be a creator. In the course of her quest, her attacks of trembling and shaking are diagnosed as stage fright, panic disorder, hysteria, conversion, psychogenic attacks, and epilepsy. Indeed, she concludes that 'the story of the shaking woman is the narrative of a repeated event that, over time, gained multiple meanings when seen from various perspectives' (182). She makes an association between the attacks of trembling and her life-long migraine and thereby considers the diagnosis of so-called 'migralepsy', which is a combination of epilepsy and migraine (157). Her migraine has given her 'lifting sensations and euphorias, floods of deep feeling that arrive in my body as lightness in my head and seem to pull me upward' (157). In addition, she states that 'a feeling of high, perfect joy has preceded my most brutal and durable headaches' (157). Her shaking and her migraine add something to her

existence, as 'the association of pathology with personality brings us yet again to a larger question: What are we?' (157).

This strongly resembles Barthes' conclusion that without migraine he would be another person. Hustvedt's migraine auras sometimes give her a feeling of 'happy immersion in the world' and that 'the borders of the self we imagine are mutable' (165). She realizes the ambivalent value of this situation, as:

> alas, my life is lived in the borderland of Headache. Most days I wake up with migraine, which subsides after coffee, but nearly every day includes some pain, some clouds in the head, heightened sensitivity to light, sounds, moisture in the air. [..] The headache is me, and understanding this has been my salvation. (174)

The 'borderland' resembles Susan Sontag's kingdoms of the healthy and the sick. Indeed, Hustvedt places her migraine and possible epilepsy in 'familiar territory' and in 'the land of Migraine' (176). And then 'it comes home again' and unfortunately more severely (176). Hustvedt is in doubt because:

> how do I know what pain means except for what it means to me? For years, I have been puzzling over Wittgenstein's meditations on language and pain in his *Philosophical Investigations*: "[Pain] is not a *something*," he announces, "but not a *nothing* either! The conclusion was only that a nothing would serve just as well as something about which nothing could be said". (180; emphasis in the original)

The something and the nothing both remind us of the beetle in the box. There can be something or nothing in the box. This may be frustrating for the sufferer, but fortunately in both situations a communicable meaning is produced.

About her headache, Hustvedt admits that she is, 'curiously attached to my migraines and the various feelings that have accompanied them. I cannot really see where the illness ends and I begin; or, rather, the headaches are me, and rejecting them would mean expelling myself from myself' (189). She concludes that her migraines are 'woven into the very fabric of [..] conscious identity' and the 'narrative self' (190), but the latter is 'a fiction founded in language' (191). Her experiences are turned into fiction. Based on her migraine Hustvedt wrote the novel *The Blindfold*, which is a clear example of how migraine can lead to creativity (the novel will be separately analyzed in part II of this book: Text as patient).

The parallel with how Barthes deals with his migraine is strong. Hustvedt's shaking attacks remain unexplained, but seen in the context of migraine, Hustvedt gains insight in her being and concludes that: 'I am the shaking woman' (199). Her experiences somewhat resemble 'the sublime', which is a strong, sensory experience between rationality and irrationality, and which can lead to the notion that next to the world of our common perception, something else exists, a world that is unreachable and differs from common reality. The sublime is strongly associated with the romantic period and also has a strong connotation with beauty and nature. Maybe this (sometimes) also true for migraine.

The 'Humpty Dumpty' in Hustvedt's quotation about her hospital stay, cited above, of course, refers to Lewis Carroll's novel *Alice in Wonderland*. Indeed, there is a clear association between that novel and migraine. The novels *Alice in Wonderland* and *Through the Looking Glass* contain much descriptions of hallucinations and illusions[27]. An example of a hallucination is the 'Cheshire Cat', seen by Alice in a tree; examples of illusions are the episodes in which Alice feels as if her neck is very long or where she feels bigger than her surroundings. The latter subjective disturbances of the perception of one's own body or the surroundings have been labeled 'metamorphopsia', a type of distorted vision. These are very common in children with migraine and occasionally occur in adults also and have led to the eponymous diagnosis of the 'Alice in Wonderland Syndrome' (Fine 2013; Blom 2016). There has been a debate about whether Lewis Carroll (synonym for Charles Ludwidge Dodgson) based these descriptions on his own suffering of migraine or not (the debate is summarized in Haan and Meulenberg *Muze* 66-74). If these were Carroll's own experiences, it can be argued that they caused destruction (in the sense of deformation of visual images) or creation (in the sense of reviving them in his works of fiction). In both cases, a discussion of these would not be relevant for the present book as the distortion concerned visual and not verbal qualities. Jill Gordon Klee (1991), however, also associates some aspects of Carroll's text with disturbances of speech. She argues that 'what more perfect description of a fluent aphasia can be imagined in the poem, "Jabberwocky"[28], which only

[27] Respectively: perceptions of something that is not present; and distortion of something that is present.

[28] For example, the first lines of the Jabberwocky poem are:

Twas brillig, and the slithy toves
Did gyre and gimble in the wabe:
All mimsy were the borogoves,
And the mome raths outgrabe.

becomes understandable when explained by Humpty Dumpty' (30). Next to this, Alice displays signs of 'pure nominative aphasia' when she is unable to name familiar things such as a tree or a fawn and even herself (30). Klee refers to Carroll's own (migraine-related?) stuttering as a possible reason for his including of these disturbances of language in his fictional text, but here maybe confuses the author with the narrator. Presuming that Carroll indeed had migraine, the disease did not destroy, but led to an inspired creation.

Conclusion

It has become clear that pain can destroy language, but can also enhance it, mainly through the production of metaphors. This is also true for the pain of migraine, but it seems that with this particular phenotype of pain, something special is the matter.

First, one of the most important aspects of migraine is its paroxysmal nature; the fact that it comes in attacks. The effects of migraine on language must therefore be considered separately in two situations: in- and outside an attack. In *The Language of Pain* (2010), Biro seems to refer to this 'on'- and 'off'-character of migraine in a nice metaphor by stating that 'while language may be impossible for those situated at pain's peaks, it is not so for those residing in its valleys' (20). Indeed, migraine patients are often silent during their attacks, but seem to compensate for this when they are headache free. Whatever the destroying effect on language of the aura or the pain of the attacks may be, there is always the hope and 'certainty' that the pain will stop (as, by definition, an attack has a beginning and also an end). Unfortunately, when patients are pain-free there will always be the fear for the next attack, called 'cephalalgiaphobia'. Svenaeus' description of the experience of subjects with pain and those without as, 'the world of the pain sufferer is totally different from the world of the happy enjoyer, in whole as well as bits' (*Hermeneutics* 410), can also be seen to address the dichitomy *within* migraine.

The world of a migraine-sufferer is divided between 'on'- and 'off', and the effects of these on language change accordingly. During a migraine attack it is:

destroy +, create –

Outside of an attack it is:

destroy –, create +

To quote the already mentioned pain-sufferer Alphonse Daudet again, although he is not speaking of headache but about pain in the legs: ‘Words only come when everything is over, when things have calmed down. They refer only to memory and are either powerless or untruthful’ (15). Here, he seems to refer to paroxysmal pain and to the difficulty of the sufferer to recall the pain afterwards. In migraine, after the previous pain comes a next pain that ‘is always new to the sufferer’ (19). Second, next to the consequences of the paroxysmal nature of migraine there seems to be another peculiar characteristic. As illustrated by the ways Barthes and Hustvedt deal with their affliction, migraine adds something to their lives. They do not complain but seem to need their migraine to be who they are. Indeed, there are many migraine-patients who ‘miss’ their disease when it is effectively treated. Here, migraine seems not only to ‘destroy’ or ‘create’, but also to determine one’s life and be important for one’s ‘self’.

Taking this together, Scarry’s balance of destruction or creation of language by pain seems to topple over to the creation side. Furthermore, migraine adds an additional aspect to the creation side due to its chronic, paroxysmal and cathartic life-determining nature.

CHAPTER 5

THE TEXT AS PATIENT

In the first chapters of this book I explained the relation between words and pain, focusing on migraine. I gave arguments how a patient (with migraine) can be read as a text and that methods used in medicine/neurology are important to make a diagnosis based on the words of the patient. In addition to these descriptive and interpretative techniques, in some of the chapters, I have discussed approaches that are more 'literary' than 'medical' (e.g. poetical, discourse analytical, rhetorical and philosophical approaches). In the following chapters, I will explore whether this 'reading' and its objects can be turned around. In other words: Can a literary text also be read as a patient? And if so, can such a text more specifically reveal something about the nature or some of the aspects of migraine?

Bal (2009) writes that an interaction between narratology and anthropology is relevant as it 'addresses implicitly the major challenge posed to narratology: that of, precisely, the social embedding of narrative – in other words, its relation to reality' (188-189). The relation to 'reality' is most important here. In this aspect, one can wonder what methods or approaches can be used best, those of medicine, the 'literary' ones, or a mixture of both?

Before addressing these questions, it must be realized that a literary text has more 'layers' than a patient: the text is made by an author, the text itself is told by a narrator, in the text the aspect of focalization rules the story, the characters are actors in the development of the plot, etc.. Whereas in the case of a patient, author, narrator and character are the same, in a literary text these are (almost always) different and clearly distinct entities. As Charon (1992) describes, 'the patient tells the story, in roughly the same way the author creates a work. The doctor listens to that story, decoding it or interpreting it in roughly the same way that a reader makes sense of a written work' (*Build a Case* 117). Of course, there are the readers of that text, but this 'party' I will only address in depth further in its combined role as 'reader' of a patient and a text. Translating the above mentioned different layers of a text to migraine, I will analyze 1): an author with migraine, 2):

narrators with migraine, 3): the description of a character with migraine (and how the other characters in that text 'see' the migraine of their 'co-character'), and finally: perhaps most importantly, how literary texts 'perform' migraine in language.

At first sight, the reading of a fictional text as a patient creates two possible, and different approaches: An interpretation that is based purely on the medical information given, or a literary analysis. This 'split' translates into a difference between 'scientific' and 'scholarly' and as such seems to echo the division into the so-called 'two cultures', which was introduced by the writer and scientist C.P. Snow in 1959. According to him, 'the intellectual life of the whole of western society is increasingly being split into two polar groups' (169). At the one pole he considered the literary intellectuals, at the other the scientists, especially the scientists of physics. He described a lack of understanding between these groups, and that they even have 'a curious distorted image of each other' (169). The non-scientists 'have a rooted impression that the scientists are shallowly optimistic, unaware of man's condition' (170). The non-scientists can therefore even develop an anti-scientific feeling. On the other hand, 'the scientists believe that the literary intellectuals are totally lacking in foresight, peculiarly unconcerned with their brother men, in a deep sense anti-intellectual, anxious to restrict both art and thought to the existential moment' (170). As main cause of the division Snow mentioned 'the pole of total incomprehension of science', which gives 'an unscientific flavour to the whole 'traditional' culture' (171). In contrast, scientists 'know of books, though very little. And of the books which to most literary persons are bread and butter, novel, history, poetry, plays, almost nothing at all' (171).

Snow's standpoints have received a great deal of positive commentary, but also criticism. Stringer (1983), for example, speaking from the field of social psychology, blamed Snow of too much focus on texts, and of generalizations, stereotyping, prejudice, polarization and positive discrimination. Arike (1996), on the other hand, agreed with Snow's thoughts and argued that the decades after his two-cultures publication have not been kind to the intelligentsia, as 'the culture of the text has been riding along on wave after wave of crisis brought on by the maelstrom of technological change' (385). For Arike, the crisis was caused by French poststructuralism, feminism, multiculturalism, postcolonialism, and deconstruction (385). In short, the answer of the 'humanities' to scientific progress was diffuse and too much based on 'the methodology and discourse of a literary-linguistic poststructuralism' (385). He even argued that literary culture's failure to attend, in any meaningful manner, to the

historically unprecedented scientific, technological, and social transformations of the twentieth century resembles ‘a retreat into the safety of bedraggled romanticism’ (386). And – even more critical – he stated that ‘the scientists and media artists, after all, have a research program, jobs, and funding; the literati seem only to have nostalgia and the lonely burden of defending what seems becoming an elite mode of communication against the onslaught of supposedly vulgar media’ (387). Therefore, his advice was to get outside of language and its recursive structures for a perspective that would pay due respect to other modes of cognition.

That was the previous century. More recently, the idea of a two cultures division has been challenged even more, not in the way of polarizing criticism or agreement, but as a positive starting point. Charon and Spiegel (2005), for example, state that ‘trying to understand the words with which sufferers register their experiences consumes and probably unites the clinicians and the scholars in the field’ (2005). As another example, Clayton (2002) explores the work of a group of writers who have ‘discerned that the relations among science, technology, and literature are shifting’ (808). The works of these writers have led to a new genre of contemporary literature that focuses on science and technology (808). In his opinion, it seems that the cultures of technology and the humanities are converging. This will not lead to ‘a seamless, integrated culture, in which literary intellectuals understand quantum theory and scientists in lab coats spend their free time reading’ (810), but to ‘an increase in imaginative writing about science’ (812). He thinks that maybe a science of imagination will follow. It seems that in this century there are many more writers than before that have knowledge of aspects of science. Clayton nevertheless concludes that the two-culture split is no longer operative because science has achieved a virtual hegemony over all other forms of discourse. In his vision, literature and the other humanities ‘have lost their claim to produce valid perspectives on the world and thus have become irrelevant to the real business of life’ (823). So, in his opinion, the division of the two cultures disappears in a ‘taking over’ of the one by the other. This was already foreseen by C.P Snow, who concluded that ‘there seems then to be no place where the cultures meet’, but immediately thereafter expressed the hope that ‘the clashing point of two subjects, two disciplines, two cultures – of two galaxies, so far as that goes – ought to produce creative chances’ (172).

An example of such a ‘clashing point’ – or call it more neutrally a ‘contact zone’ – of two disciplines, the one from ‘exact’ science (neurology) and the other from literary ‘science’ is the basis for my book. It has been said that:

> a discursive change has begun to develop across the notorious "two cultures" divide: while literary cultures have taken a renewed interest in recent mind science, the sciences of the mind have begun to draw conspicuously on the descriptive and analytic techniques of literature and philosophy (Gaedtke 274).

So, a mutual understanding seems to develop. For Tougaw (2015), this is based on 'counterfactual thinking', whereas 'science deals in hypothesis, literature deals in the creation of speculative worlds' (*Touching 347*). Frazzetto and Anker (2009) relate this interaction between art and science specifically to neuroscience and the arts and call it 'neuroculture'. They point at the 'neuro' dimension of various domains of knowledge, and at the 'hype around neuroscience' (815). One of the results of this development is a specific category of fiction, which has been called the 'neuronovel.' This is a literary subgenre that 'engages conceptually with recent interdisciplinary developments in cognitive science, neuroscience, psychopharmacology, and Anglo-American philosophy of mind' (Gaedtke 272). The rise of the neuronovel has been attributed to 'the waning of the Freudian direction' (Gillespie 631), and it has also been said that 'the neuronovel tends to become a variety of meta-novel, allegorizing the novelist's fear of his isolation and meaninglessness, and the alleged capacity of science to explain him better than he can explain himself' (Roth 9). Neuronovels deal with 'the bewildering complexity of relations between brain, body, and world' (Tougaw *Touching* 340). It appears that many novelists in the past had already anticipated the importance of this 'contact zone' and followed the discoveries of neuroscience, as – for example – described by Lehrer in his book *Proust was a Neuroscientist* (2008). He shows that the imaginations of modernist writers such as Walt Whitman, George Eliot, Marcel Proust and Virginia Woolf already foretold medical/neurological knowledge and anticipated discoveries of neuroscience (vii). Indeed, in their challenge of longstanding assumptions about subjectivity and interiority, modernist writers can be seen as predecessors of those writing neuronovels (Tougaw *Touching* 342). I will come back later in detail to the genre of 'the neuronovel', but first I want to argue that whatever the 'truth' is about the collaboration of the 'two cultures' (science and literary studies), an increase in their mutual understanding will not make our world worse, and maybe even (somewhat) better. Being a neurologist, neuroscientist and literary scholar, I have also learned to see the importance of fiction for my clinical work and I have already tried to explain the importance of literature to my medical colleagues (Haan et al., 2006; Haan and Meulenberg *Migraine*; Haan and Meulenberg *Tuinman;* Haan *Locked-in;* Minnaard and Haan).

In his article on the two cultures divide, Arike (1996) has expressed something that can be important for the present analyses of 'a text as a patient'. The creative chances mentioned by C.P. Snow can be sought in what Arike sees as 'a confusion about and a misinterpretation of what images do, what they are, how they function, whether they are essentially *representations*, or whether they don't do something else entirely' (387; emphasis in the original). Arike sees a passive model of perception of interpretation as less important than the understanding of how words and images 'work' (387), and this 'working' seems an important topic in science as well as in the humanities. I must, therefore, first explain how words 'work'.

Important here is the difference between the 'constative' and the 'performative' use of language, two terms that were developed in the so-called speech act theory by Austin and Searle in the sixties. As Eagleton (2010) describes, Austin 'had noticed that not all of our language actually describes reality', but some of it is 'more aimed at getting something done' (102). Constative language describes something, it claims to make a statement that can be assessed as either true or false (Culler *Philosophy* 504), but performative language 'does' something. It is not true or false, but actually performs the action to which it refers and as such cannot be considered as true or false but as successful or not (504). Performative language 'works', it creates meaning, performs, often dependent on the context of the utterance. It accomplishes the act that it designates (503). Or, as Culler states:

> the constative is language claiming to represent things as they are, to name things that are already there, and the performative is the rhetorical operations, the acts of language, that undermine this claim by imposing linguistic categories, bringing things into being, organizing the world, rather than simply representing what it is (*Literary Theory* 101-102).

In general, scientific language is thought to be constative, but as shown in Part I, it also creates realities, for example in the process of making a diagnosis based on words only. So, it is performative as well. Literary language is mainly performative, but it describes also. Its performative function 'stresses above all the self-reflexive nature of language' (Culler *Philosophy* 508), as 'the utterance itself is the reality of the event to which the utterance refers' (508). As an example of an 'utterance' that creates a reality to which it only refers itself, I have described in chapter 3 the discourse of migraine. In that discourse, it seems that science and literature have much in common, albeit with different accents. Both create a reality. In addition, in my opinion, it is an example of how the two cultures can come together.

Performative language may be grouped into three categories: 'official' (given force by institutions), 'explicit social' (accepted social mores) and 'implicit social' (given force by peculiarities of context) (Nolan-Grant 863). An example of this distinction is constituted by the word 'yes'. When this word is uttered by the bride during the wedding ceremony it 'performs' the marriage. When used as an answer to the question 'do you want total war?', it creates an intention, but not yet the war. When 'yes' is the answer to the question 'Do you suffer from headache?', it can be performative when uttered by someone who has headache at that moment or who describes a general state, as there may be no actual headache at all. Giving the performative an extra meaning, Culler (1997) stressed the importance of the distinction between 'poetics' and 'hermeneutics' (*Literary Theory* 62). For him, 'poetics starts with attested meanings or effects and asks how they are achieved' and hermeneutics, on the other hand, 'starts with texts and asks what they mean, seeking to discover new and better interpretations' (62). It is the clear difference between 'do' and 'mean'. The French philosopher Derrida added another aspect to the 'do' and 'mean': he argued that the performative only works as version or quotation of regular formulas (99). In other words: 'language is performative in the sense that it doesn't just transmit information but performs acts by its repetition of established discursive practices or ways of doing things' (99).

These thoughts of a relation between performativity and repetition can easily be applied to (fiction about) migraine, as with the utterance 'I have migraine' someone can express that he or she is suffering from an attack of migraine *at that moment* (performative), but on the other hand is also having the (chronic) disease called 'migraine' (which is in the criteria defined by repetition of attacks, see chapter 2). Derrida asks if a performative utterance can succeed if its formulation does not repeat a 'codified' or iterable form, or, in other words, 'if the formula that I utter to open a meeting, christen a boat, or undertake marriage were not identifiable as conforming to an iterable model, if it were not thus identifiable as a kind of citation?' (cited in Culler *Philosophy* 509). The answer to his question is probably 'no'. The meaning produced by iteration can also be recognized in migraine as every time someone uses the word 'migraine' it refers to the previous uses of the same word, be it an attack or the clinical or subclinically chronic condition. Both uses of the word contribute to its 'performative' working, to the shaping of the reality of 'migraine'. Because this is an important point, I will come back on the significance of the repetition of the word 'migraine'.

Based on these thoughts, I will analyze the importance of constative (interpretative) and performative (how words 'work') language in a

selection of literary works containing a description of migraine. According to Eagleton (2010), 'literary works themselves can be seen as speech acts, or as an imitation of them' (103). The real function of literature is performative (103). An author starts with an empty white page and creates a world out of 'nothing'. I have explained my reasons to choose the paroxysmal disorder migraine for my analysis in Part 1 of this book. In addition to its 'constative' part, it is important to realize that descriptive language – such as language about a disease – can 'do' something as well and that even so-called scientific medical language is not neutral or interpretive, but also can create realities. I will first explore (within the borderland of the 'two cultures') whether a literary text can be in some respects comparable with and thus be analyzed in a similar way as subjects of flesh and blood who have a 'problem' (such as a disease). Can a text be symptomatic? Can a text 'perform' a disease?

Patient, text, or both?

At first sight, there are several convincing arguments to answer 'no' to the question of whether a text can be read as a patient. There seem to be considerable differences between a 'patient' and a literary 'text'. Obviously, a patient is a real person, whereas a text is a cultural artifact. A patient consists of an organic body and is 'embodied', and a written text is of 'dry' material, such as paper and ink. Besides, the story of a patient is by definition 'read' currently or retrospectively, whereas the reading of a literary 'text' is a prospective act. Nevertheless, the answer can also be 'yes' as the techniques to make a diagnosis in a patient can also be applied to any other 'text'.

Ahlzén (2002), for example, argues that there are no simplified dichotomies between art and science, but that both are ways of 'approaching reality' (148). What is mentioned by means of language can be the reality of the patient or that of its representation in a text. In line with this, Daniel (1986) compares the patient's history with 'literally fiction in the root sense of a "making" ' (202), and Schleifer and Vannatta (2006) argue that 'there are elements and structures in literary narratives found in novels and short stories that parallel in many ways the narratives that patients tell their doctors' (364).

When we accept these standpoints, clear similarities between a (literary) text and a (real) patient emerge: their common 'readability', but also their 'performative' function. As Daniel (1986) states, 'the reader's experience of a poem, short story, or novel is similar to the physician's encounter with

a patient' (195). For Brody, 'the idea that a major difference exists between "real life" and fictional, or literary, first-persons accounts of sickness must be challenged' (*Stories of Sickness* 3). In her article, "On Vivacity: The Difference Between Daydreaming and Imagining-Under-Authorial-Instruction", Elaine Scarry (1995) elaborates further on how words, or what she calls 'the verbal arts' (2), or 'monotonous small black marks on a white page' (2), indeed 'somehow *do* acquire the vivacity of perceptual objects' (2; emphasis in the original). She argues that for perception or interpretation of 'the arts' three phenomena are important: immediate, delayed and mimetic perception. As verbal arts have no actual sensory content, the appreciation mainly depends on its mimetic content (3). Thus, imaginary vivacity is of utmost importance for 'the deep structures of perception' (4), and for this she cites Aristotle who said that 'images are like sensuous content except in that they contain no matter' (5). Indeed, for Scarry, the mystery of how the verbal arts enlist our own imagination in mental actions resembles in their vivacity more closely sensing than daydreaming (8). So, 'the people on the inside of the fiction report to us on the sensory qualities in there that we ourselves cannot reach or test' (14). If we want to consider a text as a patient, and when a patient and a literary text in some respects seem to belong to the same category, the pivot may indeed be how both are dealing with sensory qualities. How to translate this in constative and performative aspects?

Focusing on pain (migraine), one can argue that the (re-) presentation of pain in literature is difficult, if not impossible. The writer writes and the narrator narrates, but how do they represent pain, when at that particular writing- or narrating-moment they are *not* feeling pain? But also, when they indeed would be feeling pain, how does either of them describe it? And – one step back – how to describe from the outside someone with pain? How can such a text or a fictional one express pain? The answer possibly is that on all levels an act of reconstruction and imagination needs to be performed. According to Scarry, fiction in the form of a written text 'displaces the ordinary attributes of imagining – its faintness, two-dimensionality, fleetingness, and dependence on volitional labor – with the vivacity, solidity, persistence, and givenness of the perceptible world' (22). Here, I will translate this to the 'layers', mentioned earlier in this chapter, that determine a text and that can (or must) be analyzed separately. First there is the author, second the narrator with migraine, third the character described 'from the outside' and fourth the 'performing' text. Here, I will separately discuss these four aspects in the relation of text and pain.

Authors who write about pain can be placed in several categories. First, there are those who write 'ego-documents', in which a 'real' patient relates about his own sickness (see also chapter 4). One can of course wonder what or how much is 'real', and what or how much is 'fiction' in these texts. The reason for the author to write them is often rhetorical. These texts seem to describe a 'reality' and therefore often belong more to the category of the 'constative' (describing 'objective facts'), but they surely also contain 'performative' aspects. A sub-genre of ego-documents is so-called 'autofiction', described as a genre between autobiography and fiction in which author, protagonist and narrator are the same. Marie Darrieussecq calls autofiction 'a fiction of strictly real events and facts' (76). She argues that in autofiction a writer writes 'in the first person of an author-narrator and in his/her name' (76-77). So, these are texts produced by persons who 'really' exists, and who combine 'true' events with fictional ones. In her article "Fiction in the First Person, or Immoral Writing" (2010), Darrieussecq specifically refers to pain, of which she says that it cannot be imitated, but can carve into language a space that until then did not exist. This 'carving' is difficult to define (and Darrieussecq does not try to define it), but seems to emphasize that pain creates something special, and thus is performative.

The popularity of autofiction in the representation of disease might well have to do with the way in which the autobiographical dimension of fiction increases the emotional appeal of the narratives. The idea that there is a truth in the depicted fictional experiences helps to stir empathy. This 'rhetorical' aspect resembles the ideas of writing 'history', propagated by (among others) Hayden White who 'wrestled with the epistemology implicit in writing history' (314), as in history there is also the question of the subjectivity of the witness, the reliability of those who create the record, the problem of representation, the indeterminacy of reality, the criteria of truth, in short: the relationship of history and fiction. About history it is said that it:

> is always a selection and interpretation of those incidents the individual historian believes will account better that other incidents for some explanation of a totality, history partakes quite evidently of the nature of poetry. It is a making. [..] No two historians say exactly the same thing about the same given events, though they are both telling the truth. There is no *one* thing to say about anything; there are many things that can be said (Ong 17-18; emphasis in the original).

Now read 'ego-document' or 'autofiction' for 'history' and the meaning stays the same. There is no fixed truth in these narratives. The main

technique is that of a pretention of the constative, but the actual production of meaning by words goes in the direction of the performative.

