**Migraine as text – text as migraine: Diagnosis and literature**
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# PART I

## The patient as text

# Chapter 1

## *Pain and Words*

> There is only one antidote to mental suffering, and that is physical pain
>
> Elaine Scarry, 1985

> What therefore is truth? A mobile army of metaphors, metonymies, anthropomor-phisms: in short a sum of human relations which became poetically and rhetorically intensified, meta- morphosed, adorned, and after long usage seem to a nation fixed, canonic and binding; truths are illusions of which one has forgotten that they are illusions
>
> Friedrich Nietzsche (cited by Neilson, 2015)

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, 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). The Dutch scholar Vrancken takes this notion of pain as beholden to the suffererer even further, arguing that in pain there is an 'absolute split between one's sense of one's own reality and the reality of other persons' (441). She is right. 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. Next to physical pain there is also mental pain, and it has been shown that 'the words which patients use to describe pains of psychological origin contain the notion of noxious input just as much as the words which patients use who have physical causes for their

pain' (Merskey *Taxonomy* 301). Mental and 'emotional' pain exist in a very broad spectrum, from pain associated with feelings of shame, guilt, fear, panic, loneliness and helplessness (together sometimes defined as 'psychache'), to the feeling of loss, being broken, or even being insulted (Tossani 2013). Mental pain is in the borderland of all of these types of pain. It may be said that pain 'can be either psychic or physical, but if physical, it has psychic effects and if psychic, it has a physical, palpable quality because it is so intense' (Hartman Landon 75). Although the concept of mental pain is intriguing, this will not be the subject of this thesis since I will focus on migraine as 'pain in the head', which in most of the cases is not mental, but physical.

> The metaphor of pain as a completely private and inner entity has no basis in reality
>
> Stephen Loftus, 2011

## *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). In other words, 'we usually feel that the world of our fellows is much the same as our own, in that we seem to act each in a fashion similar to everyone else; and we accept that language methods supply identical meanings to each participant in the exchange of verbal signals' (Gooddy *Disorders* 663).

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. As Bendelow and Williams (1995) put it: '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* of the world and other people' (162; my emphasis). So, pain has to do with individual experience, but also with intersubjective articulation. Without a doubt, pain is 'a private object', as Karen B. Fisher (1986) calls it. But, returning to Wittgenstein, 'a private language, and by extension a private experience, interior and unsharable, would be completely devoid of sense' (cited in Moscoso 5). Meaning is only produced by the collective credibility of private sensations. Subjective experience becomes more-or-less objective, not through mechanisms of objectivation, but through the appropriation of the patient's testimony. Meaning is anchored in a dramatic consideration of 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. As may be said: 'they view disease as an intrusive object rather than as part of themselves' (Cassell 143). This controversy of whether pain originates on the inside or outside goes back to Hippocrates. The 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 (143). In the latter situation, the noun 'pain' came on the same linguistic level as 'chair', 'thumb', or 'mouse'.

Bourke calls this 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. For this constitution of a self, see chapter 11. 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). It has been discovered that 'certain pain-related beliefs, like faith in the persistence of pain, seem to impact on coping and compliance, while regarding pain as mysterious and inexplicable is related to worse outcome, psychological distress, and somatization' (Condello et al., 136). 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

maybe is able to interpret the complaints and to acknowledge the presence of a recognizable pattern. For such a 'validation', there is the encounter of patient and doctor. Indeed, pain is the most frequent complaint doctors are confronted with.

> They walked into the office and are now sitting opposite you, well dressed and calmly spoken, with not a single abnormal finding after two years of investigation
>
> Charles Pither, 2002

> How we interpret another's pain, or any experience, is obviously hugely important and yet often we are not good at it
>
> Julian Cole, 2007

## *Patient and doctor*

The term 'doctor' will, in this thesis, 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 thesis, 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, and sufferers' access to proper management is considered a 'human right' (Cousins and Lynch 2011). That still leaves the question of 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).[3]

As Epstein (1992) summarizes, '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

[3] I will come back to the different meanings of 'symptom' and 'sign' in the section on semiotics.

