Migraine as text – text as migraine: Diagnosis and literature

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Citation

Haan, J. (2020, May 13). *Migraine as text – text as migraine: Diagnosis and literature*. Retrieved from https://hdl.handle.net/1887/136966

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Title: Migraine as text – text as migraine: Diagnosis and literature
Issue date: 2020-05-13

Chapter 2

Migraine and words

> A headache is just a headache – simply a sensation, albeit an aversive one – until a human subject interprets it, reading it as a symptom, a bodily sign that means something is wrong inside
>
> Catherine Belling, 2010

> Headache patients were often dismissed by physicians once they were shown not to have organic disease (for example a brain tumor or meningitis); yet their head pain persisted
>
> Judy Z. Segal, 2007

After outlining in chapter 1 the medical and literary diagnostic aspects of pain, 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.[15] 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 [..]. Their anguish did not fit many of the neat conceptualizations of "real" pain, thus baffling, frustrating, and irritating caregivers. Their pain behavior was irksome because of the absence of any objective signs' (42).

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[15] 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).

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 called ‘analogical associations to the other’s experience’ (Kirmayer *Culture* 329), or be described as by Armstrong (1984): ‘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 either.

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.

> If illness is a kingdom, physicians, in general, see it as a relatively small one, admission requiring, for the most part, positive objective tests
>
> Judy Z. Segal, 2007

Headache and objective 'sign'

As said, most headache sufferers are at times convinced that they have a serious intracranial disease. As 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).[16] 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 and thus 'the human voice' (Scarry *Body* 6). Relying more on a scan than on words may be seen as bypassing the words and even 'to bypass the person in pain' (7).

Also, 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, it has been assumed that there is 'an analogy between reading a text and "reading" an instrument' (Heelan 189).

The consequence of this reading may also be described as: '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 so the Peircean theory as described in chapter 1. As explained there, Peirce's 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

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[16] 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.

‘delegated’ to the machine that makes the picture, or to the reader of that picture (mostly the radiologist). It has even been said that ‘technological capability in medicine becomes not just a better way to diagnose disease, it comes to define disease’ (Baron *Introduction* 607). For example, often only after obtaining a ‘normal’ scan do the 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’).

It has also been said that ‘technology extends the range of the eye’ (Kirmayer *Insistence* 326), and that ‘the epistemology of bio-medicine is based on the metaphor of vision, in which the eye takes in a replica of an objective world which the brain then represents or mirrors’ (326). According to James G. Brueggemann in his article “Poetry and Medicine” (1985) ‘the demands for accurate diagnostics and efficient treatments have engendered such attention to the technological aspect of the health care system that communication between patient and physician is impaired and a demand for “tests” is substituted’ (371). For him, physicians become technocrats and patients shoppers (371). It has even been said that for doctors reading 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’ (see chapter 1) 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. Said in other words: ‘the enframing of human beings through medical science and technology takes place when the embodied complaints of the patient are taken out of the life-world context of human dialogue and replaced by a medical-scientific analysis only’ (Svenaeus *Relevance* 6). Patients with pain and no abnormalities at examination or morphological alterations on a scan have a double problem as ‘the possibility that *their illness* will never be given the status of a disease where the cause and the treatment are already known adds to their physical complaints’[17] (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. 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 already overworked

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

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 puts 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.

> But there are diseases which resist being known through vigorous thrusts of strict scientific inquiry. These diseases resist (at least for now) belonging to the world of facts, substance, and empirical knowledge
>
> Carol A. Bowman, 1992

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 (see the Preface). 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’ (Epstein 31), 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 thesis (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).[18] 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[19]) (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).[20]

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).

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

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

[20] 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*).

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 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'[21], 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 chapter 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 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.[22] For the migraine aura separate criteria are used.[23] I will first place migraine in the context of other pain-syndromes, and thereafter describe why migraine is special.

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

[22] The terms photophobia, phonophobia and osmophobia respectively describe the tendency of patients to avoid light, sound and smell during an attack of migraine.

> Illness episodes, as stories of personal failures and successes, of social relationships, instruct; they provide models for and of reality. Such episodes, occurring through time and across individuals, become cultural texts
>
> Kathryn Vance Staiano (*Redefining*), 1982

> If we are to avoid undermining, belittling, or stigmatizing migraine and the people affected by it, then the words we choose matter
>
> Katherine Foxhall 2019

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 subject to the 'great deal of difficulty taking seriously any human suffering that 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). She continues that: 'in my earlier travels from one neurologist to another, migraine was never referred to as a *disease*' (16; emphasis in the original). Her conclusion is that 'diseases are ontologically more robust than just an illness' (16).[24] In line with this, since 2016 the 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).

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[23] An aura is defined as a functional bodily disturbance, mostly of vision, which lasts at least 5 minutes and not longer than one hour.

[24] For the 'robustness' of her migraine see chapter 7.

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 thesis (see chapters 3, 4 and 5).

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, perhaps it gives them the feeling of control and the illusion of being able to discuss their condition with their doctors as pears. As a result, this language can become completely dissociated from embodied experience. (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, but also then one must be cautious.

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'. 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. As Kirmayer puts it 'the suffering of pain is closely related to the apprehension, belief or conviction that it will persist indefinitely – an experience of duration that is partly given by pain itself' (*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 'but a small number of possible unrecorded, yet nevertheless remembered significations' (Kahn 85). All a doctor can use to diagnose migraine is 'remembered 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). In patients with chronic pain, '[…] the appearance of the sickness marks a radical redirection of the trajectory of the life story' (Brody *Stories* 2). In migraine, this happens over and over again. Importantly, for Brody, 'the story, for all its temporal uniqueness, is not a new thing but rather represents what has happened or supposedly happened sometimes in the past. This makes the story a sign' (31).

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 are potentially interminable. They 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.[25] 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*), which will be described in chapter 5.

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[25] 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).

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:

> 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', or as Scarry puts it:

> Melzack and Torgerson have not discovered new words but have instead uncovered a structure residing in the narrow, already-existing vocabulary, the vocabulary originated by the patients themselves. Thus necessary to the invention of this diagnostic tool [the McGill Questionnaire], was Melzack's assumption that the human voice, far from being untrustworthy, is capable of exposing even the most resistant aspect of material reality. (8)

The 'already-existing vocabulary' mentioned clearly refers to the words that are used to express pain. One can, in addition, with some fantasy, think of a second 'already-existing vocabulary', as, being genetically determined, the 'language' of the DNA also slumbers in the depth of the vocabulary of any migraine patient.

And then there is the 'vocabulary' of being pain-free between attacks. When explaining the occurrence of migraine 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 text 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.