A next category of texts I would like to call 'pure fiction', although it can also be questioned what this is. In general, one knows that one is reading fiction when things 'happen' (are described) that cannot happen in 'reality'. For example, when a text describes someone who can levitate (such as in Paul Auster's *Vertigo*), one knows one is reading fiction. The same can be said of reading about a meeting of two historical persons who lived in different centuries (such as in John Banville's *Keppler*), or of the encounter of historical with fictional persons (such as in Pat Barker's *Regeneration Trilogy*). In addition, a very simple 'definition' of fiction is given by Culler (*Deconstruction* 2004): 'if a story starts reporting a character's thoughts, expect it to be fiction' (28). One can also say that 'a work of fiction creates the world to which it refers by referring to it' (Nielsen 145). An alternative definition is to consider fiction as 'language offering propositions which make no claim for truth values in the real world' (Harshaw 229). The latter definition, however, has some pitfalls, especially when one is dealing with ego-documents and autofiction.

Jones (1994) argues that although patients' autobiographical stories have the power of connoting immediacy and authenticity, fictional stories of illness by accomplished writers may be even more emotionally powerful and may also be more pedagogically useful (198). One can question what 'accomplished writers' are, and if 'lay-writers' cannot write as good as them when describing their own problems. Yet according to Jones, 'good writers can present a patient's point of view in a compelling way even when it is imaginatively constructed' (198) and she gives Solzhenitsyn's autobiographically based novel *Cancer Ward* as example. Also, this opinion can be discussed, as one can doubt what 'good writers' are. In the following analysis, however, I will in a way follow her argument and focus on fictional texts of 'accomplished writers', defined as writers whose work has been published and reviewed. Although their works are 'fictional', they offer a challenge to be read with 'medical' (neurological) eyes, as I will show.

Next there is the story in which (fictive) narrators relate about their own pain in the first person singular. A narrator is the inter-textual (textually encoded) speech position from which the narrative discourse originates and from which references to the entities, actions and events that this discourse is about are being made. Concerning narrators, one must realize that the importance of their reliability and unreliability 'arises with respect to every speaking and reflecting participant in the literary act of communication'

(Yacobi 113). The choice between these two 'determines not our view of the speaker alone but also of the reality evoked and the norms implied in and through his message' (113). Especially about first-person narratives it must not be forgotten that in fiction there are mainly 'sentences about something that only exists by virtue of the sentences' (Nielsen 135), as they 'produce a fictional world that does not exist independent of these sentences' (145). So, the 'I' is created by means of his 'own' words and the narrator is a strictly textual category, which should be clearly distinguished from the author (who is an actual person; see chapter 6). On top of this, 'all works of representational art – including novels – are "imitations" in the sense that they appear to be something that they are not' (Rabinowitz 125), although 'fiction emphasizes the fact of the fictionality of a story at the same time it states that the story is true' (Riffaterre xv). As a consequence of this contradiction, this 'layer' must be analyzed with caution, also when someone claims to suffer from migraine.

Third, there are the descriptions of a protagonist with migraine in the third person singular, which stand in contrast to 'ego-documents', 'autofiction' and fictional narrators with migraine. Frank calls these descriptions 'less disruptive' than narratives in the first-person (*Reclaiming* 3). In their 'distance' to the patient, these texts can be compared with medical 'case histories', which are by definition written in the third person, and are mainly 'constative', which is also why one can call them 'diagnostic'. Medical observation is narratively organized and indeed the medical case history seems to borrow narrative forms and strategies from the novel (Pethes 42). Of course, there are differences, mainly because 'the epistemic genre of the medical case history is not determined by external categories such as linguistic rules, rhetorical strategies, narrative structures, or other formal literary features. It is merely shaped by an anticipation of the recipient's expectations' (26). Yet Sigmund Freud remarked that 'the case histories I write should really read like novellas' (cited in Pethes 27). Case histories are often thought to refer to empirical reality, but this can be doubted, as they often include as much imagination or vivacity as fictional texts. They often perform more than they describe, based on their rhetorical nature.

Finally, there is the 'performance' or 'embodiment' of pain by a text. The eloquent question here is whether there are similarities between patients and written texts. In patients, by definition, something is 'different', as what is different or 'wrong' (symptoms or signs) determines their being a patient. Texts are not 'wrong' in the same sense, but they can contain symptoms that can express and also 'perform' aspects of 'difference'. For example, a text can be an expression of pain and thus 'perform' pain. In addition, a text may

lack something, and this provokes the need to fill a gap, or another kind of problem in need for a solution. Indeed, Pethes (2014) concluded that 'modern subjectivity, as created by fictional literature, is based on pathological observations' (36). As an illustration of this, Darrieussecq refers to Aristotle who wrote about poetry that it 'needs either a sympathetic nature or a madman, the former being impressionable, and the latter inspired' (74). So, often the madman (or patient) creates the poetry. Grant has argued that 'in a story, characters face a problem, conflict, or difficulty that is somehow resolved in the end' (*Secrets* 181). This strongly resembles the diagnostic process in medicine: before a resolution can take place or treatment can be given, the problem must be determined; a diagnosis must be made. Can the reading of fiction be diagnostic for the problem?

Whereas spoken words are important in the diagnostic practice of a doctor dealing with a patient with – for example – headache, a diagnosis based on a written fictional text also depends on words. The main difference is that the text of a patient can be the diagnosis (as in the case of migraine), but that it in the text as text never can be more than a symptom. For both, however, counts that a 'diagnosis itself is a metaphorical process' (Jutel 6). Words get other meanings, whether spoken by a patient with – for example – headache or written down in a fictional text. There even are novels that are categorized and described as 'diagnostic novels' (Charon *Doctor-Patient* 143). In these, the characters are driven by 'the uneasy certainty that something is wrong' and they 'focus and resolve questions of meaning in their lives through diagnostic enterprises' (143).

Finally, there is another possibility. The language of fiction can become grammatical incoherent and thereby iconic for the disease it depicts. Examples of this are Mark Haddon's *The Curious Incident of the Dog in the Night Time* (autism), or Benjy in the first chapter of William Faulkner's *The Sound and the Fury* (oligophrenia). Here, the disintegration of language and as a consequence also of the narrative resembles the 'chaos-narrative' described by Frank (1995) and the destruction of language by pain as I have described it in chapter 4. One of my questions is, whether the same effect on language can be found in novels including protagonists with migraine.

In the next paragraph, I will focus on this diagnostic work.

How to diagnose (sickness in) fiction?

Howard Brody describes the relation between a patient and a doctor as follows: 'A doctor, I have come to believe, is in essence a literary critic.

Invited to hear a tale every time a patient comes to see him, he must evaluate each person's story in the same way that a trained reader would approach a literary work' (Brody *Stories of Sickness* 4). Here, he draws a clear parallel between the diagnosis of a doctor and that of a reader of fiction and points at the selective and associative reading that can occur in both situations. Writing can be compared with a performance, reading with the making of a diagnosis. In this light, it can also be argued that 'imaginative storytelling and role-playing thus give humans relatively harmless opportunities to acquire and improve their capacity for generating and recognizing distinct expressions for significant emotions' (Hernadi 33).

Some important points still need attention. What questions might a clinician pose to the text? How can the words of a fictional text 'perform' a disease? For this I will turn to one of the thinkers in the borderland of structuralism and post-structuralism: Roland Barthes. In his book *S/Z. An Essay* he elaborates on how to read a fictional text, in this case the short story *Sarrasine* by Balzac. By using various literary techniques, he dissects the text in smaller parts in order to show how the words are to be read literarily, but also how they produce meaning, opinion and even ideological standpoints. Barthes' book has been called 'a limitless and unrestricted source of connotation and allusion' (Lamarque 331). Barthes starts with mentioning that 'literature is an intentional cacography' (9), indicating that there is not so much a fictive dialogue between author and reader, but rather a 'countercommunication' (9). Author and reader together 'form' the meaning of the text, they obviously 'perform' it together. For Barthes:

> the reading part is a labor of language. To read is to find meanings, and to find meanings is to name them; but these named meanings are swept toward other names; names to call each other, reassemble, and their grouping calls for further naming: I name, I unname, I rename: so the text passes: it is a nomination in the course of becoming, a tireless approximation, a metonymic labor. (11)

This reading technique does not differ much from how a doctor makes a diagnosis (of a patient or a text). The doctor also tries to find meaning and weights the information given in a 'metonymic labor', with 'metonymic' being the style figure that uses the principle of contiguity. The 'problem' is not mentioned directly but is given in pieces to be interpreted and combined as in a puzzle. The words of the patient or of the text are 'rhetoric' or call them 'performative'; they create meaning and a reality. Does, for example, the word 'pain' describe or express something? This obviously depends on the context, as I have explained above for the word 'yes'. In medicine, the 'reading' starts with the anamnesis, which is an evaluation of the total

history of the complaints of the patient. The contribution of the patient is performative/rhetorical, that of the doctor mainly constative/analytical (but in its interpretation also performative). Its counterpart in literary studies is called 'close reading'. Broadly speaking, there are no great differences between these two methods, as both mainly depend on a subtle analysis of the meaning of words and other signs, and both use a 'frame of reading', a form of foreknowledge. No reader reads a book without certain expectations (bias) and knowledge; no doctor encounters a patient without medical knowledge (including bias).

The next step in medicine is the physical examination, which is often followed by some sort of ancillary investigation, such as a blood test or a scan. Ideally these are purely constative, and sometimes confirming (within the bias). The additional investigations produce signs that must be interpreted. In literary studies no such technology exists, but a method such as hermeneutics also makes a comparable dissection of a 'text' possible. In medicine, typically, the analysis results in a 'functional diagnosis' (what is the matter with the patient?), an 'anatomical diagnosis' (where is the lesion to be located?) and an 'etiological diagnosis' (what is the cause of the problem?). In literary studies the 'functional' (what is the problem?) and 'etiological' (what is the cause of the problem?) diagnoses can be applied. For the concept of an 'anatomical' diagnosis (where is the problem located?) a metaphorical step must be made in which the text is seen as a body and expressing a kind of 'embodiment'. Here, the distinction between the constative (seeing the words as a representation of some sort of reality) and the performative (realizing that the words create some sort of reality) is important. The 'anatomical' step emphasizes that a text can be seen (read) as a body and as an embodiment.

In line with Barthes' textual analyses of *S/Z*, in her article "Meta-Diagnosis: Towards a Hermeneutical Perspective in Medicine with an Emphasis on Alcoholism" (1992), Bowman writes that 'both the discourse of medicine and that of literature make a representation of something which must come to be understood' (267). For her, 'the truth is reached dialectically' and 'the physician or literary critic will actively participate in the story which unfolds' (271). This active participation in the interpretation of the texts seems like a mutual working of *phronesis*, or 'practical wisdom' (see chapter 1), the notion that in particular circumstances understanding is not 'thoroughly expressed in general rules' (Hunter *Narrative* 304). So, a thoughtful dialogue between text/patient and reader/doctor is needed for an interpretation, as is an appropriate analysis of the 'constative' and the 'performative' aspects of this. There is also a hermeneutical relation

between reader and text, which resembles Gadamer's 'fusion of horizons' where meaning is also reached dialectically and also partially by performance. Rimmon-Kenan (2006) even mentions 'the collapse of the body and that of the narrative, the problem of narrating the unnarratable' (241). This break-down could be the 'something wrong' I have mentioned above. A 'collapsed' text is a text that contains analyzable symptomatology. The 'anatomical' diagnosis then is the embodiment of the text that is performed.

So, what does such a text do with the reader? How does such a text create (perform) meaning?

Here, I can give an answer based on a personal experience. When preparing a book and later a book-chapter on Parkinson's disease in fiction (Haan and Meulenberg *Tuinman* 2009; Minnaard and Haan, 2016), I had to re-read several novels containing descriptions of that disease. Clearly, the texts 'performed' differently for me when I was re-reading with different eyes. A different meaning (bias) emerged from the texts in my separate readings. Was it the constative or the performative? In this context the *reader response theory* of Wolfgang Iser is of relevance. In his theory, the reader collaborates with the author in realizing the text, and in any reading-experience there is an implied dialogue among author, narrator, the other characters, and the reader. Or, to quote Biro (2010), 'we can see the consequences of the creative act in literature when an author and reader join together to breathe life into a fictional character, a being made up entirely of letters and words on a piece of paper' (119). This is the performative 'pur sang'. Here again, also Scarry's vivacity is important, especially to give the characters flesh and blood. We can create persons, situations, problems and solutions and 'fiction can be superior to a dry textbook in conveying students to the lived experience' (Lovett 18).

In his article "Pain and Pleasure in Literature" (2005), Conolly gives a possible answer, when he describes the 'pure pleasure theory'. He states that at first it is denied that we can feel painful emotional identifications with fictional characters. This notion is based on the so-called 'paradox of fiction', which points at the inconsistency of the following propositions: '1) we have emotions for fictional characters, 2) we know that they do not exist, 3) it is irrational to have emotions for non-existent objects' (305). It is, however, well known that readers can, and do feel emotions when reading fiction, so although each of the three propositions seem plausible, 'one of them must be false' (305). A possible reason why fiction causes emotions is that the occurrences can be imagined as taking place in reality, conform

Scarry's 'vivacity'. Fiction can be read as 'true' and maybe the pain described can be felt as or remind of real pain. Besides, often 'we know more about the inner lives of fictional characters than about real ones' (307), which can also be described as 'the God-like capacity of moving inside and outside people's minds' (Ahlzén 149). Conolly mentions one exception to this rule, which concerns our own inner lives, and concludes that 'when we sympathize with fictional characters, we are really sympathizing with ourselves' (307). Others however argue that 'the reader is left with an overall sense of what it feels to be the character' (Grant *Secrets* 183). According to Biro, when we examine stories about pain, we 'have the opportunity to see things from an omniscient point of view – to see pain from the perspective of both the sufferer and the observer; to see it, that is, from the inside and the outside simultaneously' (166). Here – again – *phronesis* is of importance, based on one's own experience. It is a combination of feeling one's own pain and accepting the pain felt by others.

To describe another stimulus for reading, Grant (2005) goes one step further. For his argument that one of the attractions of reading is a 'mild aversive stimulus' (187), he draws a parallel with a doctor examining a patient with a disease:

> Initially, in diagnosing the disease the physician's inspection and testing of the patient is reinforced by discovery of the nature of the disease. [..] From the outset the disease is aversive for the physician, but to eradicate the disease it is necessary that the physician be attracted to the disease, so to speak, and the physician's activities that reveal the disease are reinforced. (187)

The parallel is that the difficulties of a character in a story are an initial source of aversion for a reader, but they become a source of stimulation when the reader reads how the difficulties are resolved. For both a doctor and a reader, before removing the problem, it is necessary to identify, describe, and comprehend the problem (187), which is a method comparable with the assessment of the functional, anatomical and etiological diagnosis as described above. Fleissner (2009) states that 'fiction might be understood as a form of symptomatology' (387), and that the symptom can be called 'a disguise of a buried latent meaning' (389). Important is to realize that this meaning is not fixed, but depends on the (chosen) balance between the constative and the performative.

So, when reading a text as a patient, we need to analyze as Barthes, fuse our horizons with the text based on foreknowledge (bias), and use vivacity to mix our positive and negative emotions in the process of interpretation and

giving meaning. Most importantly, we must realize how the words presented 'work', how they 'perform', how they make meaning. For obvious reasons, I will take these important steps as a neurologist and to illustrate how this might work, I first elaborate further on the already mentiond special category of fiction, the 'neuronovel'.

The 'neuronovel'

As already mentioned in the beginning of this chapter, a separate category of novels has recently been proposed, that of the 'neuronovel' (Johnson *Consciousness* 170; Burn *Neuroscience* 213; Gaedtke 272; Roth 1; Lustig and Peacock 2013). It 'engages conceptually with recent interdisciplinary developments in cognitive science, neuroscience, psychopharmacology, and Anglo-American philosophy of mind' (Gaedtke 272). These texts are also called 'brain-based fictions', 'cognitive fiction', 'neurological realism' and 'neuronarrative' (Burn *Neuroscience* 213). More provocatively – the whole genre is called to express 'the syndrome syndrome' (Lustig and Peacock 1; Waugh 25). It is described to have 'an entanglement with larger nonliterary interests, inadvertently obscuring the extent to which the syndrome novel and other neurologically informed fictions represent a vibrant contemporary subgenre' (Burn *Mapping* 35). A neuronovel is said to deal with the anthropological figure of the cerebral subject or a character attributed to a cerebral lobe (Burn *Neuroscience* 213). Or, to put it otherwise, 'in imitation of Walter Scott, today an aspiring novelist might seek his subject matter in a neglected corner or along some new frontier of neurology' (Roth 1). One can even call the genre 'neuromania', or 'neuroflirtation' (Waugh 21), or 'a neuro-maniacal obsession with the body and the brain' (22). In all these senses, however, the concern has also been expressed that naming a syndrome makes it 'objective' and puts an invisible barrier of 'science' around the suffering (25). When that is done, the 'two culture discussion' would be restored. It is thus advised to 'not to be too 'scientific' in defining the syndrome novel' (25), but:

> there is evidently a substantial body of novels preoccupied with the biologization of the self and the medicalization of the mind. Some operate with specific disorders and some do not. Those that do usually involve neurological specialists and explore the construction of a dialectics of health and sickness. (25)

I conclude that neuronovels illustrate contemporary's interest in new problematics and 'often take as their central project the representation of the unfamiliar phenomenological conditions [..] called "the new wounded" –

patients who suffer neurological disorders and syndromes such as Huntington's, Parkinson's, Tourette's, Capgras, schizophrenia, and [..] encephalitis lethargica' (Gaedtke 272). After the 'linguistic turn' in the literary field, neuronovels are proposed to fill in the 'vacuum between literature and science' (Lustig and Peacock 2), and to represent the 'neurological turn' in literature (Lustig and Peacock 5; Lovett 170). It is a 'new engagement with neurology' (Lustig and Peacock 4). A list of neuronovels is proposed by Brindley (2013).

The basic principles of the 'neuronovel' can be summarized as follows:

> We might see a novel as a thought experiment; neuroscientists have conversely viewed pathological conditions as nature's experiments. It seems that contemporary writers are conducting a series of experiments to explore our motivations and behaviors. Neurobiology can offer valid but incomplete contributions to our understanding of ourselves, but we will always need explanations that encompass multiple levels of description. (Bracewell 167)

Ian McEwan's novel *Enduring Love* (1997), which deals with a protagonist suffering from the rare neuropsychiatric disorder of Clérambault's syndrome,[29] is said to 'effectively inaugurate the genre of the neuronovel' (Roth 4). The use of neurological case studies in fiction has been inspired by popular scientific writings of well-known neurologists such as Oliver Sacks and Antonio Damasio. Neuronovels can take the form of a third-person account resembling a neurological case-report, or that of a first-person experience then to be read as the account of an 'unreliable narrator' (for further thoughts on this term see above and chapter 5). The descriptions often lack the hermeneutical movement from symptom to cause, which is often compensated for by 'rich descriptions of the often bizarre phenomenological circumstances' (Gaedtke 273). The books of Oliver Sacks, for example, with as prototype *The Man who Mistook his Wife for a Hat*, have therefore even been compared to a Barnum's freak show (Haan et al. *Sacks*). Neuronovels are said to be 'novels stuffed with facts, names, things, impressing the reader with the author's store of "nonfiction" knowledge' (Roth 7). On the other hand, they are novels of consciousness, interiority, linguistic play and estranging description (7) resembling the 'stream of consciousness' novels of modernism. They are thus a combination of constative and performative aspects. But whereas modernist novels described everyone from the inside out, 'the neuronovel refashions

[29] This syndrome is characterized by the delusional idea of a patient that someone considered to be of higher social and/or professional standing is in love with him or her.

modernism as a special case, odd language for describing odd people, different in neurological kind, not just degree, from other human beings' (7). It uses the same 'inside out', but with emphasis of the different, individual and specific phenotypes.

Examples of third-person neuronovels are Ian McEwan's novel *Saturday* (about Huntington's disease), Jonathan Franzen's *The Corrections* (Parkinson's disease), and Umberto Eco's *The Mysterious Flame of Queen Loana* (stroke). First-person accounts are Mark Haddon's *The Curious Incident of the Dog in the Night Time* (autism), Paul Auster's *Oracle Night* (traumatic brain damage), and Luigi Pirandello's *La Toccatina* (stroke), but many other examples can be given (Haan et al., 2006; Bogousslavsky and Dieguez 2013; Lustig and Peacock 2013; Brindley 2013). Neuronovels often describe the altered ways of the perception of the world that arise from neurological disorders, and in this way 'create' new worlds.

Already before modernism, (neuro-) science strongly inspired novelists. For example, in the nineteenth century, the French naturalistic writer Emile Zola based several of his works on the theories of the (neuro-) scientist Claude Bernard (Conti and Irrera Conti 2003). An example is the novel *Therese Raquin* in which a severe neurological case is described, almost in the form of a case-report (Haan *Locked-in* 2009). A reason not to call such a naturalistic novel a 'neuronovel' is because it offers more a phenomenological description from the outside than a description of altered behavior from within. These pre-modernist novels are more constative than performative. This is expressed by the psychiatrist Lisetta Lovettt as follows:

> Psychiatrists and novelists have in common a skill for observation and deduction of motivation or reasons for behavior from careful observation. Unlike most other medical specialties, psychiatry has to rely on accurate identification of phenomenology since it does not enjoy the luxury of falling back on diagnostic tests, of which we hardly have any. We do this by honing our skills in observation and communication. (169)

Here, of course, 'psychiatrists' has to be replaced by 'neurologists'. After this change, however, the meaning stays the same, but only for the category of neurological diseases of which the diagnosis depends on words and not on scans or other 'objective' tests (see chapters 1 and 2). Of this category, migraine is a good example. Indeed, this was illustrated in a recent study (Brainstorm Consortium 2018). Genetic data from several large genome-wide association studies were combined and a comparative analysis was carried out on 265.218 patients with a brain-disorder and on 784.643 controls. It appeared that psychiatric diseases such as major depression,

schizophrenia and bipolar disorder had the most genetic overlap with one another. Neurological diseases such as Alzheimer's disease, Parkinson's diseases and epilepsy had much less overlap. Migraine took an intermediate position. This probably means that in psychiatry there is a great overlap between the diagnostic categories as determined by the current (DSM) criteria, whereas in most neurological disorders the diagnosis based on criteria and findings of ancillary tests is much more specific. The diagnosis of migraine, which is based on the words of the patients and artificial criteria, however, appeared to be less specific (or call it accurate) than that of the other neurological diseases.

Some of the literary works described in the following chapters can also be categorized as 'neuronovel'. They include protagonists with a neurological disease called 'migraine', which is why they were selected. In Part I of this book, I have tried to explain why migraine is special. It is a disease of which the so-called (constative) 'reality' is mainly based on words. Besides, I have elaborated on its discursive aspects, the relation of migraine with the destruction and/or creation of words, and its temporal aspects. Here, I will search for comparable and additional topics in a selection of novels, mainly focusing on how words of fiction 'perform' migraine. Butler has argued that 'a performative "works" to the extent that it *draws on and covers over* the conventions by which it is mobilized' (Butler 51; emphasis in the original). This seems a clear 'performative' explanation of the discursive criteria of migraine (see chapter 3). In the next section, I will first discuss the description and 'working' of pain in fiction 'in general', before turning to headache and migraine.

The depiction of pain, headache and migraine in fiction

Both Morris in his book *The Culture of Pain* (1991) and Moscoso in *Pain. A Cultural History* (2012) argue that Cervantes' *Don Quixote* includes one of the first, most important and most influential depictions/embodiments of pain in fiction.[30] Morris writes that: 'Don Quixote lives immersed in an unreal, bookish, idealized realm set apart from the banal demands of everyday life – and the penalty that Don Quixote pays for this neglect of flesh-and-blood actuality is that he rides through the novel like a comic punching bag' (90).

[30] The name of this nobleman has been written differently in many publications. The one used here is from the original title of the book: *El Ingenioso Hidalgo Don Quixote de la Mancha* (Miguel de Cervantes Saavedra 1605).

Morris thinks that ‘a dialogue between doctors and writers [..] can help to support and to extend the important changes beginning to alter our current thinking about pain’ (5), and that a reflection on Don Quixote might help in this process. For example, Don Quixote says that he does not complain of his pain at all, because ‘a knight errant is not allowed to complain of any wounds, even though his entrails may be dropping through them’ (91). In contrast, his servant Sancho Pancha sighs: ‘I must say, for my part, that I have to cry out at the slightest twinge’ (91). What we here can conclude is that a pain threshold exists, partially depending on factors from the ‘environment’. Moscoso writes that ‘Don Quixote’s pain becomes diluted in a reading that converts the misfortune and misadventure of others into a source of humor, mockery, and joke’ (42). Cervantes describes pain as an essential element of human action. At the time of *Don Quixote*, suffering was accepted as inevitable, being a symptom of the process of death, mourning, sickness, deformity and violence. Don Quixote nonetheless ‘chooses life’ (42). By accepting pain, he chooses freedom. Unfortunately, it can also be said that he is an example of the fact that ‘too much literature may clog up our mental veins and arteries’ (Hernadi 26).

In a descriptive analysis, Fraile et al. (2003) found 91 references to pain in *Don Quixote*, the majority referring to pain caused by trauma. According to Moscoso, the book possesses ‘many elements of the new epistemological order: the elusive relationship between words and things, between imagination and memory, or between reality and fiction’ (34). For me, obviously, in the light of the present book, especially the latter relationship, that between reality and fiction, is of interest. Morris includes his analysis of *Don Quixote* in the chapter “The Pain of Comedy,” and explains that the pain of Don Quixote mainly is used to illustrate that he is a brave knight. Traditionally, knights do not complain about or suffer from pain, and therefore Don Quixote ‘may not openly complain’ (92). Morris further argues that Cervantes here introduces the reader to the central paradox of comic pleasure, and that ‘comedy must implicitly include pain in order to overcome it’ (91). Moscoso finds this too simple and points at the fact that the ‘true’ (or call it ‘performed’) pain of Don Quixote is too often neglected. He argues that Morris forgets that ‘Don Quixote does complain that he is in pain, and a great deal’ (40). According to Moscoso, ‘in the framework of the different forms of configuring reality, pain is one of the least debatable elements’ (40). He adds that this is ‘not so much from the point of view of the reader – who does not pay attention to the evidence presented – as from that of Don Quixote himself’ (40).

I do not follow his argument, since pain is not 'debatable' in readers, writers and fictional characters even when it is 'performed' pain, only expressed in words. For Moscoso, pain 'found a place in all areas of the narrative structure' of *Don Quixote*. First, there is the 'extra-literary reality', reflected by the perfectly identifiable elements in the text that mirror the situation in the society of that time. Then there is the literary reality, which is at the heart of Cervantes' discourse, and that often consists of spells and enchantment. For example, Don Quixote suffers 'real wounds at the hand of imaginary beings' (41). To complete the spectrum, he mentions that Don Quixote has 'the freedom to leave his own story, denying the opposition between literary fiction and lived reality' (42-43).