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 a consequence, clearly 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'. David Biro (2010) goes one step further and describes how Nietzsche sees this as a misconception (125). Here, we are not engaged in science (uncovering truth), but in art and metaphor (creating truth). When experiencing pain, we often look for, and find, a presumed cause, whether we see the damage or not. Often, 'our metaphorical imagination reorders the temporal sequence' (126). For Nietzsche, in these cases, 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 almost always lead to wrong assumptions, and, unfortunately, also to wrong diagnoses and treatment.[4]

Here, the one who has to make a diagnosis and install treatment is important: the doctor. There is a large body of literature describing the possible variations 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 distinguishes three options: First, there is the variant of 'Activity-Passivity', in which the doctor 'does' something with/to the patient. The second model is that of 'guidance-cooperation', in which the patient places the physician in a position of power but is active as well. In the third model, that of '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.

The two realities of a patient are not easily captured in language, as next to 'symptom' and 'sign', another important distinction is that between 'illness' and 'disease'. As I will show, 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 *Stories of Sickness*, Howard Brody defines

[4] 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.

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, there may be 'disease without illness (e.g., hypertension), and illness without disease (e.g., hypochondria)' (Novack 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 and 'to make it mean something, we have to use our imagination and objectify the experiences through metaphor' (Biro 136).

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", stating that 'we tend to see illness as an objective entity that is located somewhere anatomically or that perturbs a defined physiologic process. In a profound sense, one may say that such an entity "is" the disease, thus taking illness from the universe of experience and moving it to a location in the physical world' (Baron *Introduction* 606). This strongly resembles the description of the 'ontological trap' as mentioned by Bourke (see 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 thesis.

The word diagnosis is derived from the Greek words dia (through, between) and gignoskein (to know) (Parrino and Mitchell). It is commonly thought that a 'right' diagnosis is essential for the estimation of the prognosis and a possible treatment. Surely, a correct diagnosis has many advantages, and may even act as therapy (Brody and Waters; Novack). 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.

It has been said that 'one of the primary functions of technical language is to keep non-professionals out' (Beer 88). Butler (1997) refers to this 'specialized language' and remarks that it is 'not only based on censorship, but also on a sedimentation and skewing of everyday linguistic language usage' (142). It may easily lead to 'a misconstruction of its own theoretical construction as a valid description of social reality' (145). For Foucault, 'it is no longer a question of giving that by which the disease can be recognized, but of restoring, at the level of words, a history that covers its total being' (*Birth* 95).

The 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.[5] Schott (2004) emphasizes that '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 be carefully weighted. This raises the question how words of pain may form a common reality of patient and doctor. Do patient and doctor speak the same language? Do they have a 'shared' reality? 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 here, and therefore will be further outlined. 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 described, because 'to describe pain solely in terms of intensity, however, is like specifying the visual world in terms of light flux only' (50). In this formulation, 'the word "pain" refers not to a specific sensation which can vary only in intensity, but to an endless variety of qualities that are categorized under a single linguistic label' (50-51). To specify the qualities of pain, 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

[5] 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).

> 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). The value of this specific application, however, has been doubted, for example by Nehemkis and Charter (1984), who emphasized the limits of the used pain descriptions as these ignore 'other mediating variables such as site, distribution, referral patterns and relieving factors' (254). Biro writes in his book *The Language of Pain* that 'the McGill Pain Questionnaire not only helps patients describe their pain but also substantiates the *reality* of their pain' (158; my emphasis).

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 questionnaire is still widely used, also expressed by more than 74.000 'hits' on Pubmed.[6]

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). The latter scale thus 'translates' the pain of the patient into a number and a visual image, rather than putting it into words. As such, the choice here is between giving pain a number (VAS) and expressing it in verbal metaphors, such as those of Melzack and Torgerson. The choice seems crucial in doctor-patient encounters, and also in the context of this thesis, in which I, for obvious reasons, choose the verbal ('metaphorical') version.

The migraine sufferer Siri Hustvedt (see chapter 7), 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', which literally means 'to know thoroughly'. Every diagnosis by definition is retrospective (it 'looks back' as it based on passed events). Here, the common reality of 'diagnosis' in perceptions of patient and doctor is crucial.

[6] Last accessed 24-3-2020

> Pain is to the alert physician what the compass is to the mariner. The magnetic needle is not the north pole, it is simply an indicator pointing invariably to the pole
>
> J. Alvin Jefferson, 1917

## *The diagnosis of pain with words*

As said, it is difficult to define 'pain' as such, 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. This brings me to the signifier 'pain' and to its signified.