With the example of *Don Quixote* in mind, other novels portraying protagonists with headache and migraine can be approached. There are protagonists with headache in many novels, from Shakespeare to the present day (Friedman 1972; Patterson and Silberstein 1993; Larner 2006; 2006; 2007; 2008; 2009; 2009; 2010; 2011; 2017; Haan and Meulenberg *Muze* 2009). To give some examples, there are numerous descriptions of characters with unspecified headache in the novels of Jane Austen, most often provoked by stressful situations (Larner 2007). Furthermore, the novels of Stephen King contain many descriptions of protagonists with headache, mainly to illustrate the horrific situations they are in (Patterson and Silberstein 77; Haan and Meulenberg *Muze* 98-100). William Faulkner seems to describe a patient with medication overuse headache in *The Sound and the Fury* (101-102). John Steinbeck's *The Wayward Bus* contains a description of faked 'secondary gain headache', as one of the characters regularly gets headache when she wants to get something from her parents, or 'punish' them (Friedman *History* 661-662; Haan and Meulenberg *Muze* 110-112). In many Dutch *fin de siècle* novels headache is associated with female 'hysteria' (Kemperink 1995), and Harry Potter's anguish can be explained by his suffering from cluster headache (Sheftell et al., 2007),

A remarkable example of 'non-migraine headache' is the (very special form of) hangover headache depicted in Ian McEwan's novel *Nutshell* (2017). The narrator of this remarkable story is an unborn child in his mother's womb. He can hear, but not see, and seems to possess much more than 'fetuslike' knowledge, for example about French wine, history, actuality, politics and the behavior of the adults that surround him, especially his mother – Trudy (Gertrude) – and her brother in law – Claude (Claudius) – who are going to assassinate his father in a Shakespearean plot. After his mother swallowed a couple of glasses (or 'perhaps a bottle') of Marlborough Sauvignon Blanc ('not my first choice, and for the same grape

and a less grassy taste, I would have gone for a Sancerre, preferably from Chavignol') the 'I' and his mother fall asleep. When waking up, they both have a headache that is described as: 'bad enough. But I'm having my first headache, right around the forehead, a gaudy bandanna, a carefree pain dancing to her pulse. If she'd shared it with me, she might reach for an analgesics. By right, the pain is hers' (45).

The fetus seems to know what his mother has to do to alleviate her hangover headache: 'water, she should drink more water', and after pressing his temples sighs: 'Monstrous injustice, to have such pain before my life's begun' (46). Then follows a remarkable contemplation about pain, which resembles that of Wittgenstein described in chapter 1 of this book:

> I've heard it argued that long ago pain begat consciousness. To avoid serious damage a simple creature needs to evolve the whips and goads of a subjective loop, of a felt experience. Not just a red warning light in the head – who's there to see it? – but a sting, an ache, a throb that *hurts*. [..] Those felt sensations are the beginning of the invention of the self. [..] God said, Let there be pain. And there was poetry. Eventually. [..] So what's the use of a headache, a heartache? What am I being warned against or told what to do? (46; emphasis in the original)

It seems that here a specific function is attributed to pain (headache). As described in chapter 1, in general, acute pain is considered to initiate evasive behavior and chronic pain is thought to induce protective inactivity favoring recovery (Pitts 275). It can be argued that the human pain system gave evolutionary advantages, as humans can memorize and thereby avoid pain before bodily harm becomes inevitable, and they can transmit information from generation to generation by words about threats to be avoided (276). In the quote of McEwan's *Nutshell*, pain is not only described as a warning signal to avoid damage, but also important for one's consciousness and 'the beginning of the invention of the self'. As also described in chapter 1, according to Wittgenstein, 'a private language, and by extension a private experience, interior and unsharable, would be completely devoid of sense' (cited in Moscoso 5). Here, the private sensation of this unborn child is attached to a meaning produced by a sense of collective credibility ('God', 'poetry'), of which he in fact cannot be aware. Nevertheless, this seems a reference to the beetle we all share and that forms a part of ourself.

Switching from the headache of the fetus, which is an example of so called 'featureless headache' to migraine, it can be said that migraine sufferers can be seen as a special category of the 'new wounded' as described by Gaedtke (272). The various metaphoric aspects of migraine have made it a challenging

source of inspiration for a considerable number of novelists and many protagonists with migraine can be found in the literature (Haan and Meulenberg *Muze* 2009; Haan *Metaphor* 2013). There is not only the pain, but also the (visual) aura, phonophobia, photophobia and nausea, and next to that its paroxysmal and unpredictable nature, leading to additional suffering between attacks (such as 'fear of pain' and 'cephalalgiaphobia'), even when one is free of pain.

To illustrate the 'performative' aspects of this disease, I have selected a couple of novels in which migraine plays a major role. I first followed the concept of 'neuronovels' and applied this concept to novels that have migraine as an important and 'scientifically' worked-out theme. My main emphasis will be on how the works selected 'perform' migraine. I have therefore chosen Siri Hustvedt's *The Blindfold*, James Lasdun's *The Horned Man* and Irvin D. Yalom's *When Nietzsche Wept* for further analysis, as these works of fiction – in my opinion – best illustrate the main topics of Part I of this book: how migraine becomes 'reality' within its discourse, how migraine can destroy or create language, how time is important for migraine sufferers and finally how the words 'perform' migraine.

I will read the novels as 'medical case histories', as if being confronted with a 'real' patient, who rhetorically performs her or his migraine and whose (pain-) experiences can be described as:

> if a novel happens, it does so because, in its singularity, it inspires passion that gives life to these forms, in acts of reading and recollection, repeating its inflection of the conventions of the novel and, perhaps, effecting an alteration in the norms or the forms through which readers go on to confront the world. (Culler *Philosophy* 516-517)

Important are the shaping role of language, its social conventions, what language does and says, and how to deal with the blurring of the boundaries between fact and fiction (517-518).

The main topics and therefore structure of my analysis will be addressed in the last chapter where the 'real' and fictional parts of my exploration will be compared:

- The constative: How is the diagnosis of migraine made; how is migraine described?
- The performative: How do these texts, one way or another, perform migraine?

But there is more. Based on the (mainly constative, neurological) analysis of the novels, I will try to come to an universal idea of how an analysis of the 'reality' and the 'fiction' (call it the two cultures) of migraine can add to a better understanding of (real or imaginative) patients with migraine. As final step, I will try to put these in a much broader perspective, the notion and invention of a 'migraine self'.

Towards the 'migraine self': The construction of objective subjectivity

In the first part of this book, I cited Bendelow and Williams (1995) who wrote that, 'as well as being a medicalized phenomenon, pain is, of course, an everyday experience linking the subjective sense of self to the perceived "objective" reality' (162). Indeed, subjective experience such as pain can become objective through the appropriation of the patient's testimony. This testimony may be compared with 'fiction', having subjective symptoms without objective signs, but also with 'reality' (we all know that pain can be real).

I used techniques from literary studies to analyze and interpret aspects of 'real' patients with migraine. With 'real' I meant subjects who appeared as such through (the reading of) their texts. In the following chapters, medical analytical techniques will be used to analyze different aspects of novels which depict 'fictional' patients with migraine. The main questions here are how the subjectivity of authors or characters relates to their depiction of migraine, how migraine is, in a sense, constructed by it and whether this can also be explained in a broader way.

Of course, such an analysis cannot be done without combining medical techniques with those from literary studies, as e.g. epistemology, hermeneutics, narratology and semiotics. Culler has argued that 'psychoanalytic theory [..] is the most powerful hermeneutic: an authoritative meta-language or technical vocabulary that can be applied to literary works, as to other situations, to understand what is "really" going on' (*Literary Theory* 142). In my opinion other techniques to analyze works of fiction may also explain what is 'really going on' in 'real' life when they depict (parts of) the behavior of a patient with a disease, in this case migraine.

To translate this to my analysis of patients and novels with migraine, I will first 'read' the patients and novels as fictional texts from the standpoint of literary studies, but then interpret them both as the words and deeds of a 'real' patient, read with medical eyes and with medical techniques. It will

turn out to be impossible to separate literary and medical elements completely as they appear to strongly overlap. There is a dialectical relation between them, and a combined reading is necessary. An important question is what the medical reading adds to the interpretation of the texts and what can be learned from this to be used in 'real' patients. Furthermore, does the meaning change when literature is read with medical (neurological) eyes?

The literature involved can have different 'functions' in defining migraine:

- It can be a description of patients (authors) about their own disease, as in (literary) 'ego-documents' or in various works of fiction (see above).

- It can describe a disease through a character speaking in the first-person which – by definition – must not be seen as the disease of the author. Such a description can be called mimetic.

- It can be interpreted broader, as a symptom of a disease of society (and then without mimetic relation between text and illness), or of life itself. This can be called 'philosophic'.

- It can provide the core for a construction or modelling of a subject based on the interpretation of fictional texts. It can thus give clues about a 'migraine self'.

Translating this to (the aims of) this book, I have included a work of fiction that is the creative product of an author with migraine (*The Blindfold* by Siri Hustvedt) and a novel narrated from the standpoint of a protagonist with migraine, which can thus be called mimetic (*The Horned Man* by James Lasdun). I will analyze also a 'mimetic' (philosophic) novel in which migraine is described 'from a distance' (in the third-person), *When Nietszche Wept* by Irvin Yalom. Important is the question which symptoms of migraine these texts illustrate and how. For example, I will investigate whether the grammatical order is disturbed, language destroyed, the sense of time lost, or 'reality' fragmented. I will further elaborate on how the texts contribute to the knowledge of 'real' patients and analyze how they 'do' ('perform') migraine.

As said, the next step then is a definition of a 'migraine self'. Here the core symptoms described above are important to model the subject within a certain field of forces. In the case of migraine – as I have argued in chapters 1-4 – this is mainly the loss of words, of time, of reality. The words of the patients are interpreted in artificial language, rules and criteria. It seems that migraine patients feel detached from reality. It is important to realize that in migraine this happens in attacks, which is in contrast with patients who are

constantly in pain. The attacks lead to other ‘subjectivity’ than being in a ‘stable’ state. This seems to result in ontological uncertainty during and outside attacks. Unique disease-related factors appear to determine the being of the self and the subjective world of the migraine patient. In this sense, it may even be said that migraine can be seen as illustrative for postmodernity in which nothing is certain, and no-one can be certain of his- or her ‘world’ at any time.

CHAPTER 6

THE BLINDFOLD AND *THE SHAKING WOMAN* BY SIRI HUSTVEDT

Introduction

The slogan 'the death of the author' is crucial in modern literary criticism and largely determines how to look at fictional texts. It points at the fact that one must not confuse the narrator of a work of fiction with its author. Or, as Bal (2009) writes, 'several processes are involved in ordering the various elements into a story. These processes are not to be confused with the author's activity' (8). In fiction, the writer withdraws and calls upon a fictitious spokesman. Eagleton (2010) expresses this situation as, 'it is language which speaks in literature, in all its swarming 'polysemic' plurality, not the author himself' (120). Indeed, when one would take the words and deeds of many narrators in fictional literature as 'real' words and deeds of their author, most of the authors should be put in jail immediately. Bal gives the example of Vladimir Nabokov's Humbert Humbert, the narrator of the novel *Lolita*, who has been described as 'an immoral hypocrite'. Due to the narrator's 'anthropomorphism' he was attacked by critics as if he could be disliked as a 'real' human being, and – to make matters worse – author and character were viewed as one and the same (120). So, it is of great importance that one does not confuse the narrator with the author, or the author with the narrator.

There are even situations in which an author can benefit from being 'dead'. Johnson (2016) argues that by passing through death the author can improve his status by being 'elevated to the object of desire *par excellence*' (2; emphasis in the original). He adds that 'maybe death does not destroy the Author-God but participates in its construction' (2). Indeed, many dead authors survive or become alive in their work, but nevertheless are not the same as their creations.

Authors who write fiction in the first-person remain especially at risk to be confused with their protagonists. Heinze (2008) gives an additional reason

for a confusion of author and narrator in this situation. He argues that in fact:

> the term first-person tends to underline the misunderstanding of equating "narrator" with "human-being." Proclamations about the death of the narrator argue exactly this: the "I" of first-person narrative is merely a signifier, a semiotic sign to which readers during the reading process attribute certain propositions and descriptions that also occur in the narrative. (281)[31]

So, whereas the author tries to make the text as 'lively' as possible, the reader must – in general – not fall in the 'trap' of seeing a character in a fictional story as a real person. Already in 1955, Friedman stated that the author had disappeared and was impersonalized (*Points of View* 1162). He further argued that:

> when the poet speaks in the person of another we may say that he assimilates his style to that person's manner of talking; this assimilation of himself to another, either by the use of voice or gesture, is an *imitation* of the person whose character he assumes. (1162; emphasis in the original)

Of course, the author chooses a 'voice' which certainly can resemble his or her own voice or not, but in any case one can argue that 'albeit the narrator is a creation of the author, the latter is from now on denied any direct voice in the proceedings at all' (1174).

On the other hand, authors evidently need to use their personal thoughts, experiences and lives when giving voices to the protagonists of their 'fictional' texts. They cannot deny their own voice. Because of this, in the nineteenth century, Wilhelm Dilthey placed the psychology of the author in the center of interpretation of their texts (see chapter 1). His standpoint can be described as 'the attempt to enter into the mind of an historical author' (Heelan 182). Subsequent theories, however, placed the autonomy of the text in the center, and thus the author was indeed, in a way, declared dead. As said, an influence of the mind of the author on a text can, however, hardly be denied. Therefore, there are many works of fiction in which obvious traces of the life and the thoughts of the author can be found. The case here is that for authors who suffer from the disease they write about the disease can form an important source of inspiration. There are numerous examples of such disease-based fiction, e.g. Guy de Maupassant and Alphonse Daudet who depicted the venereal disease syphilis in their novels (see chapter 4)

[31] See chapter 1 for the meaning of 'signifier'.

and Fjodor Dostojevski who suffered from epilepsy and imbued several of his protagonists with this disease (Vein 2006). In these cases, the author was not (yet) dead, but had a disease that obviously influenced the 'fiction'. Because of this, as said, one must be very cautious to see the narrator and the author of works of fiction as the same, even if they had a disease in 'real' life that was depicted in their fiction.

An exception, however, might be an author who repeatedly mentions in non-fiction texts that the disease was a source of inspiration for the fictional work. It can be argued that the narrators of such 'fictional' works may be seen as referring to an external framework, including not only their mind, fantasies, body and life, but also their extradiegetic disease.[32] By writing fiction about their own disease, in a sense, they 'define' a self in their fiction that depends on their self outside the fiction. One of such authors is the American writer Siri Hustvedt who has claimed to suffer from severe migraine in numerous texts. Her diagnosis can be read in various entries on the internet, in her non-fiction autobiographic essay *The Shaking Woman* (2010) and in a number of articles in scientific journals (Hustvedt *Philosophy*; Century et al.; Hustvedt *Wept*). She acknowledged that she began to try to make sense of these migraine experiences by letting neuroscience enter into her fiction (Century et al., 12), remarking that:

> I, for one, am not willing to trade in my childhood sensitivities and raging pains, my many auras followed by headache, or even my peculiar epileptiform, maybe, maybe not pseudo-seizures, for a more normal trajectory because these are not only part of my story but have been crucial to my life as a writer of both fiction and nonfiction. (*Philosophy* 173)

Hustvedt's novel *The Blindfold* (1992) includes descriptions of migraine with aura as one of its main themes and, therefore, I will analyze it as an example of a work of fiction in which the author and narrator cannot be completely separated. In the last chapter of this book, I will argue what the contribution of *The Blindfold* (in combination with *The Shaking Woman*) is to the concept of the 'migraine self'.

First, I will compare *The Blindfold* with Hustvedt's non-fiction work *The Shaking Woman*, focusing on the question what the relation is between

[32] The term extradiegetic is used for events that occur outside the world of the text. In other words, 'in a conventional narrative structure, the voice of the narrator is called the *extradiegetic* voice, while the narration itself constitutes the *diegesis* (Bronswaer 1; emphasis in the original).

narrator and author. Of these two books, Hustvedt has said in a literary discussion panel that:

> I published my first novel in 1992. In one section of the book, the heroine is in a neurology ward with debilitating migraine. This reflected my own experience in Mount Sinai in 1983. I had headaches for a year. I have always read deeply in psychiatry, psychoanalysis, medical history, and philosophy, but it wasn't until about fifteen years ago that I began to study neuroscience. I was invited to join a discussion group that met every month at Cornell-Weill, which continued for three years until it disbanded. [..] Then I developed a seizure symptom and wrote a book about it: *The Shaking Woman or a History of my Nerves*. The condition remains undiagnosed, but the book created a second life for me. (Century 12)

In this chapter, I will mainly address the aspect of author versus narrator, and obviously, I have to focus first on the constative: How is the diagnosis of migraine made in *The Blindfold*? How is migraine described and what is its function?

For my analysis of fact and fiction in Hustvedt's work, I have chosen to first address the 'fiction' and then the 'fact'. My first argument for this is that *The Blindfold* was published in 1992 and *The Shaking Woman* in 2010. An important question therefore is how the 'fiction' that came first influenced the 'fact', and if so, how much 'fact' is in the 'fiction' and how much 'fiction' in the 'fact'. Or, in the light of this book, has the text influenced the patient or the patient the text? This seems to contain the pitfall of Nietzsche's pin-pain confusion (see chapter 1): an interpretation of cause and effect. So, both texts must be interpreted with caution. Besides, it can be of importance to investigate how the writer Hustvedt is formed by her texts. It might be that these texts have played an important role in the forming of her 'self'. Are we dealing with autobiography, autofiction (see chapter 5), or fiction? Hereafter, I will argue that in these texts not only the protagonist/narrator becomes a 'real' self but also the author.

So, I will first introduce the narrator, then the author: first the pain, then the pin, and then the pain again.

The narrator: The story of Iris

The Blindfold is the story of Iris Vegan, a student of literature in New York, told in the first-person. It includes four separate chapters, but one can wonder whether they must be seen as one whole or as separate short stories. Indeed, Jameson (2010) sees them as 'four separate, non-chronologically

recounted yet thematically connected mini-narratives' (421). The fourth chapter seems to give a summary of the first three, puts them in some sort of chronological order and unites the text as a whole. For Jameson, 'since each section of the novel relates an experience that threatens to unsettle or annihilate Iris's sense of self, viewing the fragmented text as a survival narrative ties the episodes together' (424). So, it seems that the 'self' is fragmented and must be put together. The novel can thus be seen as a quest for something: putting together the fragments of a self. The question can be asked what the 'role' or importance of migraine is in the threat, the tying and the quest of reconstructing this self. I will discuss these topics in the light of the processes of 'destroy' and 'create' (see chapter 4), but will first give a summary of the narrative (-s), which is told by a so-called 'character bound narrator', one who takes part in the occurrences described (Bal 21).

In the first chapter, Iris, the narrator, works for a mister Morning as a research assistant, but under a 'patronym', because she has presented herself to him as Iris Davidsen (11). She has to make a descriptive catalogue of objects that once belonged to a young woman who (supposedly) was murdered. Mister Morning needs her as 'an ear and an eye, a scribe and a voice' (13) for the reconstruction of the person of the deceased by an analysis of her objects (another reconstruction of a 'self'). He wants the objects to 'speak' to Iris, and advices her to begin her description 'with the words' (16). Iris struggles and decides to pretend that 'the thing really can be captured by the word' (16). With one of the objects, however, she is lost when trying the words that must express it. 'When I tried metaphors, the object sank so completely into the other thing that I abandoned making comparisons' (25). The object told her nothing (it was a stained and misshapen cotton ball), but for her this was due to the fact that it was 'out of a recognizable context' (25). What seems to be described here is the process of ekphrasis: the description of an object in words, or 'the verbal representation of a visual work' (see chapter 1). Such descriptions indeed also depend on their context. Hustvedt is well known for the use of ekphrasis in her fiction (Grønstad 2012), as there is much 'seeing' and 'looking' in her novels. She therefore is categorized as one of the authors who write 'ocular literature', or 'oculiterature' (41). The ekphrasis of the first chapter will return later and proves to be an important aspect of the reconstruction of her migraine and her sense of self.

The second chapter introduces Stephen, Iris' boyfriend, with whom she has a difficult relationship. She secretly likes Stephen's friend the photographer George better and a sort of triadic relationship develops. At the end of a photo-session with George she runs away because she is afraid of the

expression on his face, which is 'like a person who has just eaten well' (55). Then she gets a migraine-attack in Stephens room when she discovers one of the photos made by George. First, she gets 'a slight sensation of nausea' (66) and then:

> the image was changing. With more curiosity than alarm, I noticed a small black hole in the face. How can that be? I said to myself. It wasn't there before. But not for a moment did I doubt its reality. The hole grew, eating away the left eye and nose, and then the dread came, cold and absolute, a terror so profound it created a kind of paralysis. I was transfixed. The hole was devouring the entire image, the face and hair, the shoulders, breasts, and torso, and I saw only the arm stumps hanging there alone for an instant, and then they too were engulfed, but like a person in a dream I couldn't cry out. There was no sound in me, and I watched as the hole began to swallow the picture's frame. [..] It was bonded to my hands, a part of my limbs, and then I was blind. [..] It was over, and I could feel pain in my head. I suffer from migraine and am susceptible to nervous tricks and minor hallucinations, but I have never been able to write of these aberrations that are purely neurological, because while they are happening, I am convinced that I am seeing the truth, that the terrible fragility and absence I feel is the world – stark and unclothed. That nakedness is irretrievable. (67-68)

Here is ekphrasis again, but now the description of seeing an object includes the experience of not-seeing it. This is the description of a migraine aura, which can – by definition – only be seen by the sufferer self. Iris's migraine is her blindfold. It defines her (seeing of her) self. Her not-seeing parallels the experience of pain in general that can only be felt by the sufferer and described in words but cannot be seen by onlookers. There is no signified of pain, only an image in our head.

The next morning (after a night with Stephen), Iris notices that her headache is gone (70). She then realizes that there is a parallel between the migraine-attack and the photograph made by George, as:

> the photograph had become for me the experience of seeing it in Stephen's apartment. I couldn't separate the image from the hole, and although I could describe the picture with some accuracy, could name its parts, I was unable to really see it. Its presence in my mind was, in fact, an absence that I felt as a small but constant threat. (70-71)

This is a description of not-seeing again. Her aura obviously did not destroy her words, but her vision. In these text fragments, there is a complex and subtle difference between looking, seeing and watching, which are augmented by 'not-seeing'. I will come back later on the importance of this difference in the novel.

In chapter three Iris describes how she is admitted to a hospital because the number of her migraine attacks had increased enormously after all treatments had failed: 'The Inderal, the Cafergot, the Mellaril, the Elavil, the little white inhaling box, and the famous Fish cocktail. Every day I took the test and swallowed enormous blue pills of Thorazine at regular intervals' (91). In the hospital, she realizes that:

> as a migraineur, I had low status. Admittedly, I was a bad case: I had pain in my head for seven months almost without respite. Sometimes it was mild, sometimes brutal. My bowels were racked. I peed too much. I was supernaturally tired. I saw black holes and tiny rings of light; my jaw tingled; my hands and feet were ice cold; I was always nauseated. My body had become the meeting place for ridiculous symptoms, but what I had was still a headache, and headaches had little clout on the neurology ward. (91)

She starts to feel guilty, not only because the other patients have more serious neurological diseases than she has (see the so-called 'prestige hierarchy' of diseases of Album and Westin (2008) described in chapter 3), but also because 'I had made the headache, created the monster myself, and just because I couldn't get rid of the damned thing didn't mean I wasn't to blame' (91). Here, the feeling of guilt which many migraine sufferers have is described. A new headache attack is always their own fault. They drank too much wine, ate chocolate, went to bed too late or had too much pleasure. After the double, triple or call it quadruple negation of the last quote, Iris makes a remark that is one of the most important in the light of this book. She says: 'The distance between the place were the words originated – somewhere deep within the headache – and where they had to go – out into the room – seemed impassable' (91-92). Here, she describes the impossibility of translating pain/headache into words – or call it the signifiers – that are important to give substance to the feeling of pain, their signified. The pain makes it impossible to create the right words. She clearly is a 'patient as text' but doubts whether her text can or will be read as a patient, as it is destroyed by the impossibility to translate the pain into words. On top of this problem, a confusion of words develops between her as a patient (text) and the reader of that text (doctor), as she notices that 'my doctor told me that I was improving when I was not' (92). The doctor translates her words wrongly in what Iris calls 'a ferocious editing' (93). Then she realizes that she 'had tried to tell my story to six less famous physicians, and each time, I had lost my tongue. I felt that if only I could articulate my illness in all its aspects, I might give a trained ear the clue that would make me well, but my words were always inadequate' (93). Here, again she feels guilty, as her language is inadequate. In a way it seems 'destroyed'. She feels like a person

going to pieces, whose head was in the way, and whose pain was becoming an obsession (94).

Her description of the attending physicians fits well in Charon's argument that a study of the language of doctors and patients reveals that they are engaged in a deep conflict about meaning and purpose (*Build a Case* 116). Indeed, 'doctors differ from patients in the ways in which they use language and the purpose to which they put words. Doctors use words to contain, to control, and to enclose' (116). Charon even argues that medicine unfolds in its language 'syntactical methods of disengaging patient from physician' (110). In the case of Iris, only the consulted psychiatrist spoke kindly and in a low voice. His white beard was 'reassuring' (he looks like Freud) and shortly after talking to him, she feels less nauseated although she still has a headache. This description suggests that neurologists do not listen to their patients and only are engaged with their own translation of the words of the patient and thus with 'associative condensing'. Psychiatrists – on the other hand – are kind and reassuring. Their voice is low, probably because the words are not the most important. Unfortunately, this also illustrates the prejudice that migraine is more psychogenic that organic.

The fourth chapter deals with how Iris is asked by a professor of literary studies to translate a German novel. During that work, she identifies herself with Klaus, the protagonist of the novel and tries to bring him to life by wearing men's clothes and acting as uncanny as he. The professor finds her dressed like that and in a bad state in a bar and takes her home with him to 'rescue' her. Then they start an affair. It now becomes clear that the occurrences of the first three chapters have been told in a reversed order. First Iris was in the hospital, then she had the relation with Stephen and after that she worked for mister Morning. But after the work for mister Morning a new headache episode occurred, so there seems to be some kind of circle. The headaches were 'bad ones that struck like lightning and left me wretched and depressed' (Hustvedt *Blindfold* 178). When she looks at the face of an English instructor one day, 'half his face vanished' (178). She realizes that 'that hole wasn't the first and it wouldn't be the last, but staring into the black emptiness, I believed it was real. I thought a part of his face was gone' (178). Here is the 'negative' ekphrasis again. Shortly thereafter, Iris realizes that it is a migraine aura. In the time following, she noticed that 'at any moment an ordinary thing, a table or a chair, a face or a hand, might disappear, and with the blindness came a feeling that I was no longer a whole' (179). So, after seeing a hole in reality, the migraine sufferer Iris feels that she is not 'whole' herself. Indeed, she is the composite of her symptoms and its diagnosis made by artificial criteria.

The reason for the chronological reversal or circle is not made clear and after the last sentence of the text, the reader is left puzzled. There, Iris says: 'Then I took off my shoes and ran to the IRT, ran, as they say, like a bat out of hell' (221). It seems the hell of her migraine and its negative ekphrasis that destroys the possibility to see some sort of reality and to express this in words adequately. It is the hell of her migraine 'self'.

One can wonder whether the Stephen of the first chapter is the same as the Stephen of chapter two. Iris sees holes in reality often, related to her point of view and her migraine. But it can also be wondered whether the Irises of the separate chapters are the same. There are no indications that they're not, but also none that they are. Her name suggests that she is 'the same', but how many Irises can be imagined? And then there is the hole she describes repeatedly. Iris couldn't separate this from the parts of a picture that she described with some accuracy but was unable to really see. There is the hole, the blindness and then the feeling that she was no longer a whole.

The 'hole' she perceives strongly resembles an experience described by the English writer Oliver Sacks in his book *A Leg to Stand on* (1984), which he has called 'a neurological novel' (Sacks *Leg* 15; Sacks *Clinical Tales* 21). In contrast to many of his other books, in *A Leg to Stand on* he is the patient himself. When making a trip in the Norwegian mountains Sacks falls and injures his leg. He is taken to a local doctor, brought to a small local hospital, and from there transferred to London to be operated upon. After the operation, however, his leg is not functioning properly. He self-diagnoses nerve damage but the doctors do not find any proof for this. In this situation, Sacks makes discoveries about being a patient and the experience of suffering. He develops a strange sense of dislocation and loss in relation to his leg and reflects on the 'mind-body-dualism'.

This is also important for migraine because in the chapter called "Becoming a Patient" Sacks describes a migraine attack which developed when he was in the hospital. The attack starts during a dream. Parts of the familiar pear-tree and garden-wall appeared to be missing and his mother (who was already deceased at that time) seemed bisected. Then Sacks wakes up at the moment a nurse enters his room and utters: 'Oh…ummm…its's nothing. I just had a bad dream' (97). He doesn't dare to tell the nurse that she is bisected also. Sacks realizes that he has one of his migraines, of which the aura had started during sleep. Now he finds the blindness rather funny. He giggles and asks the nurse to walk across the room to notice that she transforms into a mosaic and becomes 'inorganic'. Then the mosaic disappears. 'That's it', he says to the nurse, 'I think you helped to chase the

aura away! And the nausea is all gone' (98). After the attack, he concludes that 'a scotoma is a hole in reality', and that this is also going on with his 'missing leg', the word 'scotoma' referring to a visual change or blindness in a part of the field of vision. He continues, 'How could I be such a fool? I have a scotoma for the leg! [..] I have lost the 'field' for my leg precisely as I have lost part of my visual field' (99). In the following chapter ("Limbo"), he further philosophizes about the scotoma: 'The word "hell" supposedly is cognate with "hole" – and the hole of a *scotoma* is indeed a sort of hell' (108-109; emphasis in the original). Sacks feels himself sinking, engulfed in an abyss. He associates the lack of understanding of his doctors to this abyss and quotes Nietzsche who said: 'If you stare into the abyss, it will stare back at you' (110). He decides to become an explorer of the abyss. 'I had to be still, and wait in the darkness, to feel it as holy, the darkness of God, and not simply blindness and bereftness' (112). Wiltshire (1991) writes about this episode that 'the horror of a migrainous scotoma [...] may be felt not just as failure of sight, but as a failure of reality itself, an uncanny hole in the world' (*Deficits* 306). He calls *A Leg to Stand on* 'Sacks' descent into the underworld of patienthood' (307). Diedrich (2001) goes one step further by remarking that 'Sacks believes his accident has put him literally in a position to correct the scotoma – blind spot – at the heart of neurology, its ignorance of the patient's experience, its willed and sometimes callous objectivity' (216). The latter remark may be going a little bit too far, but the question of perception, 'negative ekphrasis' or of 'saying' remains. Iris's hole resembles Sacks' hole. Iris doesn't feel whole and Sacks has the feeling that he has lost a leg. Both stare into emptiness and feel as being in hell. Iris runs out of it; Sacks is going to explore it.

The Blindfold is about looking, seeing, watching, perceiving. Virtually on every page the 'I' looks at something or is looked at. It seems, however, that she not always 'sees', mainly due to her migraine. Indeed, there is a great difference between looking and seeing. For Bal (2009), 'seeing is a non-perceptible action, in contrast to 'looking'' (161). It is no surprise that the name 'Iris' has a strong connotation with an eye. There is her ekphrasis when she describes objects and photographs. When photographed, she admits to enjoying being looked at. But when she looks at the photograph herself there is a hole, and thus *The Blindfold* is also about not-seeing. Iris now and then sees a hole in reality and this hole is the result of her migraine. The question is whether it is her own – virtual – migraine, or that of her creator with her extradiegetic migraine. Whose hole is it? In which ontological level should it be placed? That of the narrator, the author, or in between? These are the questions I will try to answer in the next paragraph.

The author: The story of Siri

It has been argued that one of the consequences of 'the death of the author' is a transformation of the author into 'a literary subject, or a function of the text' (Johnson *Author* 5). Maybe this is true for Hustvedt as well. Her essay *The Shaking Woman or a History of my Nerves* (2010) is about her own disease. In that sense, it can be called a 'biography', or maybe more accurate 'pathography'. The latter is defined as 'the memoir of illness experience' (Wiltshire *Biography* 409) and can be called 'a critical patient narrative' (412). A 'pathography' might be written 'as an act of protest, as a recall to the fact that one is not only a body, and to rescue the whole experience of illness and medicalization from the narrower definitions of the clinic' (412).

Hustvedt describes how she was one day suddenly struck by trembling of her body while speaking at a memorial to her father a year after his death in 2004. The attack was followed by several similar attacks, almost always when she gave a lecture. Because of these symptoms Siri immediately thinks of her migraine that had 'lasted for almost a year' in 1982 (4) and that was labeled by the doctor as a 'vascular migraine syndrome' (5). For Siri, this did not explain why she had become at that time 'a vomiting, miserable, flattened, frightened ENORMOUS headache, a Humpty Dumpty after his fall' (5; emphasis in the original). The migraine experience, she writes, made her 'fascinated by neuroscience' and to write a novel, which became *The Blindfold* (5).

In *The Shaking Woman*, she describes her search for the cause of the trembling and how she consulted many neurologists and psychiatrists. First, epilepsy is considered. Uncontrollable shaking can occur in some seizures, but there is something strange the matter with her attacks, as she realizes that 'my shaking was on both sides of my body – and I had talked throughout the fit. How many talk through a seizure?' (9). Because she did not become unconscious during the attack, the diagnosis of epilepsy is rejected. In her further quest she considers and explores other possible disorders, such as hysteria, panic disorder, conversion disorder, stage fright and dissociation.[33] In the end, however, the most likely cause for her symptoms is considered

[33] A diagnosis of a conversion disorder (also called 'functional disorder) is made when a patient has neurological symptoms that are not consistent and considered not to be caused by a well-established organic cause. In dissociation disorder a person disconnects from thoughts, feelings, memories or sense of identity. Both definitions are from the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), the list of criteria used to make a psychiatric diagnosis.

to be migraine, and for her the symptoms belong to her status as 'migraineur'.

She describes her first experiences in the hospital in detail:

> I undress, put on a hospital gown, and walk back and forth across the room for her. We play clapping games. I touch my nose with my index finger. She looks in my eyes. No sign of pressure or brain tumor. She strokes my hands and feet with a cold instrument. I feel it all. Good sign. She uses a tuning fork. She tells me I have "nice, fat arteries," and I'm pleased to hear this. She wants to know if I've ever taken Depakote for my migraines, an anti-seizure medicine. I tell her no. She recommends MRI, two of them. (155-156)

On her way back home, Siri understands that 'by debunking hysteria they have raised the specter of additional neurological illness, the possibility that I have more-than-just-migraine' (156). This fits perfectly with her idea that diseases like hers 'often attack the very source of what one imagines is oneself' (7). In her case, she has become a 'migraineur'. Indeed, 'the association of pathology with personality brings us yet again to a larger question: What are we?' (158). She sighs:

> alas, my life is lived in the borderland of Headache. Most days I wake up with headache, which subsides after coffee, but nearly every day includes some pain, some clouds in the head, heightened sensitivities to light, sounds, moisture in the air. Most afternoons I lie down to do my biofeedback exercises, which calm my nervous system. The headache is me, and understanding this has been my salvation. (174)

Although this description would also fit a diagnosis of caffeine withdrawal headache, she calls herself a migraineur and that she is her headache. She seems to state this as a fact. She places herself in a disease category instead of describing herself as a person with a certain disease. She does not 'have' migraine, but she is it. This strongly resembles a process of stigmatization.

Stigma can be divided in 'enacted' and 'felt' stigma (Scambler and Hopkins 33). Enacted refers to the discrimination against patients on grounds of their perceived inferiority. Felt stigma refers to the fear of enacted stigma, but also encompasses a feeling of shame associated with the disease (33). It seems that Siri introduces a third category: the stigma 'migraineur' as self-description. She uses for herself the stigmatizing and negative term with which migraine patients are confronted (see also chapters 2 and 3), being called a 'word', or being placed in a disease category. Mostly, the disease migraine and the word 'migraineur' connote something negative. Indeed,

although migraine is the third most disabling disease (Disease and Injury Incidence and Prevalence Collaborators 2016) it is still not seen as a serious disease by many. Using the term 'migraineur' is a synechdoche standing for the patient as a whole and thus can also be described as a 'morbus pro toto'. It is argued that the term should be avoided, just as – for example – the designations 'an epileptic' for a patient with epilepsy, 'a schizophrenic', or 'a retard' (Scambler and Hopkins; Young *De-Stigmatizing* 320). It is not right to define a patient with a disease 'as' that disease. For Butler (1997), 'to be called a name is one of the first forms of linguistic injuries that one learns' (2). It can, however, be considered more injuring to be called a name based on a disease or another incapability. Indeed, as Butler says, 'to be addressed is not merely to be recognized for what one already is, but to have the very term conferred by which the recognition of existence becomes possible' (5). So, for the term 'migraineur' it can be said that 'the word not only signifies a thing, but that this signification will also be an enactment of the thing' (44). When one calls oneself 'a migraineur', one also 'is' headache and through this 'performative' an escape from hell indeed seems very far away.

Unfortunately for Siri, the MRI-scan, ordered to investigate the presence of a structural lesion to support a diagnosis of epilepsy, triggered a migraine attack. For her, the MRI 'has knocked that poor organ into familiar territory – the land of Headache. The irony makes me smile. I don't fight migraine anymore. I embrace it, and by doing that, I am also, strangely, able to feel less pain' (176). Her 'land of headache' reminds one of Susan Sontag's kingdom of the sick, or of Daudet's land of pain. The 'embracing' resembles the 'amor fati' of Friedrich Nietzsche (see chapter 8). Important for Siri is that she knows that the pain of the migraine attack will end (as otherwise it would not be called an attack), which makes it (somewhat) more bearable. Only during her periods of 'status migrainosus', one of which lasted a year, it was difficult for her to 'embrace' the pain. The migraine 'betrayed' her as it did not end and violated the definition of an attack. She writes, 'I continually checked my pain: Was it lighter? A bit. Hope waved a victorious flag inside me. Soon it will disappear and go away forever! Was it worse? Yes, it was definitely worse. I lowered the flag and returned to battle' (179).

In the end, Siri concludes that 'pain cannot be separated from our perception of pain' (180). She becomes attached to her migraines. 'I cannot really see where the illness ends and I begin; or rather the headaches are me, and rejecting them would mean expelling myself from myself' (189). Her self-narrative is formed by her migraines.

After Iris' and Siri's stories, it is clear that migraine plays an important role in both. They are obsessed by the pain which determines their 'lives'. They see holes in reality and (self-) stigmatize. This raises the question in what way their stories overlap and can be compared. This issue will be worked out in the next paragraphs.

Is Siri Iris and/or Iris Siri?

The Blindfold, the narrative told by Iris, is presented backwards or maybe even circular. First, she was in the hospital, then there was the relation with Stephen, then she worked for mister Morning, and then came her relationship with the professor of literary studies, which prompted her to place her previous experiences in some sort of chronological but still confusing order. After that she apparently suffered a new headache crisis. It seems a narrative that is (mainly) counting backwards, and one can wonder whether this order reflects a causality. I have argued elsewhere (Haan *Metaphor* 135), that the reversed chronological order might point at a migraine-attack backwards, as in part four, the blindfold would stand for the visual aura, part three would symbolize the headache phase, part two the social consequences of having migraine, and part one the recovery phase.

In the terms of Frank (1994, *Reclaiming*) Iris's story seems a chaos narrative. Being fiction, it can be said that it is not important whether the occurrences are past, present or future. Their importance are the creation of new dimensions and new ontologies, the creation of new worlds and selves out of nothing. Adventures of a protagonist of fiction may contain historical aspects, but most of it is imaginary, and the temporal order often is deliberately disturbed (Bal 8, 79-88). Likewise, illness alters the temporal and hence narrative orientation of the story of a patient (Woods 75). Migraine causes a fragmentation and thereby a disturbed perception of time. As examples I gave variants of 'achrony', such as 'anticipation-within-retroversion' (Bal 96) in which a migraine patient describes how in the past he or she thought about a future attack. A second form I described was 'retroversion-within-anticipation' which describes how the 'present' will be remembered (re-presented) in the future (97). These mechanisms are important for a 'real' patient, but of course can also be important for a narrator in a fictional work. In *The Blindfold*, which is told backwards, many examples of 'achrony' can be found. As illustration of this, here are some quotes from one of the first pages: 'Sometimes even now I think I see him in the street or standing in a window or bent over a book in a coffee shop', 'I met him eight years ago', 'On a day in July, not long before I met Mr.

Morning', 'That was two months after Stephen left me', 'In June I had done work for a medical historian' (all on page 9). A consequence of these five time-indications in a row is that the readers will be puzzled and 'lost in time'. In addition, the temporal crisscross also illustrates the confusion of the narrator herself. This is a confusion of ontology, of not knowing on what '(time-) level' one is.

The Shaking Woman, on the other hand, is told 'forward' (with memories of the past), as most 'quests'. In this sense, the two texts seem to mirror one another: the one backward, the other forward looking back. When Hustvedt wrote *The Blindfold* in 1992 she (probably) did not know that she was going to write *The Shaking Woman* in 2010. The other way around (remembering and referring to *The Blindfold* when she wrote *The Shaking Woman*) in fact suggests that the fiction came first and then the non-fiction. It is hard to estimate how much the fiction has influenced the non-fiction, but important is to realize that the 'reality' (of migraine) came before 'fact' and 'fiction'. It defined both. So, there is no reason to make an absolute distinction between fact and fiction here. As Frank writes of this in general, 'both are texts, equally intertextual, equally formulating their own "realities"' (*Reclaiming* 1). Of course, the intertextual association of *The Shaking Woman* to *The Blindfold* is stronger than the other way around, for chronological reasons, but still, the migraine came first.

About the relation between fact and fiction Harshaw (Hrushovski) (1984) wrote that:

> fictionality is not a matter of invention. "Fiction" is not opposed to "fact." Fictional works may be based in great detail on actual observations or experiences; on the other hand, works claiming to describe the truth (autobiographies, journalistic reports) may have a great deal of biased reporting. The issue is not in the amount of demonstrable truthfulness but rather that the former establish their own IFR [Internal Field of Reference] while the latter claim to describe the "real" world. This is the cardinal difference, for example, between a biography (or autobiography) on the one hand and an autobiographical novel on the other. In the second case, we are not supposed to bring counter-evidence or argue that the writer has distorted specific facts. (237)

Indeed, *The Blindfold* contains many distorted facts, including the course of time, the (non-) vision of reality, and the issue of disturbed seeing and to be seen. It 'defines' a separate person or self. The migraine and being a 'migraineur' seem fixed 'realities' in this chaotic lifeworld. They are a fixation to the extradiegetic migraine of its historical author, who once

called her protagonist 'a heroine' (Century 12), probably because she has experienced the (heroic) suffering of migraine herself.

When it was published in 1992 *The Blindfold* had to be seen as an entirely fictional work. Many years later, however, it appeared to be partially based on the 'real' experiences of the author. So, the author was 'dead' for about 18 years and then became 'alive'. When one accepts this, *The Blindfold*, however, still does not describe the 'truth', as its own 'Internal Field of Reference' remains unchanged. Jameson (2010) has written about *The Blindfold* that 'the multifaceted nature of power causes the protagonist to experience nothing less than *self-shattering*, a dangerous destabilization of any sense of personal identity' (422; my emphasis). Is this the 'heroine' the author is referring to? It is clear that Iris's migraine contributes to the shattering of her world and to her loss of control. As a 'migraineur', she falls apart in symptoms and signs and has to endure opinions and prejudices. What else could be the fate of 'a migraineur'? The same *self-shattering* and destabilization are almost eponymous for *The Shaking Woman* in which Hustvedt describes her quest to regain her sense of personal identity. Unfortunately, however, as pointed out by Tougaw (2012), when a patient finds herself in a world of contradicting physicians and still is without a firm diagnosis 'metaphors mask the limitations of science' (*Memoirs* 182). He concludes that 'Hustvedt becomes the shaking woman through writing' (189). She defines herself indeed as such in the last sentence of her text (Hustvedt *Shaking* 199), stating that 'I am the shaking woman' (199). As is said, 'suffering must be embedded in language to be conceptualized' (Rousseau 164), and 'the record of suffering constitutes a gold mine waiting to be quarried, if we will only learn to decode its signs and languages' (171). This is especially true for migraine, as I have argued in chapter 2 and which is clearly illustrated by Hustvedt in both texts.

The difficulties of decoding the language of the 'migraineurs' Iris and Siri are best illustrated in the encounters of the (fictional and/or real) patients with their (fictional and/or real) doctors, which in both instances is called 'the headache czar'. Let me consider the confrontation of Iris with her 'Czar' first:

> Every morning, Dr. Fish would poke his head into the room and wave, and I would wave back and smile. But I knew he was disgusted. Dr. Fish was a man who liked successes. He liked them so much that before I landed in the hospital, he told me that I was improving when I was not [..]. My person had become the sign of his failure, a recalcitrant body, a taunt to his medical prowess. (92)

Dr. Fish interrogates her by using a tape recorder, and Iris concludes that 'the only voice on those tapes was Dr. Fish's'. When Iris starts to tell the story of her headache, he 'grabbed a microphone from his desk and spoke loudly into it: "Iris Vegan. Case number 63912. Tuesday, September 2, 1980."' After Iris's detailed description of her attacks, Dr. Fish picked up the microphone again and dictated that 'the patient suffered a scintillating and a negative scotoma' (93). Here, it is clear that patient and doctor speak different languages. This 'ferocious editing' shocks Iris. She mumbles, coughs, forgets words, and loses track of what she is saying. Again, her words are inadequate. She went to Dr. Fish every week and every week looked better in his eyes, but unfortunately, she couldn't see or feel the changes herself and felt to participate in the deception (94).

Now Siri, who describes that:

> the rare wave through the door from the headache Czar himself, Dr. C., a man who mostly ignored me and seemed irritated that I didn't cooperate and get well, has stayed with me as the blackest of all black comedies. Nobody knew what was wrong with me. My doctor gave it a name – *vascular migraine syndrome* – but why I had [it], no one could say. (4-5; emphasis in the original)

This is a clear example of how patients and their doctors can be in completely 'different worlds', as described in chapter 1. After this experience, Siri decides to write a novel of which she says that 'I would have to impersonate a psychiatrist and psychoanalyst, a man I came to think of as my imaginary brother' (5). The novel, *The Sorrows of an American* (2008), is written in the third-person point of view. From a distance, the narrator observes his sister's 'arcs of energetic production that were followed by migraines and the blues, what she referred to as her "neurological crashes"' (55). He also realizes that 'there are times, however, when fantasy, delusion, or outright lies parade as autobiography, and it's necessary to make some nominal distinction between fact and fiction' (86). The distinction between fact and fiction is not specifically worked out further in this novel, but a 'fact' is that Hustvedt's 'imaginary brother' tells about the migraines (and apparently also about the epilepsy) of his sister Inga. He says, 'I'm convinced now that Inga was suffering from absences, what used to be called petit mal seizures, which resolved themselves spontaneously as she grew older. What has remained with her are migraine and their auras and something fragile in her personality' (25).

Migraine is a joint quality of Siri, Iris and Inga. The narrator of *The Sorrows of an American*, Siri's 'imaginary brother', seems also to refer to Siri's quest

for her 'shaking', and he apparently describes part of the biography of 'his' author and creator. In this process, he seems to associate her migraine with epilepsy. Also in this novel reality and fiction seem to interact and it looks like some 'autobiography in the third-person'.

The issue of the interaction of the imaginary and the 'real' can be placed in another context in the relation of Siri, Iris and Inga. This aspect is in a way expressed in the article "Fiction and Metaphysics" by Van Inwagen (1983) who argues that many works of fiction address themselves to metaphysical issues relating to ontology (67). He points out the fact that some philosophers think that there are things that do not exist, but with this he does not agree, arguing that there can also be some sort of 'fictional existence' (74). He illustrates this with an example from Charles Dicken's *The Pickwick Papers*, writing that:

> when Dickens wrote, "Mrs. Bardell had fainted in Mr. Pickwick's arms," he was not saying anything about someone called "Mrs. Bardell" or about someone called "Mr. Pickwick." He was not saying anything about them because he was not saying anything about anything. What he was doing was crafting a linguistic object that his readers could, in a certain sense, pretend was a record of the doings of – among others – people called "Mrs. Bardell" and "Mr. Pickwick". (73)

This may be true for pure fiction, but the situation in *The Blindfold* seems different. When Hustvedt wrote in the first-person, giving Iris (and her 'imaginary brother') a voice, she obviously used her own 'real' experiences as a migraine patient and thereby used her extradiegetic migraine experiences to create a narrator for the diegesis: she created a linguistic object with a double meaning. She defined her 'real' and 'fictional' self.

There are also other aspects to this 'defining'. For example, about narrators of first-person fiction Nielsen (2004) writes that 'such fiction is more like autobiography than like epic fiction, because the subject of enunciation in these texts narrates something that exists independent of the enunciation' (134-135). With this kind of enunciation, the narration is about something that in fiction exists prior to its narration. When there is no subject of enunciation the sentences will produce the fictional world they describe. But when there is an 'I', there must also be something prior to this 'I'. As a consequence, it can be said that all 'fictional first-person narratives do not belong to the domain of true fiction' (135), as they always relate to something outside the fiction. This is especially true for a first-person narrator who refers to something that forms part of the 'reality' (e.g. a disease) of its author. *The Blindfold* offers a clear example of a subject of

enunciation relating to something outside the fiction, in this case even a characteristic of its author. This was, however, not evident when the novel was published in 1992. At that time, it had to be interpreted as 'pure' fiction and one had to avoid the mistake to confuse the narrator with the author. Only after the publication of *The Shaking Woman* in 2010 it became clear that the story of Iris contained part of the story of Siri.

Nielsen (2004) discusses the issue of who it is that narrates in first-person (or homodiegetic) fiction. He argues that 'in literary fiction, as opposed to oral narrative, one cannot be certain that it is the person referred to as 'I' who speaks or narrates' (133). So, we need to posit an impersonal voice of the narrative. Maybe, this is reflected by Bal's theory that 'I' and 'he' in fiction are the same (20). When a narrator says, 'I have a headache' or 'he has a headache', this can also be translated to '(I say) I have a headache' and '(I say) he has a headache' (21). So, both sentences are uttered by a speaking subject, an 'I', but in one the speaker talks about himself and in the other about someone else. Nielsen further points at the fact that some narrators ('narrating-I's') narrate about things of which they cannot possibly know, or in such a quantity of detail that is impossible for any real person to remember (135). This resembles the so-called 'paralepsis', as it describes the situation of a narrator who assumes or pretends to have a competence he/she cannot not properly have (Heinze 280).[34] Thus, 'a paraleptic human consciousness [..] will almost inevitably be judged according to what we as readers know from experience human beings could or should not know or be able to do under the specific circumstances of a fictional situation' (283). One way out would be to label a paraleptic first-person narrator unreliable, based on the anthropomorphic argument that no first-person narrator can have privileged knowledge (283). A subtype is 'illusory paralepsis', where paralepsis seems to be present, but where 'delayed disclosure reveals that there are natural, realistic sources of the character narrator's unusual knowledge' (285). *The Shaking Woman* can be seen as such a 'delayed disclosure' for Iris's migraine as it is based on detailed descriptions of Siri's migraine.

So, on the one hand there are 'sentences about something that only exist by virtue of the sentences' (Nielsen 134-135), but there can also be things that exists independent of the narration, which existed prior to the narration. These intra- and extradiegetic issues then represent different ontologies of the same situation, such as is true for *The Blindfold* and *The Shaking*

[34] Paralepsis is the rhetorical strategy of emphasizing a point by seeming to pass over it.

Woman. It can even be claimed that for these two texts, the fictional first-person narrative does not belong to the domain of true fiction, as it approximates the narration of the third-person narrative. On top of this, 'a story told from the *limited* point of view of a single protagonist may highlight the utter unpredictability of what happens: since we don't know what other characters are thinking or what else is going on, everything that occurs to this character may be a surprise' (Culler *Literary Theory* 91; emphasis in the original). There is no doubt that *The Blindfold* is based on 'real' (extradiegetic) experience, so one can wonder to what category of literature it belongs.

Thinking about real or 'virtual' pain, in her article about 'autofiction' (see chapter 5), Marie Darrieussecq states that pain cannot be imitated (76). One of her arguments is that of Plato who called fiction 'a copy of a copy' or a 'simulacrum'. In line with this thought, the question emerges how pain can be copied or represented in fiction or – more in general – in words. This is the main question of this book, but here one can ask whether *The Blindfold* is pure fiction, autobiography (a copy of a copy) or autofiction. And – more important in the light of this book – is the migraine imaginary or part of (some sort of) reality? Darrieussecq also warns to confuse the author with the narrator in fiction in the first person, but maybe we should not to be reserved about this in case of *The Blindfold*. Concerning the *The Shaking Woman* it can, in my opinion, not be ignored that Iris clearly is a reflection (or mirror, or copy, or simulacrum) of Siri. Note that this sentence contains a double negation (not, ignored), which at least expresses some doubt about the issue at hand.

In chapter 5, I have described another category of fiction called 'neuronovel', which includes novels of 'consciousness, interiority, linguistic play and estranging description' (Roth 7). It is clear that *The Blindfold* can be seen as such a 'neuronovel', as its stream-of-consciousness narration is dominated by an 'anthropological figure of the cerebral subject [and] a character attributed to a cerebral lobe' (Burn *Neuroscience* 213). The cerebral lobe in question is suffering from migraine, as can be read on many of the pages.

Another issue related to neuronovels is discussed by Burn who points at the theory that so-called 'confabulation'[35] (…) is 'emblematic of what it is to be human' (36). In other words, we all fill in the gaps in our perception of

[35] The term confabulation is used when someone has a disturbance of memory and unintentionally fills this gap with fabricated, often distorted and misinterpreted memories about oneself or the world.

reality. In line with this he argues that 'postmodern fiction has found in the centrality of confabulation an answer to the great question of where fiction could go after the realistic novel' (36). This could be one of the reasons for postmodern fiction's engagement with neuroscience and the publication of numerous 'neuronovels' (Brindley 2013). Furthermore, it could be that 'the simple fact of having a first-person narrator with a neurological disability is a positive thing, in that it forces the reader to question the structures of normativity that usually prevail' (Peacock 81). One must, however, be careful to overestimate medical conditions for their symbolic value as this detracts from real illness and suffering. It is therefore important that the symbolic function of migraine in *The Blindfold* is put in perspective in *The Shaking Woman*, which is a story of personal and 'real' suffering.