According to the structuralist Ferdinand De Saussure (1857-1913) the meaning of words (which he specified in terms of 'signifiers' and 'signifieds') depends on their difference with the meaning of other words (eg. 'mouse', 'spouse' or 'house'). To him signifiers may be indirectly attached to 'real' objects in reality, but yet when thinking about a 'mouse', 'spouse' or 'house' these occur first of all as images or ideas in our head. These images or ideas, and by implication some entity 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'. In this way, the problem of mimesis – language as imitating or representing what it refers to – was put by De Saussure on a different footing (Meisel and Saussy xv). De Saussure 'reconceived the problem of reference as one of signification' (xv). So:

> By reconceiving reference as signification rather than as mimesis, Saussure and his disciples no longer allow for granted the assumptions that mimesis as a notion traditionally puts in place: the separation of word and thing, subject and object, self and world (xvi).

But now about the signifier 'pain'. Of this word, almost everyone has one's own 'image', idea or sensation (see above: the beetle in the box, but also the 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).

Linguistic meaning evolves by the distinction between signifieds and signifiers. 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.

> In their reciprocity, signifier and signified produce a world that is both wholly concrete and wholly conceptual at one and the same time. Indeed, the world itself – the real, external world – is a matrix of signification, real because it is symbolic and symbolic because it is real (xvii).

According to Scarry, 'the only state that is as anomalous as pain is the imagination' (162). For her, 'while pain is a state remarkable for being wholly without objects, the 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). This 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). He realizes that 'to speak about the thoughts of others, to try to say what they have said has, by tradition, been to analyze the signified' (xvii). Seen as such, pain, may be seen as a signifier without a signified. Signifier and signified assume a substantial autonomy and 'one may even exist without the other' (xvi). 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' (Sullivan 6). The common experience mentioned above may be called 'reality', or at least 'part of reality', or, in the words of Robert Kugelmann (*Symptom* 2003), 'pain cannot be understood only as private and incommunicable' (36). We all have a box and in all our boxes sits a beetle waiting for existential explanation.

> Interaction with the physician may be successful if the pain has been placed in a context which makes sense to the sufferer
>
> Mariet A. E. Vrancken, 1989

## *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, or, as Pither puts it: 'We have to take the representation as we find it; we can no longer disbelieve' (571). In addition, as the migraine-sufferer Hustvedt expresses: 'although some empathy in one's doctor is certainly desirable, an ethical position requires respect, above all, the simple recognition that the patient in front of you has an inner life as full and complex as you' (*Philosophy* 73).

Stenner and Eccleston (1994) emphasize the importance of language in the broader context of 'being', which may be translated as its importance in 'reality'. They argue that 'being gains and maintains its "reality" only and always within a complex and ongoing of meaningful practices' (91). For them, 'textuality, in affirming both the material substance of language and the textual substance of material, is presented as both a defining feature of being, and as a way of addressing Being' (85). To translate their way of addressing being to 'pain', 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, where a text is anything that may be 'read', or according to Harvey Brown:

> The idea of "text" is no longer restricted to a written representation. Any statement of experience or (more strongly) any lived or imagined experience is a discursive practice that is both culturally embedded and historically situated. A text might be a mathematical symbol or an archival record, a novel or a myth, a ritual or a public program. Indeed, culture itself is seen as an ensemble of "texts". Correspondingly, meaning does not reside autonomously within a text but is created in the process of transforming experience into text in dialogical relation with other texts and contexts. Thus, a text becomes an intertextual network. (190-191).[7]

In narratology, a text is 'a finite, structured whole of signs' and in any text a first and last word is to be identified (Bal 5). The word 'text' originates from the Latin 'textum', which has a reference to weaving. This 'weaving' of meaning uses words, but also all other signs that may transmit a message, such as a painting, a street sign, grimaces, clothes, etc. This production of meaning will be outlined below, but of course with a focus on the words used to describe pain.