The typical neuronovel also is one of 'weariness and loss' (Lustig and Peacock 11) and this description can also easily be applied to *The Blindfold*, mainly because Iris loses sight of reality and seems to suffer from this. In addition, neuronovels are described as 'a variety of meta-novel, allegorizing the novelist's fear of his isolation and meaninglessness, and the alleged capacity of science to explain him better than he can explain himself' (Roth 9). Here, another link between the 'fiction' (*The Blindfold*) and the 'non-fiction' (*The Shaking Woman*) becomes clear, especially the fear for meaninglessness of the writer, which motivates her non-fiction quest. This is expressed in both texts and in this sense, the texts taken together can be seen as a sort of 'metaneuronovel', as they illustrate issues of consciousness, cerebral (dys-) function, loss of control and a feeling of insufficiency from the perspective of a narrator and an author. In this way, they apparently seem to point at one central 'quest': the definition of the self of someone with migraine.

Conclusion

It can be concluded that Iris is not Siri. This would of course be impossible, as Siri is someone of flesh and blood and Iris consists of words on a white page. Iris produces a chaos-narrative of loss, pain, and incoherence of storytelling and time. Her language 'cannot re-socialize what has happened' (Frank *Reclaiming* 7). The story of Siri is a quest, including a call, road of trials, and return. After her quest she is renamed and her name is 'migraineur', which in Frank's terms can be seen as 'another layer in the sedimentation of identity' (11). Likewise, 'the boom at the end of this quest is not restoration of health but renewal of subjectivity, including the

recognition that much of the previously "healthy" identity was imaginary' (12). In short this is the defining of a new self.

The Blindfold illustrates what Lamarque (1990) in his article "The Death of the Author: An Analytical Autopsy" states as 'the author function is distinct from the author-as-person' (325). He adds that 'it is a convention of some kinds of fiction that they draw attention to their own fictional status, that they point inward rather than outward, that they teasingly conceal their origin, and so forth' (329). This seems also true for the majority of the contents of *The Blindfold*, but with an important exception. The question 'is Iris Siri?' is not important, but rather that of 'is the migraine of Iris the migraine of Siri?' After my comparison of *The Blindfold* with *The Shaking Woman*, the answer seems to be 'yes'. In both instances the migraine consists of words and although the persons using those words are different and in different 'ontologies', the words are the same. This makes their 'selves' also 'the same'. So, the author of *The Blindfold* is not dead in all aspects, as part of her is alive and this part is called 'migraine'. As Frank puts it: 'the value of this voice is not its assurance of truth, but simply that these narratives are signed in the name of an ill person' (*Reclaiming* 17). The death of the author, however, is mainly about the loss of the authorial voice, and not about the eclipse of the real person. Nevertheless, the way in which the 'real' author infiltrates characters and narrators remains important. The complex relation between the authorial voice and the voice of a real person will be further worked-out in chapter 8 (about Irvin Yalom's *When Nietzsche Wept*), where it will emerge in a double form.

CHAPTER 7

JAMES LASDUN'S *THE HORNED MAN*

James Lasdun's *The Horned Man* is a subtle psychological novel that portrays and explores the thoughts of a disturbed character bound narrator. The text is built up as a thriller, with strong 'who's done it?' aspects and cliffhangers. The logic is that of a detective-story with all its epistemological aspects. It turns out, however, that none of the events described or solutions proposed 'thrill' anything else but the mind of the narrator. The story can therefore better be approached as the interior monologue, perhaps even as a quest, of a neurologically disturbed individual; a patient.

It appears that migraine plays an important role in this narrative and in the occurrences described. Migraine seems crucial for the portrayal of the narrator and the things he has in mind. In this chapter, I will analyze the role of migraine in this text, how it is described and what importance it has for the narrative. In his epistemological confusion, the narrator of *The Horned Man* will turn out to be an 'ideal' object to be analyzed and diagnosed as a 'real' patient. His fictional 'I' will also be of great help to further construct the 'migraine self' (see chapters 4 and 8), as he symbolizes the confusion of a 'real' patient though in the guise of a modernist logic of the detective.

In this chapter, I aim to answer the question why and how this narrator narrates what he narrates by first introducing relevant parts of his (medical) story and then focusing on the importance of his migraine in a literary / medical context. The key issue will prove to be an epistemological confusion that is characteristic of migraine.

The story

Lawrence Miller, the first-person narrator, is an English professor of Gender Studies at an American university and a prominent member of the Sexual Harassment Committee of that university. He was left by his American wife shortly before the narrative starts and she now accuses him of stalking. Since the divorce, Lawrence lives alone and is desperately lonely. For example, he sends himself telephone messages which he does not answer in order to

be able to imagine that these are from his wife. He speaks of 'calls to my own machine at home; silent hang-ups initially, made simply so that I wouldn't have to return to a non-flashing machine' (52). When at work, he fanatically tries to avoid contact with female students, because he is afraid that they will accuse him of posing a sexual threat. When he cannot avoid talking to one of them, he leaves the door of his room wide open, so that passersby can look in and witness that nothing irregular takes place. Here is #me-too-fear avant la lettre. Indeed, what is in Lawrence's mind on occasions like this makes him blush vehemently.

One day, Lawrence starts noticing some apparently insignificant changes in his office. A bookmark has been moved, there is an unknown number on his telephone bill, a Bulgarian coin disappears from his room and a file has been removed from his computer. He hears that the predecessor of his position at the University – a woman – has been murdered and he finds her clothes and the probable murder weapon in his office. All of these signs point at one of his former colleagues, the Bulgarian writer and teacher Trumilcik, who has disappeared from the university not long ago after alleged sexual misconduct. Lawrence fears that Trumilcik is not far away and now stalking him. He could – for example – have been the one who took away the coin and deleted the file on the computer. It does, however, not become clear whether Lawrence's reconstruction is 'real' or must be ascribed to his self-declared 'professorial forgetfulness', which he compares with 'so-called parapraxis, Freud's term for the lapses of memory, slips of the tongue, and other minor suppressions of consciousness that occur in everyday life' (1). Indeed, many varieties of these 'lapses' form the main topic of Lawrence's frequent therapeutic sessions with his psychiatrist and seem to appear abundantly in his acts and thoughts.

More strange things happen. When hiding in Trumilcik's alleged hideout in his room, Lawrence is a voyeur of a woman, who later turns out to be also a member of the Sexual Harassment Committee. She leaves him a note to invite him for a private encounter in response to a letter she received from him, although Lawrence cannot remember having written her a letter at all. At their rendezvous, he tries to kiss her, causing a violent rejection and an accusation of rape. He still tries energetically to find out who murdered his predecessor at the university but is accused of this murder himself. When searching his ex-wife in a shelter for victims of domestic abuse he is accused of more acts he doesn't remember committing.

During one of his further attempts to get contact with his ex-wife, Lawrence encounters a man in an abandoned synagogue:

> Immediately, I caught a familiar smell: the acrid male rankness I had smelled in Trumilcik's hideout. [..] As I turned to leave, I felt a kind of raging force rearing up toward me out of the darkness. I was aware of this in a purely animal way, before I saw or even heard the immense, bearded figure lurch across the doorway in my direction. It was the only time I did see him, pale and tattered, stinking of dereliction, his gray hair thick and flailing, his copious, rabbinical beard matted with filth. I bolted to the door. As I did, something rock-hard erupted out from him, smashing into my face. (125)

The smell is familiar, but the man is as much a creature as a human being, filled with raging fear. He, or it, seems to possess a horn that smashes Lawrence in the face at the spot where he will later grow a horn himself. This suggests that, in terms of reference, he may have smashed into a mirror, which in turn suggests that the man/creature embodies another side of Lawrence; the more brutal one. In this context, it is small wonder that Lawrence is described as 'blundering around his own personal hell' (Royle 306). In one of the last chapters of the story, he visits an exhibition in the Cloister Museum of the so-called Unicorn Tapestries, on which is depicted how the unicorn first saves other creatures in the forest by dipping his horn in a stream, then is attacked by a bunch of huntsmen, kneels before a beautiful woman and in the end is 'brutally gored to death', but thereafter miraculously is restored to life. When Lawrence sees the tapestries, he feels 'dazed, engulfed almost, as though I had just sat through some long, harrowing film full of scenes that stood in relations of dreamlike reciprocity or mysteriously revealing opposition to my own life' (187). After this, Lawrence feels a sudden rising into the air, and wonders if he 'truly had passed into the realm of the fantastical' (190). To his delight, in this levitated condition he sees his ex-wife approaching and he hopes to be united with her again. Unfortunately, she cries 'get him out of here' to the two large guards who have their hands under Lawrence's elbows and have lifted him into the air. Now Lawrence realizes the true explanation of his airborne state (190). He has wrongly interpreted 'reality' again. Despite being a member of the university's Sexual Harassment Committee, he still seems to remain blind to his own escalating acts of harassment, stalking, and (probably) violence.

Next to the gender theme there is the theme of the horn and where there is a horn, the devil is not far away. This is so evident that *The Horned Man* has been called a 'gothic novel' (Royle 302). In this context the horn is introduced when Lawrence finds a long elaboration on the importance of horns in a manuscript written by his father, who had died from a brain tumor when Lawrence was five years old. In fact, his father's manuscript is the reason why he came in contact with the woman who later would become his

wife (and ex-wife), as she was interested in the text while preparing a book on the medieval cult of the Virgin Mary, which included the unicorn hunt described above. The creature was lured into captivity by a virgin before being killed (120). The horn was said to have medicinal action due to its polar opposites of benign and evil (121). Some saw the unicorn as a symbol of Christ, but the homoeopathists considered it as the ultimate toxic substance, the unicorn being an 'aggressive, highly unsociable monster' (121). Furthermore, the unicorn is 'maddened by the enormous pain caused by the toxins distilled in his horn' (122).

In the end of the narrative, it becomes clear that there are things in Lawrence that struggle to get out. One of these things is the horn. The other seems to be his 'migraine'. The question is: are these the same? I will argue in what follows that indeed the metaphor of pain materializes in the horn.

Lawrence's migraine

One day, shortly after reading Franz Kafka's unfinished short story *Blumfeld, an Elderly Bachelor* Lawrence gets a migraine attack. In Kafka's story a man called Blumfeld, when one day arriving home, finds two balls bouncing off the ground on their own accord. The balls start to follow him wherever he goes, and they annoy him, mainly because of the intolerable noise they produce. So, Blumfeld decides to get rid of them. He is described as a very lonely individual and an egocentric misanthrope, because of his crankiness and condescension towards other individuals. Before starting reading, Lawrence thought that he did not know the story, but he discovers that he has marked in the text 'little underlinings and scribbles' (25), probably with the intention to use it in one of his classes. He does not remember a word of the text, so 'a complete mental evacuation must have taken place' (25). Then the attack starts, and he remembers that he once was diagnosed with migraine:

> Abruptly, before I had finished the story, a small, pulsating silver spot appeared in the corner of my field of vision.
>
> I hadn't experienced this phenomenon since I was twelve or thirteen, but I recognized it immediately, and put the book down with a feeling of alarm.
>
> The spot began to grow, as I had feared it would, flickering and pulsating across my vision like a swarm of angry insects. [..] After a while all I could see were a few peripheral slivers of the ceiling and walls surrounding me. And then for a minute or two I became completely blind. (25-26)

Shortly thereafter, the sounds from his surroundings suddenly become pronounced, and then 'as rapidly as it had come, the occlusion faded. And right on cue, as the last traces vanished, my head began to throb with an ache so intense I cried aloud with pain' (26). He went to his bedroom to lay down on his bed in darkness, while, 'the pain concentrated itself in the center of my forehead. It felt as though something were in there trying to get out – using now a hammer, now a pick-axe, now an electric drill' (26-27).

It seems that Lawrence has an attack of migraine with visual aura. He had had these attacks for a period as a boy. The headache then lasted five or six hours, and:

> after all other medication failed, my mother had taken me to a homeopathic doctor, an old Finn in a peculiar-smelling room, surrounded by dishes of feldspar and a sticky substance he told me was crushed red ants. He gave me five tiny pills, instructing me to take one a night, five nights in row. I hadn't had a migraine since then – not until now. (26)

Now, he feels as if being slowly compressed in a room with contracting walls and wonders what has been in the Finn's little pills. 'With the confused logic of the afflicted, I tried to think what substance might have a homeopathic relationship with this particular form of pain' (27). He leaves the house to drink a triple espresso in a bar, but the caffeine does not work. In the bar, he discovers a poster of a play based on the Blumfeld-story containing the words 'adapted for the stage by Bogomil Trumilcik' (28). To find this suspected murderer, he goes to the theatre, still with a severe headache. He meets the actor who is in the pause of playing the role of Blumfeld in the stage adaptation of Kafka's story. Lawrence's head is hurting more than ever:

> 'Are you by any chance suffering from migraine?' the man asked as I moved off.
>
> The question stopped me in my tracks.
>
> 'How did you know?'
>
> 'Your eyelids are all puffed up and your lips are almost white. My brother had migraines as a kid. I know the symptoms. Here, if you'll allow me…'. (31)

The man puts his hands on Lawrence's temples and presses both thumbs into the center of his forehead, 'extremely hard'. For a moment Lawrence

thinks that his skull is about to split. Then the pain is gone. After the attack, he feels 'light-headed, almost elated' (31). Later, he remembers that he has seen this person before. It was at a party, shortly before his wife left him. He then suddenly realizes: 'The actress was Blumfeld. He was a woman' (41). This confusion of gender (by a professor of gender studies!) adds to numerous other examples of the same kind. In some of the telephone messages that he sends to his own home telephone, for example, Lawrence imitates his ex-wife's voice by sending:

> little friendly messages to myself, first from me, but then, as the sense of the need to inhibit myself in what I took to be an entirely private act diminished, from Carol [his ex-wife] – my imitation of her crisp phrasing and intonation, if not her actual voice – telling me she loved me, begging me to return her calls. (52)

In order to look for his ex-wife in a shelter for victims of domestic abuse (130), he puts on the clothes of his female predecessor who was murdered. In the shelter he is unmasked by a nun, who recognizes his blushing as an attempt to hide something. After a smash with her knee in his groin, he is thrown out, and thinks that this is because he is mistaken for another 'man' (for instance: Trumilcik). As in general 80% of stalking victims are women, 87% of stalkers are men, and a female stalking a man is a rarity (Pulda 200), Lawrence's stalking is very exceptional, as here a man in woman's clothes (who thinks he is stalked by another man) is stalking a woman. The 'gender confusion' adds to the confusion of the narrator and part of this confusion seems to be linked to his migraine.

A little later, he gets another attack. Being stressed, because he feels 'guilty of fraud and general duplicity' (174), he enters his apartment, which 'feels emptier and more silent than ever' (175), and he succumbs 'to a heavy, familiar inertia' (176). Then, a flickering silver light spreads across his field of vision 'like a great, sunlit shoal of mackerel' (176). He realizes that it is 'an emissary from the world of pain, come to pay me another call in its familiar metallic delivery' (176). A burst of childish self-pity emerges; he thinks again of his mother who 'had taken up the management of these migraines when I was a boy, entering so intimately into the interstices of my pain, it seemed she might be capable of assuming the burden of it herself, relieving me altogether' (176). But, to his shame, he has lost all contact with his mother many years ago. 'I had always been aware of something not quite natural about this, but now, for the first time, I seemed to come face to face with its full, appalling strangeness' (176-177). Then he gets a pounding ache, hammering the inside of his skull. Even the slightest efforts intensify the ache in his head. He goes out and encounters the same

person that relieved the pain of the first attack by pressing on his head. Now the pressure of only one thumb is applied. This one-hand-touch 'seemed to make my head even worse' (180). The pain continues, and Lawrence wants to lie down in darkness. Then, he forces himself 'to stand still and confront my reflected head, I had the sensation of fainting rapidly through successive layers of consciousness, but without the luxury of passing out' (184). It seems that a thick, white, horn-like protrusion had grown out of his forehead, and then he is no longer in pain.

Indeed migraine?

The first question for the present book is whether this patient is indeed suffering from migraine. The description of the visual symptoms could surely be diagnosed as a migraine aura, with the personal and original metaphors used. A small silver spot that grows, flickers and pulsates as a swarm of angry insects, and that in the second attack resembles a great, sunlit shoal of mackerel, is not the description of many of my migraine patients, but the growing and moving visual phenomena fulfill the current criteria of a migraine aura (although the duration of the visual symptoms is not mentioned here). That these sensations feel as 'an emissary from the world of pain' brings into mind Susan Sontag's switch to the 'kingdom of the sick' (*Metaphor*). The visual symptoms of the first attack make him 'completely blind', which is not typical, as a migraine aura almost always causes a disturbance of a visual hemi-field. Most patients, however, indeed speak of 'complete blindness' although the true extension of this only becomes apparent when they are interrogated carefully. Then, the resolution of the symptoms of the first attack, including the sensation that his room is 'disturbed in some furtive activity of its own' (33), are in strong contrast with the premonitory (forewarning) symptoms of the second, when he feels that his apartment is 'emptier and more silent than ever' (175). Indeed, premonitory and resolution symptoms of a migraine attack often 'mirror' one another, be it for example yawning opposed to hyperactivity, or retaining fluid opposed to frequent micturition. It is in line with this that Lawrence's first attack is followed by an elated feeling and the second preceded by a feeling of inertia. The headache of the attacks is throbbing, pounding, hammering and causes Lawrence to lay in his bed in darkness. The pain is severe enough to let him cry; it worsens at movement. Next to an apparent sensitivity to light, there is a sensitivity to sound, as the sounds from his surroundings suddenly become more pronounced. In his youth, the attacks lasted five or six hours, but the duration of the recent attacks is not mentioned. They can, however, be calculated from the text, to be

approximately in the same range. A presence of nausea or vomiting is also not mentioned, but this is – according to the criteria – not an absolute prerequisite, especially so when sensitivity to light and sound are present.

Migraine's occurrence in Lawrence's lifetime is rather atypical, as not many (male) patients have attacks that cease around the age of twelve or thirteen to return (much) later in life. In addition to this, the apparently successful preventive treatment with five (homeopathic) little blue pills and the alleviation of the attack by external pressure with two thumbs (and the failure to do so with one thumb) can also be called remarkable in the sense of atypical. Further, the location of the pain – in the middle of the forehead – is uncommon. Besides, not many patients can be recognized 'from the outside' having migraine on the basis of externally visual symptoms such as puffed eyelids and white lips. Nevertheless, at first sight, there is little reason to doubt the diagnosis. On the other hand, any 'diagnosis' must be seen in the context of a literary work, with a certain artistic purpose, to which I will come back.

It appears that Lawrence not only has 'migraine', but also suffers from an unpredictable and embarrassing tendency to blush, which he calls 'a self-perpetuating problem' (4). He sighs, 'I sat back in the sofa and lapped frantically at my tea, hoping to conceal the scarlet fire racing up over my face. But I had become luminous: I felt it; pulsating incandescent! My whole head was throbbing like a beacon' (146).

These metaphors (pulsating, throbbing) indeed resemble those used by most 'real' patients with migraine. Lawrence thinks that blushing has to do with sex (147), but is told that the scientific explanation for blushing is that it is 'an evolutionary anomaly that answers to the interests of the social group rather than those of the private self [..] and alerts people to the fact that something duplicitous is occurring in their midst' (147). Maybe this relates to his feeling of being 'guilty of fraud and general duplicity' (174) mentioned above.

An association of blushing and migraine has indeed been described (Telaranta 2003). It is argued that the association points at a common disturbance of the autonomic nervous system (the part that is not under voluntary control), an opinion which has been debated much. In the light of the narrative, it is of importance to realize that both the blushing and Lawrence's migraine are visible from the outside. They 'mark' the sufferer, and later even seem to 'unmask' him. So, it can be concluded that at least something special is the case with this particular migraine-patient. He is

'semiologically' different from other migraine patients in which the signified (migraine) depends completely on the word of the patient (the signifier) and the criteria (see chapters 1, 2 and 3). In this case, however, something can really be seen from the outside. In Lawrence's case this is one visible sign of his migraine. The horn seems to be the other one.

After this description of the 'patient' and my argumentation why his 'migraine' probably indeed 'is' migraine as it looks like migraine and even fulfills (part of) the present criteria (see also chapter 3), I will now discuss how the disease diagnosed is important in the narrative. An important aspect is the un-/ reliability of this 'patient'. All taken together, it seems that Lawrence is not one person but several persons and that his migraine plays a role in this.

Uncertainty, reliability and unreliability

The Horned Man is a strange story, mainly because the narrator Lawrence seems to go from surprise to surprise, as is the case – for example – with his final 'levitation'. Although as an I-narrator his words create the narrative, he at the same time seems to be a 'victim' of the occurrences. The resulting uncertainty must point at something. What?

Lawrence tells his story in retrospect; it is in the past tense. The first words are 'one afternoon earlier this winter' (1), and a subsequent remark like: 'unknown to me at the time' (69) suggests a form of prolepsis.[36] The past tense, however, stands in contrast with stream-of-consciousness parts that are necessarily in the present tense. The stream of consciousness technique may be defined as 'that narrative method by which the author attempts to give a direct quotation of the mind – not merely of the language area but of the whole consciousness' (Bowling 345). It introduces the reader directly into the thoughts of the character. In the narrative of Lawrence, the contradictory mixture of tenses and of different modes of stream of consciousness create a feeling of uncertainty. Why does everything that happens in the present, for instance, comes as a surprise for Lawrence as he already knows retrospectively that it has happened? The story mixes a retrospective story with a problem and solution as in a restitution narrative which is prospectively 'controlled' by the narrator (Brody) with a quest or chaos narrative. Maybe Lawrence is one of those narrators that 'merely *report* unreliably but do not evaluate or interpret unreliably' (Heinze 280;

[36] One speaks of prolepsis when a future act or development is put down as if already accomplished or existing.

emphasis in the original). In Lawrence's case, his unreliability cannot explain in a satisfactory way his exceptionally detailed knowledge of occurrences and chronology, which resembles the paralepsis described by Heinze (2008; see also chapter 7).

In the light of this, it is telling how in a past-tense narrative, in a crucial scene, Lawrence suddenly turns to the present tense. While in his second migraine-attack, he again encounters the actress who played Blumfeld and suddenly makes an association between the actress, his ex-wife and Trumilcik: 'Only now do I see the cruelty of that smile: the same indolent, foreknowing expression that I note in retrospect as I recall the moment at our table months earlier' (Lasdun 178). So, seen from an undefined 'now' the narrator sees in retrospect a situation in which he sees in (further) retrospect a situation of some months earlier. This is a form of 'achrony' (Bal 97) that is distinct from 'anticipation-within-retroversion', in which someone is referring forward within a back-reference. It is also distinct from a 'retroversion-within-anticipation', in which the narrator tells us how circumstances in the 'present' will be re-presented in the future. These two forms play an important role in migraine as is described in chapter 5. The situation here can be best described as 'retroversion-in-retroversion' and when this is applied to migraine, it describes how a migraine patient during an actual attack thinks of how he thought of the past during a previous moment in time.

The question emerges what the meaning of this new enigma is; this retroversion-in-retroversion. Is this double layer one of the examples of a 'mise-en-abyme' reflecting the protagonist's confused 'migrainous' mind? To answers this, the article "Truth in Fiction: A Reexamination of Audiences" (1977) by Peter T. Rabinowitz can instruct us how to approach the topic of the un-/reliability of a narrator – and maybe also of a 'real' patient with migraine for that matter. With Rabinowitz the issue is not considered on the basis of the characteristics of a (fictional) narrator, but from the opposite perspective: that of the spectrum of several, possibly real or fictional, readers. Here, I will not address the role of the real readers of flesh and blood, but rather the fictive ones. In my opinion, Rabinowitz's approach can shed some light on the issue of reliability – unreliability of a narrator like Lawrence and therefore I will discuss his theory in some detail.

Rabinowitz's starting point is the question 'how do we even begin to talk about truth in fiction?' (122). He bases his ideas on the fact that 'the act of reading demands a certain pretense' (124). According to him, there are at least four audiences implied in any literary text (125). First, there is the

actual audience of flesh and blood which is the only audience that is real and 'the only one over which the author has no guaranteed control' (126). This audience, as said, is not an issue here. Second, there is the hypothetical audience to which the writer of the novel rhetorically addresses his work. Rabinowitz calls this the *authorial audience*. With regard to migraine, for instance, *The Horned Man* may mainly address those readers who already know what migraine is. Yet, again, the aspect of the reading of external readers is not the topic here. The third category is that of the *narrative audience* and according to Rabinowitz:

> since the novel is generally an imitation of some nonfictional form (usually history, including biography and autobiography), the narrator of the novel (implicit or explicit) is generally an imitation of an author. He writes for an imitation audience (which we shall call the *narrative audience*) which also possesses particular knowledge. (127; emphasis in the original)

For this category, he gives the example of Tolstoy's novel *War and Peace* in which the narrator appears to be an historian, who 'is writing for an audience which not only knows that Moscow was burned in 1812 but which also believes that Natasha, Pierre, and Andrei "really" existed, and that the events in their lives "really" took place' (127). So, these fictional readers must do more than only join the authorial audience. They must also '*pretend* to be a member of the imaginary narrative audience for which this narrator is writing' (127; emphasis in the original). They must abandon their real beliefs and accept in their stead so-called facts and beliefs which even more fundamentally contradict perceptions of reality (128). To illustrate this function in a narrative, Rabinowitz uses the example of Franz Kafka's *Metamorphosis*. In this narrative, the various readers are 'asked to accept the single fantastic fact that Gregor has been transformed into a gigantic beetle', and to do this without surprise (129).

Likewise, the fact that Lawrence grows a horn must be believed, just as the fact that he has migraine. In general, the choice between 'reliability' and 'unreliability' of a narrator 'determines not our view of the speaker alone but also of the reality evoked and the norms implied in and through his message' (Yacobi 113). Every 'I' in fiction is created by means of his 'own' words. Nevertheless, an 'I' in fiction can be distinctly a character, of which Lawrence is a good example. He is characterized by his confusion, uncertainty and epistemological desire to get grip on 'reality'. He is both the creator and the creation of the sentences. His stream-of-consciousness is confused, and his migraine seems one of the only 'true' aspects of his story. Real patients should be believed unconditionally, as I have argued,

and the fictional Lawrence for that reason probably also should be believed. For this, however, he obviously needs a narrative audience.

As fourth audience Rabinowitz distinguishes what he calls the *ideal narrative audience*. This audience 'believes the narrator, accepts his judgments, sympathizes with his plight, laughs at his jokes even when they are bad' (134). For obvious reasons, a doctor would be the 'ideal narrative audience' for a patient. In *The Horned Man* most of the characters (e.g. his ex-wife, the female member of the Sexual Harassment Committee, the nun) do not believe Lawrence and thus are not his 'ideal narrative audience'. Only the actress who plays Blumfeld seems to feel what is the matter with him. The topic of their mutual understanding is his migraine, located at the center of his forehead and increasingly visible from the outside.

Such visible signs ask for an epistemological reading of this narrative in the light of the issue of representation. This becomes especially important in one of the last scenes. There, it is described how Lawrence flies from the Cloister Museum after being thrown out at the command of his ex-wife and walks twenty miles to a wooden booth at the countryside. The door of this hideout is locked, but Lawrence gets an extradiegetic idea and suddenly addresses his readers directly: 'The reader of this account, not having just walked twenty miles, will surely be a few steps ahead of me here, though in my own defense I should say that it didn't take me so very many steps of my own before I too thought of what I should have thought of immediately' (Lasdun 193).

This enigmatic sentence appears to be the key to the (reading of the) whole story. It is as if Lawrence's rhetoric suddenly needs an extra impulse to become more credible and become an issue of representation. One can wonder at which audience / reader his words are directed here and what the scene tells us.

First, the 'I' seems to blame the reader not to have walked many miles, but to have sit still and read. Still, that is what most 'real' readers do. Then, the 'I' supposes that the reader will be steps ahead. Yet how can any reader be 'ahead' with so little reliable and so much confusing and unreliable information? Furthermore, the reader is also blamed for taking more steps than necessary to realize what the 'I' thought of what he 'should have thought of immediately'. The already sparsely informed 'reader' is, however, not informed what this 'thought' should have been and it is thus not easy to join Lawrence's (ideal) narrative audience. It is clear that the 'I' tries to defend himself in relation to his fictive reader by attacking him/her

with words. The question emerges who, or rather what kind of reader, is addressed here.

After having blamed his readers for this and that, Lawrence indeed produces a little key from his pocket and is able to open the door. Here again, the narrative switches to the present tense:

> I sit here too, using the ledge as a desk, where I have been preparing a full and scrupulous account of the events that led to this enforced retirement from the world. Though the powers arrayed against me have proved themselves to be formidable, I am confident that my account will bring this unpleasant isolation to an end, perhaps even reunite me with my wife. (193)

So, this time and place is when and where Lawrence was producing his retrospective but at the same time also prospective text. The little key turns out to be the key to the story, as a 'Deus ex Machina'. The scene touches on the issue of what is diegetic and what is extradiegetic here and raises the question where to place the narrative of Lawrence, as both its extradiegetic narrator and the protagonist of the diegesis can be referred to as an 'I' (Bronswaer 5). Lawrence sometimes seems to need 'extradiegetic' confirmation of his words, such as 'the reader of this account' in the citation above. Yet, normally, 'the extradiegetic reader needs not to be mentioned by the narrative text' (8). In this scene, there probably is no extradiegetic reader, but a readership invented by Lawrence because of his agony. He needs someone who believes him unconditionally and did not find such a person in his ideal narrative audience so far. This 'reader' is 'invented' by Lawrence as an audience that is even more close that an 'ideal narrative audience' in Rabinowitz's sense. Nevertheless, even these 'more than ideal' readers are getting information that is incomplete and puzzling. This adds to the suggestion that Lawrence must be severely disturbed and desperate. An important question therefore is why his mind is so disturbed and which audience he needs in order to be 'helped'. This calls for a more in-depth analysis of the migraine described.

The diegetic function of migraine in The Horned Man

The Horned Man can be seen as an example of a 'diagnostic novel' in which 'the characters are driven by the uneasy certainty that something is wrong' (Charon *Doctor-Patient* 143). Here, what is wrong appears to be related to the migraine of the protagonist, which – of course – lies outside his 'guilt'. Lawrence focuses on questions of meaning in his life through diagnostic

enterprises, that is to say: through an epistemological quest. He very much resembles a detective, here. In such a story the protagonist detective:

> is a witness who learns from the narratives he or she encounters: the detective inhabits a world of rules, a system of general laws, and is presented with an array of particular narrative and evidentiary instances which need to be apprehended as connected to a particular rule or a particular characterization of events. (Schleifer and Vannatta 376)

This description is, however, somewhat misleading in the case of Lawrence. He resembles more a kind of 'reversed detective' in his description of the meaning of objects and occurrences, as after each description of a new discovery, things become more confusing. The world Lawrence lives in is not one of rules and laws; it is one of confusion and a lack of logic. He sees signs that are not there, lets himself be surprised by changes that he obviously made himself, interprets things wrongly and seems to come to wrong conclusions. He seems stupid, absent-minded and straightforwardly sick, with an important role played by his migraine. He relates everything in retrospect, but, as said, still is also surprised by certain occurrences (for example the disappearance of the coin or the file from his computer). Whereas one of the prototypes of a detective, Edgar Allen Poe's Dupin, 'possesses enormous knowledge and [..] demonstrates his ability to apprehend coherent relationships among different and disconnected facts' (376), Lawrence judges all signs, facts and relationships wrongly, for some reason. I suggest he is some sort of anti-detective because of his migraine.

At first sight, the two attacks described by Lawrence broadly seem to fulfill the current criteria of a migraine aura (a one-sided neurological deficit, mainly visual, that gradually develops over time, lasts less than one hour and is often followed by a headache) and those of migraine headache (severe pounding or throbbing headache that worsens on activity, makes the sufferer lay down in his or her bed and is accompanied by sensitivity to light and sound). So, it can be said that these attacks fit in the current discourse of migraine. As explained in chapters 1 and 2, however, 'pain' is a signifier without signified and as explained in chapter 3 a diagnosis of 'migraine', in addition, depends on an international agreement (by means of criteria) on when to call a headache 'migraine'. So, nothing is 'real'. It can easily be understood that such quicksand can confuse its sufferer.

In my opinion, *The Horned Man* must be seen in this perspective. The description of the aura (a silver spot that grows; a swarm of angry insects; a great shoal of mackerel), but also the pain (a pick-axe, an electric drill, compressing, pounding, hammering) heavily depend on metaphors, which

are not more than 'shadows' of reality. The metaphors used are part of the discourse of migraine and in this text that discourse gets a special meaning, being 'materialized'.

The story is retrospective, and the question arises what the motivation is to describe the migraine-attacks in such detail. On the one hand, they might be seen as an attempt to create an anchor to 'reality' (Haan *Metaphor*). They could, however, also be seen as indices to the reliability of the medical information given by 'real' patients to their doctor (see Part I of this book). In that situation the words of the patient must be believed unconditionally and maybe that is also the main message of the migraine included in this text. The consequence is that the words of a (fictional and) disturbed mind such as Lawrence's should also be believed. Although the protagonist is fictional, pivotal parts of his story resemble that of someone with 'real' migraine and this has its implications for the story as a whole.

This issue of 'belief' is addressed in the article "Fictional Reliability as a Communicative Problem" (1981) in which Yacobi distinguishes five distinct principles that are important in 'the reliability in narrative and literature as a whole' (113). Here I aim to put the – at first sight – realistically described migraine attacks of *The Horned Man* in the context of her theory. First, Yacobi defines the *genetic principle* that 'resolves fictive oddities and inconsistencies in terms of causal factors that produce the text without coming to form part of it' (114). As examples, she mentions the creative process, history of the finished product and characteristics of the author. Examples of factors that are important in the second category, the *generic principle*, are 'a certain simplification of reality', 'referential stylization', and 'a generic compromise' (115). These factors contribute to the projection of 'a fictive world that parallels and approximates to extraliterary reality' (116). Next, the *existential principle* is 'the linkage and resolution in terms of the world', though this is not limited to institutionalized models. It manifests itself 'wherever the loose or divergent finds its place in an appropriate referential framework' (117). In other words, through this principle, historical, institutionalized or individual, but also verisimilar or even fantastic manifestations can be recognized. The *functional principle* serves 'thematic and normative ends' (117) and – finally – the *perspectival principle* 'brings divergent as well as otherwise unrelated elements into pattern by attributing them, in whole or in part, to the peculiarities and circumstances of the observer through whom the world is taken to be refracted' (118).

The presentation of the two 'migraine' attacks in *The Horned Man* poses several challenges to this theoretical framework for the problem of reliability and the issue of representation. Concerning the *genetic principle* there is little uncertainty. The novel does not seem to refer to causal factors outside the text, or peculiarities or deviances of the worldview, associated with the person of the author, the creative process, or his environment. In other words, it is – for example – not important for the analysis of understanding of the text to know whether the author (James Lasdun) suffers from migraine or not.[37] As for the *generic principle*, it can be said that – of course – the text offers a 'certain simplification of reality', but seems to be too confused to do this abundantly. There is no 'generic compromise', but a 'generic chaos' in the information given by Lawrence. Within this category, it is said that the 'I' sticks to 'generic frameworks that extend the area of institutionalized deviance (or from the reader's viewpoint, resolution) even to internal inconsistency' (115). Such internal inconsistency is easily found in *The Horned Man*. Whereas according to Yacobi, 'the generic legitimation of inner tensions and discontinuities within the represented reality promotes the economy and the effectiveness of the many-sided outer attack on outer reality' (116), here, there is a 'double' discourse, or (again) a mise-en-abyme. The word 'migraine' can be considered as a 'disguise' in the real world, as it refers to a signifier without a signified and also to a linguistic or discursive agreement (see chapters 2 and 3).

The *existential principle*, then, 'includes but is not limited to the institutionalized models' (116). The fictive world reconciles explanations derived from reality, but these are not a sine-qua-non. Yacobi also gives the example of Franz Kafka's story *Metamorphosis* in which Gregor Samsa turns into a giant insect. Such a fictive world, accommodating the transformation of the human into the inhuman, 'derives more from the peculiar structure of reality the reader attributes to the work than from any pre-existent constraints or legitimations' (117). The parallel between *The Horned Man* and *Metamorphosis* indeed seems strong, as both refer to an anthropomorphic change. Samsa turns into an insect and Lawrence (temporarily and/or only migraine-metaphorically?) into a unicorn. Although these occurrences both are virtually impossible, the ideal narrative audience accepts them as belonging to some sort of 'reality', here that of 'horn-producing' migraine. For this, the transformation described in *The Horned Man* seems to use an institutionalized model, that fits into the discourse of

[37] This is in contrast with the migraine of Iris in *The Blindfold*, which is based on the migraine of its author – as described in chapter 6.

migraine. The pain is described as something trying to get out using a hammer, a pickaxe, or an electric drill. In reality, language is our key to understanding the world, but here it creates a double layer by using the same words that normally indicate something else to produce another meaning, that of the pain of migraine.

In the *functional principle*, the work's aesthetic, thematic and persuasive goals operate as a major guideline to making sense of its peculiarities (117). It imposes itself on the thematic or normative end, as some sort of teleological principle. In *The Horned Man* this principle seems absent. There is no teleological principle as nothing works towards an understandable end. As a consequence of this, both the real and fictional reader is left 'puzzled'. All of this adds to the general confusion in this text, not so much representing that of 'real' migraine patients but performatively enacting it. Whereas the existential operation more or less plausibly relates the experienced anomaly to some referential feature or law, the functional operation explains the function of that anomaly, without necessarily integrating these laws with the world of the text. Migraine gives pain in the head and can indeed feel like a horn. The metaphors in this novel apparently can also become part of one's physical reality.

The description of the materialization of Lawrence's migraine seems (another) proof of his confusion between the feeling of pain and that of reality. This is enhanced by the following scene. When the horn has grown out of his head, Lawrence leaves his room to go the museum. He decides to cover the horn with the maroon beret which belonged to the female colleague that was murdered. The result is: 'The horn bulged oddly underneath the baggy fabric, giving it the shape of a child's bicycle helmet – a surreally soft one – but at least it was concealed' (185). This is the state in which he encounters his ex-wife in the museum. There are many aspects here (and elsewhere in the novel) that associate the horn – and by implication the migraine – with a phallic symbol, and as such with Lawrence's guilt and his 'fraud and general duplicity' (174) that heralds the second migraine attack. So, the frequently blushing member of the Sexual Harassment Committee covers a phallus-like protrusion under the beret of a murdered woman. Yet it seems that he has no other choice in a state of confusion that is caused by migraine.

Finally, there is the *perspectival principle* in which a '*limited* figure observes (narrates, experiences, evaluates) the represented world' (118; my emphasis). Lawrence indeed seems to be 'limited' due to his migrainous confusion. In *The Horned Man* some sort of recognition is postponed to the

last pages where he addresses the (created) readers. So, some emphasis on his performance is needed.

Lawrence's performance

In my reading, the migraine attacks play a crucial role in *The Horned Man*. I also think that the novel plays with different possibilities of representation based on these attacks. The disturbed visual perceptions (insects, mackerels, etc.) add to the disturbance of most migraine patients to 'see' reality as it is. In addition, it leads to a translation into strange but enhancing metaphors. The pain described contributes to the feeling of horror. The consequent descriptions offered by the narrator are not unreliable, but disturbed. The pain only consists of words, just as would be the case if Lawrence was a 'real' patient. It does not completely destroy language but provokes a rhetorical construct, which then is subject to artificial criteria to determine its meaning. In the end there is the materialization of the pain into a horn, with which the bearer can damage, but also can be damaged. Maybe, such a material horn is something that many migraine-sufferers would like: a visible and in that sense *provable* sign for their pain. It would be ideal if their agony not only had to rely on symptoms (words) but also on signs. Indeed, many migraine-sufferers feel guilty for having migraine without 'signs' that are visible from the outside, as Lawrence during his second attack when he is stressed and feels guilty. The duplicity of his confusing narrative, to the point of being an extremely unreliable narrator, is enhanced by his switching from the kingdom of the 'healthy' to that of the 'sick' as any 'real' migraine patient does. No one can blame Lawrence for this, as no 'real' patient can be blamed. They have no 'guilt'. This is why, in conclusion, it can be said that the novel is establishing the uncertainty of a patient with migraine in a performative way.

This is nicely expressed in the last words of *The Horned Man* in a citation translated from the *Gnostic Gospels*, which is a piece of text that was excluded from the discourse of the *New Testament*: '*If you bring forth what is within you, what you bring forth will save you. If you do not bring forth what is within you, what you do not bring forth will destroy you'* (195; emphasis in the original).

Indeed, what is in must come out and what comes out will/might save you. Yet in the case of migraine this only happens when you encounter someone who believes your words unconditionally as an ideal narrative audience (or a doctor). As said, as is the case with most pain, migraine is a signifier without signified. In that sense Lawrence's words are not different from

those of a ‘real’ patient. He uses words to describe his pain as a ‘real’ patient would do and uses them for the same purpose: to find someone who believes them. The migraine-diagnosis exists on the basis of the agreement to classify the words of the patient in a certain way (see chapter 3). So, when Lawrence’s words are read as those of a ‘real’ patient they must also be read as ‘truth’. In neurology, therefore, even the words of a confused patient must be believed unconditionally. As there is no unreliable patient, it can be argued by analogy that in the case of a narrative about pain or migraine there also is no unreliable narrator, as any (presumed) unreliability can be explained as an expression of the disease itself. Nevertheless, the epistemological drive of a confused self as Lawrence asks for and provokes trust in the words of the patient, but also leads to basal uncertainty. One must not forget that the mind of migraine patients can be confused and thus their texts can become confused as well. Migraine, moreover, can destroy words and thoughts (see chapter 4).

The migraine attacks in this novel are referential to the ‘reality’ of patients of flesh and blood, but in a sense only to the unreality of their reality, as one needs someone who can recognize the signs, reads the words correctly and believes the words. For a diagnosis of migraine, one needs a doubly artificial discourse, which is mainly based on metaphors. Taken to their limit, the discourses can seemingly become material, like a palpable substance, as happens with Lawrence’s horn. Yet such a horn still is one that consists of words only. We must not forget that Lawrence’s ‘horn’ also exists only by virtue of words. As is the case with migraine in general, this particular horn on the one hand has, but on the other has no ‘real’ signified. In this way, this novel gives us another double layer, or maybe even a double ‘mise en abyme’, that works in order to believe the words of a fictional person as those of a real patient.

The occurrences in *The Horned Man* can come as a surprise for the one undergoing, reading or hearing them, but as an imitation of a confused reality they should be believed as something that exists independently of the words and metaphors used. The double discourse adds to the ‘intrinsic’ unreliability of migraine in its double artificiality: that of its metaphors and of its discourse (see chapter 3). A lot of rhetoric force is needed to give migraine any substance and that is what Lawrence seems to do in his quest. He even seems to stumble over his rhetoric in order to tell his truth. His attempts lead to the exceptional situation that his migraine can be perceived from the outside. First, it is recognized because his eyelids are puffed and his lips are white (31), later it takes the form of a horn that is palpable from the outside and even able to change the shape of a beret into a child’s bicycle

helmet (185). The longing for external visible signs as 'proof' for the diagnosis produced by a fundamental epistemological uncertainty is one part of the definition of a 'migraine self'.

CHAPTER 8

IRVIN YALOM'S *WHEN NIETZSCHE WEPT*

It is well known that the philosopher Friedrich Nietzsche, who lived from 1844 to 1900, suffered from debilitating headaches. Many scholars mention that he gave his pain the name 'dog' and in this way tried to take distance of it by describing it as having 'dog-like attributes such as being faithful, obtrusive, shameless, entertaining, and clever' (Frank *Storyteller* 116). By doing this, Nietzsche could 'scold it and vent his bad mood on it, as others do with their dogs' (116)[38]. So, he took (some) distance from his pain by giving it a name, by attaching a word to it, thereby making it controllable. It even seems that he tried to replace the signifier 'headache' by one with a clear signified such as 'dog'. By doing so, for Frank, 'the parent for the quest story is Nietzsche, who named his pain and thus gave it a use, making it an opening for himself and to others' (*Storyteller* 180). As described in chapter 1, a 'quest narrative' describes a search for health; the sufferer accepts the illness but seeks to use it (115). That is what Nietzsche did. As I will argue, Nietzsche used his headaches in several different ways.

There are many articles that describe and discuss Nietzsche's headache (Kain *Skepticism* 1983; Sax 2003; Orth and Trimble, 2006; Kain *Horror* 2007; Owen 2007; Hemelsoet et al., 2008; Koszka 2009; Danesh-Meyer and Young 2010; Perogamvros et al., 2013). It was long thought that his headache was part of an infection with *Treponema Pallidum* (the cause of syphilis), but there are many arguments against this (Sax 49-50; Orth and Trimble; Hemelsoet et al 12; Koszka 163; Danesh-Meyer and Young 967-968; Perogamvros et al 176). There is now consensus that he suffered from a severe form of migraine (Sax 49-50; Orth and Trimble 440; Hemelsoet et al 10; Danesh-Meyer and Young 969; Perogamvros et al 176). His self-described headache came in attacks that lasted between 4 and 44 hours, but occasionally were longer, even up to 6 days (Hemelsoet et al 10). He often had to lie in a darkened room due to sensitivity to light and also suffered

[38] In his book *Untimely Meditation*, Nietzsche writes 'The dog's joyful greeting. Its sad attunement when left behind' (cited by McNeill 58). It is not known whether he is referring to his migraine here, but it could be so.

from nausea (Danesh-Meyer and Young 967). Once, Nietzsche counted 118 days of (migrainous) headache in the previous year (Orth and Trimble 440). This means that he was not suffering from 'chronic migraine' – a diagnosis made when someone suffers from at least fifteen headache days per month of which at least eight with migraine-characteristics (see chapter 3) – but from 'frequent episodic migraine' (International Classification of Headache Disorders 2013; 2018).

In general, it is considered tricky to identify past diseases and make retrospective diagnoses in historical persons. A good example is Vincent van Gogh, who received more than 20 different medical diagnoses based on his works and behavior (Ter Borg and Kasteleijn-Nolst Trenité 2012). Another example is the suggestion that Pablo Picasso suffered from migraine, which was later rejected (see chapter 4). Cunningham discusses the questionable legitimacy of retrospective diagnoses in his article "Identifying Disease in the Past: Cutting the Gordian Knot" (2002). He warns for the use of modern concepts of disease backwards in time, and even calls this 'sources of unjustified assumption' (15). Foxhall (2014) gives the example of how in retrospect the abbess Hildegard of Bingen, who lived from 1098 to 1179, was diagnosed with migraine. As migraine leaves no physical, structural or other measurable traces, a possible retrospective diagnosis had to be based on other information and in the case of Hildegard the diagnosis was made on her drawings. In 1913, these were 'recognized' as being 'migrainous' and since then it was believed that she suffered from migraine. The neurologist Oliver Sacks adopted this view, which was, however, seriously challenged (Foxhall *Making*; Haan et al. *Sacks*).

In Nietzsche's time, the term 'migraine' had a meaning that was different from its current use, as the current criteria (see chapters 2 and 3) obviously did not yet exist. Nevertheless, in his writings, Nietzsche described headache that came in attacks and lasted between 4 and 44 hours. During attacks he had to lay in a darkened room due to sensitivity to light and suffered from nausea. Based on this, a retrospective diagnosis of migraine is still not 'proven' but remains very likely in the light of the current criteria. So, from now on, I will base my arguments on the presumption that 'Nietzsche's migraine' existed.

Nietzsche's migraine is one of the most important sources of inspiration for the novel *When Nietzsche Wept* (1992) written by the American psychiatrist Irvin Yalom. It describes how a fictional character called 'Friedrich Nietzsche' deals with and 'uses' his migraine. He seeks and accepts the help of a person called 'Josef Breuer', historically an eminent Viennese physician

and psychotherapist *avant-la-lettre*, but here of course also a product of fiction. Nietzsche and Breuer never actually met (Yalom 307; Gillespie 632). For his migraine, Nietzsche had consulted many physicians throughout Europe, but never the famous and eminent Josef Breuer (Yalom 309). Nevertheless, Yalom brought these two together in a fictional form with a focus on Nietzsche's migraine. It appears that a 'double doubling' emerges. The first doubling is within the diegesis: the Nietzsche's described in- and outside attacks are very different. The second is that of the real and the fictional Nietzsche, both suffering from migraine. It seems that when Nietzsche is talking about himself, he is talking himself into a 'migrainous' being, as I will show. Here, I will analyze what the importance of these doublings is for the conceptualization of 'migraine'.

To do so, I will first summarize the story of *When Nietzsche Wept* and then reflect on the specific role of migraine in the text and its association with the philosophy of the 'real' Nietzsche. Special emphasis will be given to the performative aspects of the description of migraine.

The fictional Nietzsche

When on holiday in Venice, the Viennese physician Josef Breuer is approached by a woman called Lou Salomé, who asks his attention for Friedrich Nietzsche, a friend of hers, because he suffers from severe headaches and has already consulted in vain 24 other physicians to get relief. She is afraid that the mental state and severe migraine of her friend might drive him to suicide. Although Breuer is not enthusiastic by taking up the treatment of this unknown person as 25th doctor, he allows Lou Salomé to visit him in his office in Vienna after returning from his holiday. At this meeting a couple of weeks later, he is even more attracted to this beautiful woman, and 'caught himself gazing at his visitor's bosom rather than at her face' (19). Shortly thereafter – and maybe because of this – he promises her to take up Nietzsche's treatment, although he at first hand fails to see how he as a general medical doctor could treat someone suffering from despair of the mind. At the end of their encounter, Lou Salomé demands that her role has to remain a secret for Nietzsche.

At his first appointment with Nietzsche, Breuer's secretary announces him as having 'a gentleman's bearing but not a gentleman's grooming. He seems shy. Almost humble' (49). After meeting Nietzsche, Breuer agrees with the description and sees 'something curiously insubstantial about his body, as though you could pass your hand through it' (50). He learns that Nietzsche has traveled a lot through Europe as a consequence of his illness.

At the end of this consultation, Nietzsche has three questions: 'Will I go blind? [..] Will I have these attacks forever? [..] Do I have a progressive brain disease which will kill me young like my father, drive me into paralysis or, worse, into madness or dementia?' (65). The questions fascinate Breuer. He decides to accept Nietzsche as his patient and after some hesitation from Nietzsche's side (and after a severe migraine-attack, see below), their treatment sessions start.

After a discussion with his young friend Sigmund Freud, Breuer chooses to apply a kind of 'talking cure' for Nietzsche's despair, as he has already used it in some other patients. This approach, however, at first seems not very successful in Nietzsche's case, as Breuer has to admit, 'please don't misunderstand me, Professor Nietzsche, your words are beautiful and powerful, but when you read them to me, I no longer feel that we're relating *personally*. I grasp your meaning intellectually: yes, there *are* rewards of pain – growth, strength, creativity' (180; emphasis in the original).

After some therapeutic encounters, the doctor – patient relationship of Breuer and Nietzsche is reversed. First Nietzsche expresses that, 'my time will come again, Doctor Breuer, my illness never strays too long or too far. But now it's *en vacance*, let's continue our work on your problems' (184; emphasis in the original).

The 'problem' of Breuer is that he is unhappy in his marriage and feels trapped by the responsibilities towards his family. His despair is augmented by his fascination for a female former patient who he has tried in vain to cure from her hysteria by means of the same talking cure he intends now to use on Nietzsche. After Nietzsche has mentioned his 'problem', Breuer takes 'refuge in a new thought: maybe he could help Nietzsche better by letting him help himself' (199). As a consequence, the two men are going to counsel one another.

So, first Breuer is not going to try to treat Nietzsche's migraine, which is (by definition) not apparent during most of their encounters (but '*en vacance*'), but Nietzsche is going to heal Breuer's despair. It appears that Breuer experiences great relief by unveiling his inner thoughts to Nietzsche, whose main advice is to make clear choices, for example to leave his wife and children for his former patient. It indeed seems that Breuer follows this advice, makes-up with his wife and leaves Vienna, but this whole scene turns out to be a long dream, elicited by hypnosis applied by Freud (271-272). In fact, Breuer decides not to follow Nietzsche's advice, but stays with his wife.

In the next treatment-session Breuer explains to Nietzsche why he is not going to follow the advice to leave his wife. His fascination for his female patient has ended after the hypnosis-session. He is 'cured' and does not need treatment anymore. Nietzsche responds with, 'in the beginning [..] I was embarrassed for you – never had I heard such candid revelations. Next I grew impatient, then critical and judgmental. Later I turned again: I grew to admire your courage and honesty. Turning still further, I felt touched by your trust in me' (283-284).

After admitting that he cannot bear loneliness any longer, Nietzsche is haunted by the fear that he will die alone and that his body may not be discovered for days or weeks after his death, he also reveals that he had been dishonest with Breuer and has been hiding his love for Lou Salomé. It becomes apparent that part of the source of his despair lies in her unanswered love. Then tears run down his cheeks, and he raises his head to face Breuer directly, saying 'that is my confession and my shame. Now you understand my intense interest in your liberation. Your liberation can be *my* liberation' (287; emphasis in the original). Now, Breuer on his part admits that he had met Lou Salomé and that she was the main reason for his first appointment with Nietzsche.

After an emotional dialogue, the two men forgive one another for being dishonest. Nietzsche rejects Breuer's offer to come and live in his house to be treated further. The two men decide to end their therapeutic relation (-s). Breuer is cured and Nietzsche has found the strength to go on. The novel then ends on the following note:

> At noon, on 18 December 1882, Josef Breuer returned to his office, to frau Becker and his waiting patients. Later he dined with his wife, his children, his father- and mother-in-law, young Freud, and Max and his family. After dinner, he napped and dreamed about chess and the queening of a pawn. He continued the comfortable practice of medicine for thirty more years but never again made use of the talking cure.
>
> That same afternoon, the patient in room 13 at the Lauzon Clinic, Eckart Müller, boarded a fiacre to the train station and thence traveled south, alone, to Italy, to the warm sun, the still air, and to a rendezvous, an honest rendezvous, with a Persian prophet named Zarathustra.[39] (301)

[39] Frau Becker is Breuer's secretary; Max is his brother-in-law; the Lauzon Clinic is where Breuer has internalized Nietzsche for the treatment; Eckart Müller is the pseudonym under which Nietzsche was admitted there (Yalom 46).