When a patient experiences pain, there are often symptoms but no signs (more on these two concepts later, see note 3). Nevertheless, if possible, 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), and considered to represent 'an inescapable circularity between the order of the body and the body of the text' (Kirmayer *Insistence* 324). According to Epstein (1992) the patient is '*clinicalized* in medical language' (31; emphasis in the original). The patient's own words must be transcribed into a diagnosis, and 'this narration *as narration* embraces the heart of medical practice' (32; emphasis in the original). It is about how 'the body can be written up into language' (33). In translating the patient's experience into a clinical text, a differential diagnosis is made. A critical

[7] 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).

moment, however, appears when one tries 'to detach the told to the telling' (34). Nietzsche's pin – pain metaphor lays around the corner here.

Stephen L. Daniel (1986) further elaborates the patient-text association, by stating that:

> 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 explores the question 'on what basis can we compare a patient to a text in literature?' (195), emphasizing that medicine is an interpretive art (as a form of 'hermeneutics', see later in this chapter). In his view, consequently, 'the body has become a grammar of signs in a language any observant physician could read clearly and completely' (198). He concludes that the first step is the literal sense, by taking an objective distance and seeing the patient as an 'object of observation' (203). The second step is the 'effort to find meaning for the clusters of literal signs and symbols' (204). Here, the process of 'differential diagnosis' is important, 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, with empathy defined as 'a vicarious, spontaneous sharing of affect, provoked by witnessing another's emotional state, by hearing about another's condition, or even by reading' (Keen 208).

The idea of 'reading' (the pain of) patients as a text has been adopted by other scholars, such as Leder (1990), who states that he 'will regard as a text any set of elements which constitutes a whole and takes on meaning through interpretation' (*Interpretation* 11), and Berger (1987) who starts his article "Bodies and Texts" with the explanation that he sees 'text' not as a thing, but as a function – '*text* is the value we give to whatever we treat as an object of interpretation' (150; emphasis in the original). He distinguishes '*the order of the body* and *the order of texts'* (147; emphasis in the original), but in the end realizes that both are logocentric. He also emphasizes that 'any text will always mean more and other than any reader can make it mean' (150). In his opinion, 'reading is a kind of writing, so writing is a kind of reading. But if writing does to the world what writing does to a text, if writers address and respond to the world as readers to a texts, then isn't the world a kind of text?' (150). Here, he emphasizes that 'text' is a very broad concept. Then he turns to the literary critic Fredric Jameson who:

> describes textuality as "a methodological hypothesis whereby the objects of study in the human [and biological] sciences [..] are considered to constitute so many texts which we [..] *interpret*, as distinguished from the older views of those objects as realities or existents or substances which we in one way or another attempt to *know*." (151; emphasis in the original)

As such, the reader of the text (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'. The text of the patient may therefore rather be seen as a 'citational text' (155).

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 section "The Interpretive Maze: Reading Doctors Reading Patients", King and Stanford state that:

> meaning emerges, not by a reader's correct discovery of the truth inherent in a written or spoken text, but by the interaction between reader (or auditor) and text (or speaker). Considering the doctor-patient encounter in terms of the reader-text encounter provides insight into the problem of obtaining and interpreting information. Using as our model what rhetoricians call *the communication triangle* (with author, subject, and reader occupying the interior of the triangle), we can position patients as authors, the story they tell as the subject, and the physician as reader. (191; emphasis in the original)

Wim Dekkers accepts the metaphor of 'the patient as text', but only under one condition, that it should also include the metaphor 'the body as a text' (280). He argues that also the body itself 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, but points at important issues, concentrated in the questions 'What is the text to be interpreted? What kind of text is it? Who is the author and who the reader?' (281). George S. Rousseau (1986) finds 'the patient as text' a cliché, but sees the option as 'an end in itself, as crucial as suffering and pain' (176), as long as it is realized that 'there are senses in which the patient clearly is *not* the text' (177; emphasis in the original). As examples of such senses, he mentions empathy and compassion, which a doctor needs to 'envision an imagined world' (160). 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 'patient as text' as one of four possible 'texts'. The other three are the illness itself, in the text of which the patient is one character (137); the pathography, in which patients record and interpret

their own illness; and the text with 'joint authorship' in which 'doctor and patient co-author the story' (138). The latter resembles the current practice of 'shared decision making', mentioned earlier. In the variant of 'patient as text', the patient is seen as 'the bearer of the story, and the physician uses an armamentarium of interpretive tools from invasive procedures to hermeneutics to decipher the patient-text' (138).