Earlier that day, during his emotional dialogue with Breuer, Nietzsche got a migraine aura, which was immediately and successfully treated by his doctor. In the next paragraph I will deal with Nietzsche's migraine and its importance for this novel. It will become clear that Nietzsche is very different in- and outside an attack. The described self of this fictional character is doubled, and this double-ness is pivotal for my analysis of migraine.

Nietzsche's migraine: Cerebral labor pain

The first description of Nietzsche's headache in the novel is given by Lou Salomé when she approaches Breuer in Venice. She describes his complaints as:

> Headaches. First of all tormenting headaches. And continued bouts of nausea. And impeding blindness – his vision has been gradually deteriorating. And stomach trouble – sometimes he cannot eat for days. And insomnia – no drug can offer him sleep, so he takes dangerous amounts of morphia. And dizziness – sometimes he is seasick on dry land for days at a time. (5)

Back in Vienna, Breuer discusses the description of these symptoms with his young friend Sigmund Freud, and adds that the patient is, 'extremely ill and has already stumped two dozen physicians, many with excellent reputations. She described to me a long list of his symptoms – severe headaches, partial blindness, nausea, insomnia, vomiting, severe indigestion, equilibrium problems, weakness' (44).

He concludes that this is a 'bewildering clinical picture' and challenges Freud to make a diagnosis, who suggests multiple sclerosis, an occipital brain tumor or lead poisoning, to which Breuer adds hemicrania and delusional hypochondriasis, or that the patient maybe has two separate diseases. So, he considers the diagnosis of migraine ('hemicrania') already on the basis of a description by a friend of the sufferer alone, without seeing or speaking to the patient at all.

Then follows Breuer's first encounter with Nietzsche, who carries with him a briefcase containing a heavy folder crammed with papers about his previous medical consultations. Breuer says that he prefers to 'read a play before reading reviews' (51) and Nietzsche immediately agrees as in his opinion 'interpreters of texts are *always* dishonest' (52; emphasis in the original). About his illness, he remarks that its most important feature is that it always awaits him (53). After Breuer has asked him to describe everything

in his own words, the complexity of Nietzsche's ailments surprise him. His notes fill page after page with a gruesome collection of symptoms such as:

> monstrous, crippling headaches; sea-sickness on dry land – vertigo, disequilibrium, nausea, vomiting, anorexia, disgust for food; fevers, heavy night sweats which necessitated two or three nightly changes of nightshirt and linen; crushing bouts of fatigue which at times approximated generalized muscular paralysis; gastric pain; hematemesis; intestinal cramps; severe constipation; hemorrhoids; and disabling visual problems – eye fatigue, inexorable fading of vision, frequent watering and pain in his eyes, visual blurring, and great sensitivity to light, especially in the mornings. (55)

These symptoms come in attacks. Nietzsche also describes that 'there have been times when, on the day before an attack, I have felt particularly good – I have come to think of it as feeling *dangerously good*' (56; emphasis in the original). Typical attacks last from twelve hours to two days and sometimes, especially after a longer attack of several days, Nietzsche feels refreshed, cleansed. He then explodes with energy. Then his mind 'swarms with the rarest of ideas' (56). Breuer concludes that 'such a situation – the majority of one's days a torment, a handful of healthy days a year, one's life consumed by pain – seems a natural breeding place for despair' (57), but Nietzsche does not agree. He argues that this may be true for some people, but not for himself, saying that, 'Despair? No, perhaps once true, but not now. My illness belongs to the domain of my body, but it is not *me*. I am my illness and my body, but they are not me. Both must be overcome, if not physically, then metaphysically' (57; emphasis in the original).

Here, he makes a Cartesian distinction between body and mind. Then, he compares his headache with pregnancy and taps his temple, saying that inside his head there are books, his head is pregnant with books, 'books almost fully formed, books only I can deliver. Sometimes I think of my headaches as cerebral labor pain' (57). He must admit, however, that this 'cerebral labor pain' also dictates his life in a negative way (60).

Not long after his first encounter with Nietzsche, Breuer speaks to Freud again. The latter is ashamed to still not know the diagnosis of this patient. Breuer now is certain that it is:

> Hemicrania, or migraine. And don't feel ashamed about not thinking of it: migraine is a house-call disease. Clinical aspirants rarely ever see it because migraine sufferers seldom go to the hospital. Without doubt [Nietzsche] has a severe case of hemicrania. He has all the classical symptoms. Let's review them: intermittent attacks of unilateral throbbing headache – often familial,

> by the way – accompanied by anorexia, nausea and vomiting, and visual aberrations – prodromal light flashing, even hemianopsia. (79-80)

Breuer is not only certain of the diagnosis, but also of its cause, which he considers to be stress. He proposes to Nietzsche the talking cure and ergotamine for the individual attacks. At first, Nietzsche refuses, but then he gets a severe migraine-attack. Because of this, Breuer is warned by the proprietor of the 'Gasthaus' where Nietzsche stays that his guest is very sick. Breuer finds him in an almost comatose state clad only in his underwear noticing that:

> The enamel basin on the floor next to the bed was half filled with blood-tinged, light green vomitus. The mattress and Nietzsche's face and chest glistened with dry vomitus – no doubt he had become too ill, or too stuporous, to reach for the basin. [..] Nietzsche looked moribund: face gray; eyes shrunken; his entire body cold, pallid, and pockmarked with goose pimples. His breathing was labored, and his pulse feeble and racing at one hundred fifty-six per minute. Now Nietzsche shivered, but when Breuer tried to cover him with one of the blankets frau Schlegel[40] had left, he moaned and kicked it away. Probably extreme hyperesthesia, Breuer thought: everything feels painful to him, even the merest touch of a blanket. (127)

Breuer notices that the patient also has hyperesthesia to sound and light and concludes to 'bilateral spastic migraine' (127). Part of the patient's symptoms (mainly the stupor) must have been caused by the ingestion of chloral hydrate. After treatment with nitroglycerine and a massage of the temples, Nietzsche recovers. Breuer goes on with his regular work in his office and when he returns after a couple of hours, he finds Nietzsche awake and asks how he feels. '"Not pleased" – Nietzsche's voice was soft and his words slurred – "to be living. Not pleased. No fear of darkness. Awful, feel awful."'

Breuer's treatment apparently had aborted the attack, but still Nietzsche utters 'Am I living? Dying? Who cares?' (130). Now, Breuer realizes that deep inside Nietzsche there must be a 'second' or 'double' person in despair. To his relief Nietzsche now agrees to undergo his treatment and to be admitted to his Lauzon Clinic, where he visits his patient almost every day to apply his talking cure.

It now has become clear that there is a great difference between the Nietzsche in- and outside the migraine attacks. When not having migraine, he is confident, dominant and authoritative. During an attack his words

[40] The wife of the owner of the 'Gasthaus'.

become sparse, he is dependent on others and deplorable. So, Nietzsche's fictional self is 'doubled' in a sort of dr. Jekyll and mr. Hyde manner. At the same time, Breuer's situation is doubled also. He switches from being a doctor to being a patient and back. At one time, he is a person in despair and shortly thereafter a 'life-saving' doctor. This switch is enhanced during their last encounter, when Nietzsche gets a second migraine attack: '"My head – I'm seeing flashing lights – both eyes! My visual aura." Breuer immediately assumed his professional persona. "A migraine is trying to materialize. At this stage, we can stop it. The best thing is caffeine and ergotamine"' (288).

Here, Breuer clearly switches to the role of doctor. The treatment applied by Breuer indeed aborts the attack. He watches Nietzsche to recover. 'Thank God for the migraine! He thought. It forces Nietzsche, even for a short time, to remain where he is' (290).

There is not much doubt about the diagnosis of migraine, as depicted in this novel. The sufferer has attacks of severe headache with nausea, vomiting and sensitivity to light and sound. He also has visual auras (288) and allodynia (tactile stimulation felt abnormally strong; see chapter 8). This is a 'clear-cut' case of migraine according to the current criteria, but there are some remarkable aspects. First, the doctor (Breuer) was able to make a diagnosis of migraine ('hemicrania') already before he had seen the patient at all, purely on the basis of the words of an acquaintance. This emphasizes the importance of words to make this diagnosis (see chapter 2), which can be made even without seeing the patient. Another remarkable aspect is that the doctor (Breuer) later is able to witness (two) actual migraine attacks. This is remarkable as nowadays patients with migraine only visit the outpatient clinic when not having an attack ('When you see them, they do not have it. When they have it, you don't see them'; see chapter 2). Migraine-patients tend to cancel their appointments when having an attack, and house-calls for individual migraine-attacks (such as that of Breuer) are virtually never been made anymore.

From the above, it becomes clear that in migraine there is some sort of 'doubling': being in- or outside an attack. Below, I consider an analogy of this doubling in the 'real' and 'fictional' Nietzsche.

Nietzsche: The doubling of 'real' and 'fictional' migraine

Next to the doubling of the self of a fictional character with migraine described above, another doubling can be detected not so much in, but *through* this text. *When Nietzsche wept* includes many aspects of the

philosophy of the 'real' Nietzsche that are important in relation to his migraine and the 'doubling' of the 'traces of reality'. So, migraine is intra- and extradiegetic (see chapter 7, note 2). Of these traces, I will discuss *amor fati*, eternal recurrence, pain as benefit and the 'real' Nietzsche's standpoint on suffering in relation to the fictional Nietzsche and his migraine.

It has been argued that Nietzsche's severe migraine not only has had a marked effect on his life, but also on his philosophy (Owen et al 626). Especially of amor fati (to love one's fate), one of his most important philosophical constructs, is said that it was 'conceived primarily from his attempts to cope with, understand, and overcome his own painful illness' (626-627). It seems that 'his migraines, which debilitated him every few days, were part of the reason he approached philosophy as he did, through some bursts of thought and writing rather than the long and patient treatment that characterizes most philosophical treatises' (Nehamas *Reply* 144). Furthermore:

> there is no reason to think that it makes sense to imagine Nietzsche without his headaches but with the works he actually did produce, and so there is no reason to think that a life without headaches would have represented a "better possibility" *for him*. Without the headaches, there is no way to know whether Nietzsche would even have become a philosopher in the first place or whether he would ever have written anything. (144; emphasis in the original)

In his book *The Gay Science*, Nietzsche reflects on his poor health. He remarks that 'sickness and pain can eliminate "trust in life" and make life a "*problem*" and he then contends that this need not one make "gloomy"' (cited by Brodsky 48; emphasis in the original). Nietzsche uses a metaphor from the battlefield, writing that 'if one endured, if one *could* endure this immense sum of grief of all kinds while yet being the hero who, as the second day of battle breaks, welcomes the dawn and his fortune, … this would surely have to result in a happiness that humanity has not known so far' (48; emphasis in the original). In my opinion, this metaphor can be read as referring to his migraine, as he not only mentions his 'sickness and pain', but also the welcomed dawn and happiness of the second day. Indeed, most migraine-attacks resolve after sleeping and therefore last one day.

There is a paragraph in one of his other books (*Ecce Homo*) that indeed suggest a relation between his migraine and his creativity, when Nietzsche writes that:

> in the midst of the torments that go with an uninterrupted three-day migraine, accompanied by laborious vomiting of phlegm, I possessed a dialectician's clarity *par excellence* and thought through with very cold blood matters for which under healthier circumstances I am not mountain-climber, not subtle, not *cold* enough. (cited by Shepherd 23; emphasis in the original)

Shepherd sees this as 'the ability of this sickly variety of health to produce clear thinking' (23), the 'sickly variety of health' being migraine. This interpretation does suggest that Nietzsche's migraine did not destroy but fostered creativity (see also chapter 4). In line with this, one step further, in *Ecce Homo*, Nietzsche wrote about amor fati 'that one wants nothing to be different, not forward, not backward, not in all eternity. Not merely bear what is necessary, still less conceal it… but *love* it' (cited in Kain *Horror* 53; emphasis in the original). In addition, in *Zarathustra*, Nietzsche wrote: 'The will is a creator. All "it was" is a fragment, a riddle, a dreadful accident… until the creative will says to it, "But thus I willed it." Until the creative will says to it, "But thus I will it; thus I shall will it"' (cited in Kain *Skepticism 3*74). To turn a 'thus it was' into a 'thus I willed it' is to accept fate fully, to love it and this obviously included his migraine. Amor fati is indeed the idea that we should love our respective fates and respond positively to being told by a demon that our fate had recurred and will recur eternally, exactly as it has been (Brodsky 35). The latter thought forms the concept of 'eternal recurrence'. In Nietzsche's words (from *The Gay Science*) the demon informs one that he or she will 'have to live once more and innumerable times more; and there will be nothing new in it' (cited by Brodsky 37). Or, in other words, from the same book, 'the eternal hourglass of existence is turned upside down again and again, and you with it, speck of dust' (37-38). Amor fati has been called the best response to eternal recurrence, and maybe also to recurring pain.

The Nietzsche of *When Nietzsche Wept* also seems to associate eternal recurrence with migraine when he says 'my whole life has become a journey, and I begin to feel that my only home, the only familiar place to which I always return, is my illness' (51). He then explains his ideas about eternal recurrence to Breuer as follows:

> Josef, try to clear your mind. Imagine this thought experiment. What if some demon were to say to you that this life – as you now live it and have lived it in the past – you will have to live once more, and innumerable times more; and there will be nothing new in it, but every pain and every joy and everything unutterable small or great in your life will return to you, all in the same succession and sequence. (Yalom 249)

This is an almost literary quote of Nietzsche's words from his book *The Gay Science* as cited above.

In his article "Nietzsche, Eternal Recurrence, and the Horror of Existence" (2007), Kain also uses this quote, but slightly changes Nietzsche's original words, with a certain reason. He changes his words to:

> now imagine that at your worst moment, your loneliest loneliness, a demon appears to you or you imagine a demon appearing to you. And this demon tells you that you will have to live your life over again, innumerable times more, and that everything, every last bit of pain and suffering, *every last migraine*, every last bout of nausea and vomiting, will return, exactly the same, over and over and over again. (55; my emphasis)

Kain introduces migraine in Nietzsche's text about eternal recurrence and elaborates further on a possible association of eternal recurrence, amor fati and migraine. In an earlier publication he had already suggested such an association, arguing that the doctrine of amor fati might have been based on Nietzsche's response to the suffering of migraine (*Skepticism* 374). Nietzsche was often ill, confined to bed, unable to work because of his migraine and he was unable to fight it. Perhaps his solution therefore was to turn 'thus it was' into 'thus I willed it' (374). Kain wonders why this has been overlooked by all the commentators, as:

> try to imagine yourself with a migraine. Imagine yourself in a feverish state experiencing nausea and vomiting. Imagine that this sort of thing has been going on for years and years and that you have been unable to do anything about it. Extreme care with your diet, concern for climate, continuous experimenting with medicines—all accomplish nothing. You are unable to cure yourself. You have been unable to even improve your condition significantly. You have no expectation of ever doing so. Suppose this state has led you to see, or perhaps merely confirmed your insight into, the horror and terror of existence. (*Horror* 55)

How to deal with such a situation, with this horrible disease? Sit still and suffer? One may also curse the demon and love one's fate and deal with it. One can also invent amor fati and try to be productive.

It has been said that Nietzsche's view seemed to oscillate between sickness and health (Domino 295). Sometimes he is in the kingdom of the healthy and at other times in that of the sick, which strongly resembles Susan Sontag's 'dual citizenship in the kingdom of the well and in the kingdom of the sick' (*Illness* 7; see also chapter 2). It also reflects the double situation

of many 'real' migraine patients. In line with this, Nehamas (2014) cites Nietzsche, who wrote that:

> what I am to image recurring is whatever I find significant in my life. Insignificant events are, precisely, events whose occurrence does not make a difference [..] By contrast, significant events are those that do make a difference [..] Those are the events that I would want (or not want) to recur if I were to live again. (cited in *Reply* 143)

Nehamas connects these words with eternal recurrence in general, but it can also be argued that Nietzsche is writing about migraine here. Indeed, he 'could face the thought of the eternal recurrence with the attitude I *could* have had a life free of chronic debilitating headaches – but my *actual* life is the one I would crave again' (143-144; emphasis in the original).

An additional question raised by Nehamas is why Nietzsche would prefer his actual life to a life that was in every other respect identical with his but without his debilitating headaches or said in other words whether a life free of migraines would represent a 'better possibility' for him. Maybe the answer is that 'things are never equal in this context. Nietzsche's migraines cannot be what the thought of the eternal recurrence presupposes and, more importantly, one of his *reasons* for affirming his actual situation in all its detail' (*Reply* 144; emphasis in the original). So, the 'real' Nietzsche decided that he would not change one single detail of his life, including not one moment of pain. He decided to love his fate. The 'fictional' Nietzsche had no choice, as he was 'fixed' in black words on a white page. For both, migraine leads to the doubling of their selves, and it can even be suggested that this doubling due to migraine is at the basis of Nietzsche's philosophy. My question, however, is whether this doubling is pivotal in the light of a migraine self.

The benefit of suffering

Suffering pain is generally considered in a tragic light, and by consequence connotes tragedy. Morris describes 'tragedy' as follows: it 'is the literary form that takes as its main social function an extended meditation on human pain and suffering' (*Culture* 246). An important question here is, whether tragedy described as such can also be turned around and whether one can even benefit from it. One of Nietzsche's famous quotes is, 'the most suffering animal on earth invented for itself – laughter' (Morris *Culture* 79). So, maybe suffering can create some sort of benefit and pleasure, or it can even also give strength, as according to Nietzsche, 'what does not kill me

makes me stronger' (195). Indeed, pain and in his case the headache of migraine does not only destroy but can create also (see chapter 4).

The character Nietzsche indeed sees some benefit in his migraine. As he says to Breuer, he sometimes feels refreshed and cleansed after an attack (Yalom 56). At those moments he explodes with energy, gets inspiration and at the question whether he in any way profits from this misery, he answers:

> I have reflected on that very question for many years. Perhaps I do profit. [..] You [Breuer] suggest that the attacks are caused by stress, but sometimes the opposite is true – that the attacks dissipate stress. My work is stressful. It requires me to face the dark side of existence, and the migraine attack, awful as it is, may be a cleansing convulsion that permits me to continue. (95)

About the consequences of this, the character Nietzsche also says that:

> If you choose to be one of those few who partake of the pleasure of growth and the exhilaration of godless freedom, then you must prepare yourself for the greatest pain. They are bound together and cannot be experienced apart! If you want less pain, then you must shrink, as the stoics did and forgo the highest pleasure. (179)

So, there is no doubt that both the real and the fictional Nietzsche saw some benefit of (their) pain, but with some sacrifices.

Indeed, in real life, migraine also seems to have the peculiar characteristic of sometimes giving benefit. For example, for both Roland Barthes (chapter 5) and Siri Hustvedt (chapter 6) it seemed to add something to their lives. They both seemed to need their migraine to be the one who they were/are. It is known that many migraine-patients 'miss' their attacks when their migraine is effectively treated or for some other reason stays away. For example, for Biro's (virtual) migraine patient Rachel, who has had attacks for as long she can remember 'in a strange way, the pain is like an old friend' (79-80), although their encounters 'never get any easier' (80). When, however, an 'expected' attack does not come, she feels uneasy, unreal. For Scarry, pain may even exist as the primary model of certainty (4). After many years of suffering, the absence of the familiar pain feels like a void. In a recent survey among 11.266 patients with severe migraine who did not respond to preventive treatment, 57% mentioned at least 1 positive aspect of living with migraine (Martelletti et al). Among these, 11% thought that migraine had made them stronger. Thus, migraine seems not only to 'destroy' or 'create', but the presence and absence of attacks also seems to

determine the identity of the sufferers, which in some cases can be seen as a kind of benefit.

Nietzsche was accustomed – and during his frequent migraine attacks obliged – to lie still for long periods of time. He wrote in *Ecce Homo*: 'Sickness gradually liberated me […] and likewise gave me the right to a complete change in my habits. […] It bestowed on me the compulsion to lie still, to be idle, to wait and be patient. … But all that means, to think!' (cited in Parkes 58). This is another example of a relation between his headache and his work, and another with the suggestion that his migraine has had some sort of positive influence, as is the issue here. He was forced to think. Or, as he has written in *Nietzsche contra Wagner*, 'only great suffering is the ultimate emancipator of the spirit' (cited by Kain *Horror* 50).

Still, headache means suffering and Nietzsche has written elsewhere that 'all pain is per se, and especially when in excess, destructive [..]. Mere pain can destroy life' (cited by MacDonald Critchley *Citadel* 180). So, there must be some balance between destruction and creation. In "Nietzsche, Eternal Recurrence, and the Horror of Existence", Kain elaborates further on this duality. He not only mentions the importance of suffering in Nietzsche's work, but also the creative influence of migraine on Nietzsche's thoughts. First, he cites Nietzsche, who said that 'all we can expect as human beings is to suffer' (cited in *Horror* 49). Nevertheless, human beings can deal with suffering as long as it is not meaningless (49). Nietzsche wrote in a letter: 'Around 1876 my health grew worse. There were extremely painful and obstinate headaches which exhausted all my strength' (49). It seems that he suffered a lot. It can be concluded, then, that 'the philosopher who introduces eternal recurrence, the philosopher who believes in *amor fati*, is the very same philosopher who also believes in the horror of existence' (55; emphasis in the original). So, there is not only benefit of migraine, but also its horror.

Eternal recurrence, as that of migraine, may be part of the horror of existence and 'most people would assume that a life of intense pain and suffering is not at all the sort of life it makes any sense to want to live again' (56). Nietzsche, however, tried not to become a slave of his illness. In this context, it is important to make a distinction between suffering and meaningless suffering. As described, people cannot bear meaningless suffering and so they give it a meaning by means of a symbol, metaphor, or any signifier (like 'dog') or the interesting sounding description 'migraine', which has a pseudo-objectivation in the form of artificial criteria (see chapter 3). In the chapter "The Meanings of Pain" of his book *The Culture*

of Pain, Morris (1991) sums up some possible other meanings that one can give to the suffering of pain, for example that it came from the Gods or that it is a punishment for something. It can also be 'deeply social', as it is in large part been constructed or shaped by culture (38).

In their article "Nietzsche and the Dilemma of Suffering" (1999), Johnston and Johnston further elaborate on the relation between pain and suffering. They emphasize that in Nietzsche's thoughts about suffering the most important issue is that 'one has to "suffer well", in order to self-overcome' (187). Internal, individual 'positive' suffering can be life-affirming. 'Nietzsche propagated positive suffering and 'a Yes-saying without reservation, even to suffering, even to guilt, even to everything that is questionable and strange in existence' (188). Indeed, in his book *Human, All too Human*, he argued that: 'When a misfortune strikes us, we can overcome it either by removing its cause or else by changing the effect it has on our feelings, that is, by reinterpreting the misfortune as a good, whose benefit may only later become clear' (cited in Johnston and Johnston 189).

The question is then whether suffering belongs to illness or to health. Johnston and Johnston point out that suffering does not stand alone, that it is always related to something. Specifically, they point at the thoroughgoing connection of suffering with amor fati, and in this context cite Nietzsche's words from *Ecce Homo*:

> my formula for greatness in a human being is amor fati: that one wants nothing to be different, not forward, not backward, not in all eternity. Not merely to bear what is necessary, still less conceal it … but love it. So, to love one's fate means to find all distress, all pain, all suffering as authentic, meaningful, and ultimately beneficial. (190)

One can wonder how to adjust this to pain returning again and again as in migraine. Nietzsche sees this (double) dualism of pain – no pain as self-overcoming, self-creating, allowing joy, suffering and pain 'to be willed again and again, in a constant process of self-creating' (190). He clearly refers to the paroxysmal nature of migraine. His self is thus doubled, leading to continuous self-creativity, or call it invention, after each attack.

As expressed by the character Nietzsche in *When Nietzsche Wept*, 'yes, I should bless my illness, bless it. [..] Personal suffering is a blessing – the training ground for facing the suffering of Existence' (Yalom 96). What can be concluded is that the words of the 'fictional' Nietzsche almost always are near-identical to those of the 'real' one, which adds to the notion of 'doubling' of reality and fiction here. This leads to the important question

what kind of text *When Nietzsche Wept* is in its relation to the perhaps thin line between fiction and reality. In order to answer this question, I will analyze the text in the context of its focalization.

Focalisation in When Nietzsche Wept

In contrast to the novels described in the previous chapters, *When Nietzsche Wept* is not written in the first-, but in the third person. As explained by Bal (20-21), however, so-called third-person texts are also uttered by a speaking subject, by an 'I' (see chapter 5). Both in first-person and in third-person narratives the narrator is the producer of the sentences and of the narrated world. Thus, it can be said that 'third-person narrative and first-person narrative are both characterized by not having a narrator who speaks *about* something, but rather an impersonal voice that creates the world to which it refers' (Nielsen 145-146; emphasis in the original). In *When Nietzsche Wept*, the narrator never refers to him- or herself as a character in the story, so he or she must be categorized as an 'external narrator' (Bal 21). The text does not display linguistic markers signaling the presence of a speaker. Nevertheless, the narration of *When Nietzsche Wept* is not 'neutral'. The 'external' narrator always follows the thoughts of the character called Breuer and never those of the one called Nietzsche, Freud or Salomé. Only Breuer's thoughts, emotions and opinions are described 'from the inside'. So, the focalization virtually always lays with him. The reader knows what Breuer knows, sees, thinks and feels. Breuer can therefore be called 'a character-bound focalizor' (Bal 25). The reader sees most of the occurrences through his eyes. The character called Nietzsche is only described 'from the outside' and we only learn about him by means of descriptions of the external narrator, the opinions of Breuer and through a literary reproduction of Nietzsche's words, when they are presented in 'direct discourse'. In addition to this, there are in the text the words of two different Nietzsches, those of being in- and outside an attack, but still only heard by Breuer.

The question can be asked to what genre a novel with this kind of focalization belongs. In general, one can say that 'based on experience, we generally assume that our competence as readers includes the ability to attribute a given text to the appropriate genre' (Pihlainen 47-48). This is, however, not so easy in the case of *When Nietzsche Wept*. It is clear that the novel must be categorized as fiction, as we can read Breuer's thoughts. And, as 'a story starts reporting a character's thoughts, expect it to be fiction' (Culler *Deconstruction* 28; see also chapter 5). In other words: when an idea or metaphor used by the narrator is 'shifting over into the language or

thoughts of the character described we become aware of the fictionality of the text' (Pihlainen 53). The fact that the focalization lays with the fictional character called 'Breuer' makes *When Nietzsche Wept* fiction. The novel must thus be analyzed as such and not as 'real' history. Nevertheless, in the text references to 'real' persons are included and there are descriptions of historical associations, such as those of Breuer and Freud, and of Nietzsche and Lou Salomé. Besides, Nietzsche's theories about amor fati, eternal recurrence and suffering are also 'real', and one must not forget the real 'history' of his migraine. Although Nietzsche and Breuer never met and that part of the story is invented by the author, there are aspects which suggest that the novel is not 'pure' fiction, as it is partially based on historical events. So, the text is not only fictional, but also referential. Here, in that sense, we seem to deal with an example of epic fiction, as the subjects of enunciation ('external narrator' and/or 'character-bound focalizor') narrate something that exists independent of the enunciation (Nielsen 134-135). The narration must be about something that existed prior to its narration, and one of these 'somethings' is Nietzsche's migraine.

When Nietzsche Wept probably cannot be called a historical novel as most of the occurrences described never really took place. A historical novel 'essentially shows us historical reality as seen through the eyes of (fictitious) people living in the past' (Pihlainen 54), and this is not the case in this novel. It can also be argued that 'literature of testimony is [..] often imbued with an authority based on the classical idea of authenticity: the person speaking is that person who saw these things' (Margaronis 139). The third-person narrator of this novel pretends to be present during the occurrences, but there is so much focalization through Breuer that the authenticity can be doubted. The problems of a historical novel can be described as:

> To write a historical novel is to enter a no-man's land on the borders of fact and fantasy. All fiction is written on this territory, but when the work explicitly engages with historical events – when it is part of the writer's project to reimagine them – the ground becomes a minefield of hard questions. What responsibility does a novelist have to the historical record? How much – and what kinds of things – is it permissible to invent? For the purpose of fiction, what counts as evidence? What are the moral implications of taking someone else's experience, especially the experience of suffering and pain, and giving it the gloss of form? (138)

All of these questions can surely be asked for *When Nietzsche Wept*. Yalom takes responsibility for the historical record by modelling most of the characters described to persons that 'really' existed, and especially by using Nietzsche's migraine. The thoughts and deeds of the characters, however,

are purely fictional. As 'moral implication' of describing Nietzsche's pain, one can point at the fact that it gave him suffering, but also pleasure and inspiration.

Maybe the novel can be called *postmodern* as it plays with the borders of fiction and reality. Breuer never met Nietzsche and the reproduction of his thoughts must have been invented, considering that he never wrote them down exactly as presented here. Alternatively, maybe the novel is then better called an 'alternative history', 'alternate history' or 'allohistory' which is a genre of fiction in which the author speculates on how the course of history might have been altered if a particular historical event had had a different outcome (Collins Dictionary; Rosenfeld). Although the occurrences described are very intriguing, it is not very likely that they would have changed the lives of Breuer and Nietzsche if they had really occurred. For Breuer the therapeutic encounter with Nietzsche did change nothing in his life and Nietzsche probably would have stayed the same Nietzsche, writing the same books. In French there is also the so-called 'exofiction', described as a category of novels inspired by the life of a real person, which also includes inventions such as fictional dialogues and internal monologues. *When Nietzsche Wept* fits well in this category, but this does not add much to the question of its 'meaning'.

Maybe, however, the text can best be seen as 'historiography', which is described as the process of 'fictionalizing the facts' (Philainen 39). In historiography the difference between a historian and a novelist results in differences in the text. Whereas a historian aims at a narrative that is as 'true' as possible, a novelist does not (49). Nevertheless, one can argue whether there is a fundamental difference between the fictional and historical narrative. It can even be asked whether 'real' history exists, as also in history there is the question of subjectivity of the witness, the reliability of those who create the record, the problem of representation, the indeterminacy of reality and the criteria of truth (White 314). So, history and fiction 'share a strong reliance on imagination' (Philainen 50) and thus cannot be fully separated. In this context, an important issue is the referentiality of the text, reflected in its extratextual, extradiegetic and intertextual associations. Whereas 'the process of narrative construction is quite similar in both literary and historical narratives, the difference that referentiality brings is reflected in the narrative form, or rather, in the system of signification that the narrator employs' (42). Nevertheless, reference and 'truth' do not provide sufficient criteria for the separation of historical narratives from historical novel (48). Even 'true' history needs some fictionalizing to become a readable and understandable text and 'stories are

invented, not found, and their invention by historians is structurally continuous with the efforts of authors of fiction' (White, cited by Pihlainen 39). In both historiography and literary fiction stories are constructed rather than rediscovered.

In the kind of fiction such as *When Nietzsche Wept*, one knows that the occurrences described are not true, but that they are partially based on facts from reality and could have been true. *When Nietzsche Wept* can thus be seen as a double, or mixed historiography as the history of Nietzsche and Lou Salomé (and Nietzsche's migraine) on the one hand is historical and that of Breuer and Freud also. So, *When Nietzsche Wept* is not pure fiction as it does not only refer to itself and therefore is not a 'closed' text, but it also refers to extradiegetic historical or historiographical occurrences. The most important extradiegetic facts are that the persons named Nietzsche, Freud, Breuer and Lou Salomé really existed, that they did what they did, suffered how they suffered and thought how they thought. In addition, there are intertextual references to and literary quotes of several of Nietzsche's works. In the light of this book, the 'real' and 'fictional' migraine are very important also, stressed by the fact that their 'historical' descriptions, as emerging from 'historical' texts, virtually do not differ from their 'fictional' description in the novel. It can be concluded that *When Nietzsche Wept* is a mixture of fact and fiction, but with an emphasis on fact as long as migraine is considered. It is the migraine that has led to the concepts of eternal recurrence, amor fati and the benefit of suffering.

As said, *When Nietzsche Wept* contains a mix of fiction and non-fiction. In his book *Nietzsche. Life as Literature* (1985), Nehamas argues that the 'real' Nietzsche 'looks at the world in general as if it were a sort of artwork; in particular, he looks at it as if it were a literary text' (3). This 'not only provides him with a literary model for many of his views but also motivates him to create what we may well call a literary product' (4). Nehamas even calls Nietzsche 'a creature of his own texts' and 'a literary character who is a philosopher' (8). So, even in 'real life', Nietzsche might have been 'double': a real and a fictional character created by words. The result of this is a strong connection between literature and life, enhanced by Nietzsche himself who is 'notoriously unwilling to accept any straightforward distinction between fact and fiction' (165). According to this logic, or getting this logic to its ultimate consequence, in *When Nietzsche Wept*, Nietzsche has become a literary text himself. According to Nehamas, 'literary objects, and in particular literary characters, are constituted simply as sets of features or effects that belong to no independent subjects' (5). He is right, but not for Nietzsche's migraine. One of the most important features

of the fictional Nietzsche is how he deals with his migraine. This was, however, also important for the ‘real’ Nietzsche, who had to live and construct his fate.

In their migraine-elicited doubling, the fictive Nietzsche offer important contributions for the construction of a ‘migraine self’, which I will define in the last chapter of this book.

CHAPTER 9

CONCLUSION: PERFORMATIVE AND THE MIGRAINE SELF

Many kinds of histories, for example the history of the world, or – on a much smaller level – that of an individual migraine-patient, mainly get their meaning through their representation in words and through a subsequent interpretation of those words (see chapters 1 and 2). The adequacy of this representation depends on what Korsten (2005) calls 'a double attitude to language' (260).[41] On the one hand, language is insufficient in its depiction of what really happened or what is the case, and on the other, it is powerful enough to shape histories and produce realities (260). So, the least one can say is that there seems to be a delicate balance between the description of a 'reality' and the creation of this 'reality' with words.

In line with this, in this book, I have posed the questions of how language both describes and produces the reality of migraine in an individual sufferer and what the analysis of fictional texts that include a description of migraine can add to this. In both instances (a real patient suffering from migraine or a fictional text dealing with migraine) the 'performative' function of words in relation to pain is crucial (see chapter 5). For migraine in daily reality, the words of the patients mainly get their meaning through their repetition in a patient's mind, between patients and their fellowmen, between patients and other patients, between patients and doctors, and between doctors and doctors. The stereotypical and repetitive nature of how patients describe migraine has been acknowledged. It is through repetition that words and descriptions turn into the 'reality' of the 'diagnosis' by means of artificial criteria (see chapter 3). For a doctor, making a diagnosis of migraine is difficult, as it entirely depends on what patients say. Nevertheless, an unconditional belief in, and correct interpretation of their words are crucial for the diagnosis, treatment and prognosis.

In this book I have focused on the words of patients with pain and migraine and not on their readers. Of course, I had to mention the role of the reader

[41] Translated from Dutch into English by me (JH).

now and then, for example when mentioning the role of the doctor (in several chapters), that of 'phronesis' (chapter 1) and the role of the reader in interpreting descriptions of sickness in fiction (chapter 5). I have focused more on the construction of the 'patient as text' than on the specific function of the reader of those texts. Of course, both sides cannot exist without one another: there is no text without a reader and no reader without a text. Yet my emphasis lays on how migraine was *expressed*.

A consequence of this is an emphasis on the performative. This notion comes from so-called 'speech act theory' that, after starting out as a philosophy of language, traveled to other fields (Culler *Philosophy*; Butler). As may be clear, the speech act theory deals with the problem of how language acts. Instead of language referring to reality (called 'constative', see chapter 6), the performative implies that language has a shaping force. It shapes history and creates reality. Important for my book is how words and texts 'create' or 'produce' something and how they 'work'. The important point is that words do not only 'perform' when they are uttered by a real patient, but also when they are part of invented situations such as in fiction. So, in combining part I and II of this book, I hope to show hereafter that not only 'the relationship between the writer and the reader and the relationship between the patient and the doctor have much in common', as argued by Charon (*Doctor-Patient* 144), but that they are virtually the same when one realizes the importance of the performative qualities of the texts that are presented. Of course, there are the caveats not to interpret the patient as a text too uncritically (see chapter 1) or to read fictional texts as descriptions of the 'reality' of their author/patient (see chapter 7). Nevertheless, both types of text 'perform' and thereby create some sort of reality.

In chapter 1 I described that the central question of this book is defined by the interstice between medicine and literary studies: 'What is the relation between pain and language?' In chapter 2 I tried to justify my choice of migraine as a distinct topic to study this question in this interdisciplinary field, with as main arguments its unique paroxysmal nature and specific additional symptoms. Considering that there is indeed such a field, it is obvious for me that this also concerns the border between part I and II that connects the texts of 'real' and those of 'fictional' patients. What I have tried to show is that both have many common aspects. The performative power of words is the most important aspect.

My study led me to conclude that one must not see medicine and literary studies as two completely separated cultures, but as cultures that can work

together and strengthen one another. The emergence of so-called neuronovels in which cognitive science, neuroscience, psychopharmacology, philosophy and literature are combined is an example of such a strengthening bond (see chapter 5). My own daily practice is another. To further illustrate this, I have tried to make many cross-references between the 'medical' (I) and the 'literary' part (II) of this book.

As I have shown in chapter 4, pain (and migraine) can destroy, but also create. This creative power is part of both the medical and literary processes of how words describing migraine have a performative force; how they not only 'work' but can be of help. In what follows, I will first elaborate on this performative power, of which I gave an introduction in chapter 6. For now, my emphasis will be on 'iterability' and its role in migraine.

Iterability and the performative use of language

According to Butler (1997), humans are beings who require language in order to be; they are 'in some sense, linguistic beings' (1). For her, 'we do things with language, produce effects with language, but language is also the thing that we do' (8). In my opinion, she is right that words 'perform' and thereby create. Many utterances not only describe a given reality, but also change or even create the reality they are describing. An important question is whether this is also the case with words about migraine.

As already described in chapter 5, in his article "Philosophy and Literature: The Fortunes of the Performative" Culler calls the performative 'an utterance that accomplishes the act that it designates' (503). He does not only find questions about the constitutive force of language in general of great importance, but also that of literature as a performative act and mentions a simple test to determine whether an utterance is performative or not. The test is to put the word 'hereby' before the verb of a sentence in the sense of 'I hereby promise…' or 'I hereby order you...' and then consider its meaning and effect. Following Austin, Culler distinguishes locutionary acts (the act of the speaking of a sentence), illocutionary acts (the nature of the acts we perform by speaking the sentence – the 'hereby' mentioned above) and perlocutionary acts (the acts aimed at or accomplished by performing the illocutionary act; those that are performed as a consequence of the words). Translating this to literature (considered here in terms of fiction), one can say that 'the literary utterance, too, *creates* the state of affairs to which it refers' (506; emphasis in the original). It brings characters and their actions into being; one can call this the 'world-making' force of language.

Culler also pointed at Derrida's addition that the performative depends on its iterability and citationality (509). Words conform to an iterable model when they are identifiable as a kind of citation. In their repetition from one situation to the next the words get their meaning. Language is performative in the sense that it doesn't just transmit information but performs acts by its repetition of discursive practices or ways of doing things (Culler *Literary Theory* 99). Indeed, also for Butler the performative must be repeated in order to work (147). The performative then has two aspects. First, 'literary works claim to tell us about the world, but if they succeed they do so by bringing into being the characters and events they relate' (Culler *Philosophy* 510). Second, literature does not do this out of the blue. It depends on already existing words, descriptions and conventions, and contributes to a repeatable repertoire. In other words, literature creates through referring to a state that came before, that is, and will come after. Thus, it can be said that 'once a convention is set, and the performative participates in a conventional formula – and all the circumstances are appropriate – then the word becomes the deed' (Butler 146).

In this light, both word ('fictional migraine') and deed ('real migraine') depend on repetition to become events. For Butler, there is a 'discursive performativity' which she does not see as a 'discrete series of speech acts, but a ritual chain of resignifications whose origin and end remain unfixed and unfixable' (14). In her opinion, there is always also 'a deliberation that precedes that doing, and that the words will be distinct from the things that they do' (44). This is what she calls 'politics of the performative', a phrase that reflects the fact that words, whether or not deliberately chosen and depending on the effect wanted, have the power to organize worlds. A word does not only signify a thing, but also can enact it, and this can be 'politically' determined, whether unconsciously or rhetorically, with a certain goal in mind (see also chapter 3).

The theories of Austin, Derrida and Butler are specifically fruitful in relation to migraine which in both its 'real', 'fictional' and 'rhetorical' state depends heavily on repetition of words that are interpreted through a discourse. Or, as Culler has put it for such a discourse in general:

> a work succeeds, becomes an event, by a massive repetition that takes up norms and, possibly, changes things. If a novel happens, it does so because, in its singularity, it inspires a passion that gives life to these forms, its acts of reading and recollection, repeating its inflection of the conventions of the novel and, perhaps, effecting an alteration in the norms of the form through which readers go on to confront the world. (*Philosophy* 516-517)

This can indeed be also be held to be true for migraine, as not only words, but also their *repetition* in different circumstances defines this disease. Before I turn to this repetition, and the patterns it connotes, I need first to be more specific about the performative force of words of, or on, migraine.

The performative use of migraine language

Consider the utterance 'I hereby state that I have migraine'. Resulting from the unique paroxysmal (acute) and chronic nature of migraine there are two separate performative possibilities in this situation. Patients can refer to the chronic disease called 'migraine' according to the criteria (see chapter 3), or to the fact that they actually have an attack of migraine at the moment of the utterance. In chapter 2, I have described the situation of 'real' patients uttering to have 'migraine' at a moment of not having an attack. They can look into the sky for words to describe the remembrance of past pain. In such a performance, a new world has to be created with words on a new ontological level. This situation can be called theatrical in its need to re-stage what happened, and this is mainly caused by the rhetoric need of the patient to describe the suffering and anguish as accurate as possible to get recognition of the listener or reader (in this case: a doctor). In this situation, language is indeed used in a performative way. Although those patients are not having migraine at the moment of the utterance of their words, their words aim at recognition of the chronic (and paroxysmal) state they are in. Their words perform not their actual, but their general state. Indeed, 'a person who does not have headaches can *talk* of headaches' (Fiser 11; emphasis in the original). The behaviour of patients who actually are in an attack is completely different and can better be defined as dramatic. They do not 'look into the sky', but instead try to hide from their surroundings. It is also very likely that their words are changed, or maybe even destroyed, due to the state they are in (see chapter 4).

Similar rhetorical and performative situations in- and outside an attack can also be found in fictional texts. Of the novels analyzed in chapters 7 to 10, three are in the first tense, which seems to be an explicit icon for performative language. The fourth (*When Nietzsche Wept*) is in the third tense, but this text also has performative aspects, as I have argued and will show in more detail below. It appears that all four novels illustrate a different aspect of the performative in relation to migraine.

In Hustvedt's *The Blindfold* (chapter 7) the narrator (Iris) describes her migraine-attacks in the past tense. She relates from a distance how she was admitted to the hospital because of her migraine, as the pain was permanent

and sometimes brutal (91). Nevertheless, she felt guilty of not having a more serious disease, calling herself 'a migraineur', who is someone with a not very serious disease. The words of this narrative do not directly perform migraine in the sense of describing it from within an attack but refer to the status of being a 'migraineur'. About this word ('migraineur') it can be said that its 'power is understood on the model of the divine power of naming, where to utter is to create the effect uttered' (Butler 32). Calling oneself 'a migraineur' is such a form of naming which certainly can be seen as performative.

The Horned Man (chapter 7) is also in the past tense, but it ends in the present tense. The migraine-attacks are described from within, how they were experienced at the time they occurred. The past tense and the feeling of surprise and alarm caused by these attacks ('I hadn't experienced this phenomenon since I was twelve or thirteen'; 25-26) add to the feeling of estrangement and horror of this novel. The words that describe the attack 'perform' it for the reader. The words of the narrator are even performatively effective in terms of a diagnosis of migraine. The fact that the narrator of *The Horned Man* in one instance addresses a certain 'you' directly, forms a special aspect of this 'performative'. Speaking to a 'you' in or outside fiction is always more performative than descriptive. In the case of *The Horned Man*, the 'you' can be the (extradiegetic) reader or a fictional character within the diegesis. Whatever or whoever the 'reading subject' is, both options confirm the performative aspects of this text.

Unlike the novels mentioned so far, *When Nietzsche Wept* is narrated from a third-person perspective. Nevertheless, this text also has performative aspects. Migraine is not described from within, but from the outside through the focalization of the protagonist Joseph Breuer. The patient, Friedrich Nietzsche, describes to Breuer that he had monstrous, crippling headaches with nausea, vomiting, anorexia, disgust for food, and fevers (Yalom 55). Considered in terms of a constative, the question would be whether this was truly the case. Considered in terms of the performative it is the description that is fortuitous in that Breuer believes this to be the case and acts likewise. He reacts to the words of the patient (by trying a 'talking cure') and to his 'deeds' (in this case the attacks). Nietzsche's words and deeds perform by letting Breuer perform. This is performative language from one fictional character to another within the diegesis.

In conclusion, there is a pivotal performative quality in the depiction of migraine in the works of fiction selected. My next step will be to trace a repetitive, or recurring *pattern* in this performative quality. That is: I will

come to define a 'migraine self' (as announced in chapter 6). To define this notion of a self, I will try to combine aspects of the 'patient as text' and the 'text as patient', with 'patient' here specifically meaning 'patient with migraine'.

The migraine self

For Bourke, pain 'participates in the constitution of our sense of self' (*Story* 5) and in line with this Hustvedt argued that her pain determined the borders of her own self (see chapter 6). On the other hand, other scholars have argued that (chronic) pain has a debilitating effect on the patients' sense of self (Lavie-Ajayi et al., 193). In this dichotomy, I take as intermediate standpoint that the pain of migraine can destroy but also create (see chapter 4). As described in chapter 5, my final aim is to make a model for analyzing novels depicting migraine that can also be used for an analysis of real patients, and thereby come to the core symptoms of what I want to call a 'migraine self'. I aim to link this subjective sense of self to a perceived 'objective' reality, to which 'fiction' contributes next to 'reality'. The questions posed were how the subjectivity of authors or characters relates to their depiction of migraine, how migraine is constructed by the words used and whether this effectively leads to a 'migraine self'.

First, however, for a possible definition of the 'self' I will return to fiction:

> Your self, you say. There's a coincidence. I've been giving some thought lately to the mystery of the self. Some say it's an organic element or process embedded in neural structures. Others insist that it's an illusion, a by-product of our narrative tendencies. (McEwan *Machines* 70)

These words are 'spoken' by Adam, a synthetic human who is one of the main characters in Ian McEwan's novel *Machines Like Me (and People Like You)*. Although not science but fiction, I will us them because they implicitly refer to the 'two cultures' discussion (see chapter 5). Indeed, also the 'migraine self' must be a combination of language (narrative) and biological features. To come to an application of this definition, I will first analyze fiction (the novels of chapters 6-9) and then add themes from 'real cases' (as described in chapters 1-4).

The Blindfold (chapter 6) seems to provide several aspects that, taken together, would constitute a migraine self. First, there is the feeling of guilt. The novel clearly describes that there is not only the 'guilt' of having another attack (too much wine, chocolate, etc), or of having a disease that

has no high rank in the 'prestige hierarchy', but also includes the feeling of guilt caused by the fact that language becomes inadequate to describe the experience of pain. Second, there is the loss of vision caused by migraine. Although this is mainly due to the visual aura of the attack, it becomes a broader topic as the hole that occurs in an attack becomes a hole in reality. For this patient it causes 'a feeling that I was no longer a whole' (*Blindfold* 179). This feeling reflects the falling apart of the subject with migraine. The dichotomies that define the dynamic of this falling apart are the subject's being in and outside of an attack, head versus body, body versus mind, words about pain versus having pain, etc. Most important, however, is the inability to express one's pain in words, what I have called the signifier/signified problem. Hustvedt adds to this that patients and doctors often speak different languages. This causes a double barrier between the pain one feels and (medical) 'reality'. Next comes the stigma of having migraine and being a 'migraineur'. In this novel it takes the form of 'auto-stigmatization' which closes the circle as it produces a feeling of guilt on another level. In *The Blindfold* time is reversed and depicted as a circle. The sense of time of the narrator is disturbed. This reflects the disturbed sense of time of 'real' migraine patients. For migraine patients there may be two 'now's' (see chapter 5) and this further adds to their insecurity. In response, sometimes, only one thing remains to be done, as is expressed by Hustvedt in *The Shaking Woman*, who states: 'don't fight migraine anymore, but embrace it' (176), see also chapter 10.

The Horned Man (chapter 7) illustrates that a narrator with migraine should be believed unconditionally, despite an 'intrinsic' unreliability. Lawrence's words not only seem unreliable, but now and then even become incoherent, probably due to his migraine. In fact, his narrative is also a demonstration of a double artificiality: that of the (invented and sometimes incomprehensible) metaphors of migraine and of its (invented) discourse. Here the words of Riffaterre may come to mind: 'Words may lie yet still tell a truth if the rules are followed' (xiii). Lawrence may lie, but with respect to his migraine he is able to capture its true nature. By using the present tense now and then, his text is in a way reflecting the 'presentism' described in chapter 5. His narrative can in addition be seen as a strong longing for an externally visible sign as proof of his reliability and on a meta-level as proof for his 'migraine'. This need I consider to be part of the 'migraine self.' In that sense, *The Horned Man* can even be read as a call for the (urgent) need to develop a biological test for migraine.

When Nietzsche Wept (chapter 8) offers various other possible contributions to the migraine self. The novel emphasizes that ('eternally recurring')

migraine can be seen as unavoidable and meaningless suffering, but also that this can be turned around into the giving of benefit and even of pleasure. Important is that pain indeed seems to be able to be at the basis of forms of creation, as described in chapter 4. *When Nietzsche Wept* is based on 'true' philosophy and 'true' migraine, and its most important contribution is that it describes one of the philosophical ways of dealing with migraine, namely in terms of an 'amor fati'. This is also the choice made by the protagonist of *The Blindfold*.

On the basis of the aspects derived from these works of fiction and in the light of the considerable overlap with the aspects dealt with, a proposal for a 'migraine self' can be made. It consists of the following core characteristics.

The self of someone suffering from migraine can be defined by:

1.) a loss of subjectivity;
2.) a loss of words, of grammar, of language in general;
3.) a loss of perception, and by consequence of an independent sense of reality;
4.) a loss of stability in between attacks, as one is never sure when a new attack will materialize.

The words of migraine patients are as a Wittgensteinian beetle in a box, as they must be interpreted in a common but artificial language. Only through rules and criteria they become 'reality'. Ironically, it also appears that migraine patients lose their place in 'reality', due to their altered ways of perception – of light, sound, smell, touch and time. As a consequence, they can lose their sense of an individual center; there is no 'fixed' point anymore. It is important to realize that in migraine this happens in attacks, which is in contrast with patients who constantly have pain. The attacks lead to another aspect of the 'self', namely that there is no 'stable' state. One can never be sure of the future and there is always the fear of forthcoming pain, or so-called cephalagiaphobia. So, also the periods between the attacks are characterized by suffering and ontological doubt. Still, this may also lead to increased creativity and liveliness and even to *amor fati*. Seen as such, three separate forms of subjectivity may be distinguished in migraine:

1.) the subject of being in an attack;
2.) the subject being outside attacks;
3.) the subject having the 'chronic' condition of migraine which includes a possibly life long on-off situation.

I must emphasize here that migraine does not lead to a *loss* of self – on the contrary. It does, rather, determine and enhance the self's status. I gave an example from fiction illustrating the importance of headache (of a hangover) in chapter 6. In Ian McEwan's novel *Nutshell* headache is presented as being important for 'the beginning of the invention of the self'. Fiction is not fictitious here, but rather indicative of a more general state. Some examples of how migraine can lead to the notion of a 'real' self are given in chapter 4. There, the poems of Jane Cave Winscom demonstrated her narrative composition of a self 'who has overcome this enforced silence to speak about the experience of head pain'. By writing her poems she succeeded in 'the construction of a self who is able, somehow, to express the inexpressible'. Likewise, Roland Barthes appeared to need his bodily pain to be himself. He did not present migraine as something that destroys, but that produces a feeling of 'self'. Siri Hustvedt too was curiously attached to her migraine and wrote 'the headaches are me and rejecting them would mean expelling myself from myself' (*Shaking* 189). So, migraine is important for the 'self', and determines its status. And there is more.

The 'migraine self' can even be considered as a symptom of a historical condition, in terms of a postmodern ontological uncertainty. There are > 10% of subjects in Western society that suffer from such an altered ontological state. In migraine there are unique disease-related factors that determine the being of the self and the subjective world of its sufferers. More in general, it can be argued that migraine can be seen as symbolizing a state of affairs that has been defined as postmodern: a state, in which nothing is certain, in which language is both a last resort and an untrustworthy vehicle of representation, in which no-one can be certain of his- or her 'world' at any given time. As already hinted at, with migraine being unavoidable for its sufferers, the only productive way to deal with this might be 'amor fati'.

What if?

My attitude towards my own efforts throughout this study and in the conclusions of this book is ambivalent. On the one hand, as a medic, I hope that tomorrow a diagnostic test for migraine becomes available, and that the diagnosis will not depend on words and artificial criteria alone anymore. Next to that, I also hope that soon a causal and complete treatment for migraine will be developed. On the other hand, such a biological test would make more than 90% of the words of my book superfluous and result in an almost complete 'victory' of science over literary culture in this matter (see

chapter 6). Besides, an eradication of the disease migraine would definitively make my efforts not more than a nostalgic exercise and above all completely useless. More important, however, it would force > 10% of subjects in the Western society to redefine their subjectivity and even their 'self'. For, as I may have made clear, migraine is not just a disease that people suffer from but that defines their very being. They are defined by their migraine. As long as we do not enjoy the luxury of being able to fall back on diagnostic tests and certainty, we must rely on our skills in observation and communication and in this communication the words and metaphors of the patient are of central importance. The reading of patients as a text – and as this book suggested, the reading of texts as patients – is only possible by means of a literarily trained skill called *phronesis*. It involves the practical wisdom that makes the fortuitous interpretation of signifiers without signified possible, and that may even give some insight as to what kinds of beetles are living (or crawling) in other people's boxes.

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