There are, however, also some scholars who warn against the tendency of too easily accepting the metaphor of reading patients as text. As Rimmon-Kenan (2006) argues, '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. At the same time, this language is completely dissociated from embodied experience' (246). In other words: 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. Now, 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', as we are 'always already embodied', and 'it implies erroneously a previous state in which we had no body or sense of bodily experience' (Friedman *Oral* 290). In psychology, 'embodiment' is studied in several sub-domains, such as language comprehension, autobiographical memory, gestures, facial mimicry and problem solving (Dijkstra and Post 2015). In philosophy, 'embodiment refers to the body's direct and immediate involvement in the social construction of meanings, collectively and individually' (Willig 558). An alternative term for 'embodiment' is 'lived body', in which the 'relationship with our body oscillates between *being* and *having*' (Vrancken 441; emphasis in the original). In the 'lived body', the body is a subject, as may be said: 'I am my body'.

Becoming a subject, however, is not possible without language (441). In phenomenology, a 'body' becomes 'embodiment' as the physical body, and especially its 'split between subject-object has to be deemphasized' (Baron 608). In linguistics, a common definition is to speak of 'being embodied, meaning that mind and body are inextricably linked and on equal planes' (Biro 44). A Cartesian split between mind and body is thus rejected. Rather, embodiment is seen 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, expressed by Nick J. Fox as:

> The anatomical body is not the carapace of the self. The lived physical body and the self which 'experiences' itself as being 'inside' the body are both consequences of reflexive, normative ways of thinking (territoralizations) about embodiment and individuality. The 'self-inside-the-body' is the body without organs. (*Refracting* 352)

The use of the word 'carapace' or 'shell' emphasizes that the distinction between body (shell) and mind (self) must be abandoned. The shell cannot be seen apart from the mind.

In her article "Reading Patients – Cautions and Concerns" (1994), Anne Hudson Jones mentions the fact that 'in medical settings, patients' stories quickly become doctors' stories' (192). For her, the 'reading' of a patient by a doctor harbors the danger of a paternalistic distance (193). This is especially true for 'monologic' and less so for 'dialogic' reading, the latter of which she finds more desirable. For her argument, she quotes King and Stanford's article "Patient Stories, Doctor Stories,

and True Stories: A Cautionary Reading" (1992), in which these authors refer to Mikhail Bakthin's literary theories about monologic and dialogic reading. Bakhtin was a Russian philosopher and literary theorist who criticized De Saussure and the formalists (Eagleton 101). Instead of 'objective' linguistics, he shifted to 'the concrete utterances of individuals in particular social contexts' (101). He saw language as 'dialogic'. The meaning of a sign could change, depending on context and social relationships. He introduced the concepts of 'heteroglossia' (remarks about a text from which becomes clear in what context a reader has read the text) and polyphonia (the different 'voices' that constitute a given text). The concepts of heteroglossia and polyphonia may also be applied to medical texts and the patient-doctor encounter in particular.

In their article "Hearing the Patient's 'Voice': Towards a Social Poetics in Diagnostic Interviews" (1996), for example, Arlene M. Katz and John Shotter apply Bakhtin's theories to the patient-doctor dialogue. They emphasize that 'it is Bakhtin's introduction of living, responsive, dialogic relations between different "voices" into the movement and structuring of our utterances as they unfold that opens up a vast new realm of phenomena for study' (927).

As possible safeguards against paternalistic misreading, Hudson Jones (1994) mentions the acknowledgement of 'the patient's interpretive role' and 'that the purpose of the doctor-patient relationship reaches beyond the scope of the reader-subject-author analogy' (194). It is important to seek a dialogical reading, as well as 'to learn about the patient as a person rather than as a text' (197). King and Stanford indeed caution against 'paternalism in a modern dress' (186) and 'over-reading' and 'one-sided reading' (189). They stress the 'collaborative nature of interpretation' and propose to call the doctor-patient encounter 'a heteroglot text in itself' (191). In their conclusion, 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 an interpretive model that 'allows for the incorporation of the patient's personal reading of his own body and condition' (214). The patient is not merely or always a text, but 'thinking of the patient as text may be salutary, for "text" implies richness and complexity, layers of possible meaning, and a wholeness which is greater than the sum of the parts' (214). Baron in his short article "Medical Hermeneutics: Where is the "Text" we are Interpreting?" (*Hermeneutics* 1990) also emphasizes the fact that the texts of patients are not fixed things. 'Patients are *not* static things in the way that the Folio Edition of Shakespeare is' (27; emphasis in the original). He warns for making the patient a 'source document' and rather starts from the assumption that 'there is no text to be found' (28). This idea is also expressed by Shapiro (2011), who emphasizes that 'patients' stories can change in both content and emphasis from one telling to the next' (68). The texts of patients must not be seen as 'objective truth', and not lead to 'narrative fundamentalism'. Illness narratives are 'constructed' and 'most people are chronically self-deceiving beings whose self-presentations lack transparency and honesty' (68). I do not agree with her 'self-deceiving' and 'lack of honesty', but a lack of transparency is indeed often the case, and this is not only true for patients, but also for 'readers' (doctors).

Despite the notion of dialogue connoting an equal position, the doctor-patient relation obviously is not equal. Patrick Heelan frequently puts the word 'text' in parenthesis, for example in 'what a measurement process provides is a "text" [..]; this is an artifact, like a text, that a trained scientist can read' (188). He argues that not only the 'text', but also the 'reading' is of importance. 'The "reading" of an instrumental response as a 'text' shares in the information theoretic aspect of linguistic texts'

(193). Indeed, paradigms and rules determine the ‘text’ and the ‘reading’. In line with Heelan’s thoughts, Kirmayer (1992) states that:

> any attempt to give autonomy to the study of either body or text, divorced from the other order of experience, is epistemologically naïve. How can we say the body is “so and so,” when that knowledge is worked out through language that imposes its own structure on experience and thought? On the other hand, how can we claim to encompass all possible worlds of meaning in the permutations of language when bodily pain and suffering up-end our orderly lives and drive us to the most desperate gestures of faith? (324)

He obviously 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 the context of migraine (chapter 4).

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 diversity of social speech in a novel’ (32) and 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 (a topic which will be referred to in Part II of this thesis).

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 – for example – is emphasized in the words of Kathryn Montgomery Hunter (*Making* 1988), that ‘there is always a distance between author and narrator, narrator and characters, the readers and the read’, 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 – for example – 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 ‘it is precisely because it takes no object that it, more than any other phenomenon, resists objectification (in language)’ (5; my addition between parentheses). Morris quotes the novelist (and doctor) Richard Selzer, who argued that ‘the doctor runs through the standard

questions and then translates the patient's halting response into the clinical vocabulary of medicine. But 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.

> It is as if physicians and patients have come to inhabit different universes
>
> Richard J. Baron, *Introduction* 1985

## *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). In other words, 'what the words represent, though, may be highly divergent for the speaker and the listener' (Charon *Novelization* 35). The doctor who 'takes' a clinical history may be compared with a 'historian' (Riese 437), and this encounter may lead, as Rimoldi states in his article "Diagnosing the Diagnostic Process", to the conclusion that 'the diagnostic process may be interpreted as a problem-solving situation in which doctors become active searchers and selectors of information which, they hope, 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 as 'men always mean something other than what they say and do, and they always say and do something other than what they mean' (White 24). Thus, the medical 'history' – also that of patients with pain – may be considered unreliable, as the patients have to describe (their pain) 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, as described by Leder (1984):

> In the physical examination the patient experiences her/his body as a scientific object beneath the dispassionate gaze and the probing, palpating fingers of the doctor. For Sartre, (disregarding the possibilities of objectification inherent in the individual's lived-body) it is the look of the Other which primarily turns the conscious "for itself" body into the thingliness of the "in-itself". (*Medicine* 33)

Toombs (1987) says of this situation that the patient 'perceives himself to be an object of investigation, rather than a suffering subject. He is acutely aware of the disparity between his experiencing as a subject and his being observed as an object' (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'). It may be described as 'a mysterious totem of authority [..] and ritual incantations and rites' (McCullough 123). Or, as William Gooddy describes it:

> 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 adds that 'the clinic was probably the first attempt to order a science on the exercise and decisions of the gaze' (89). The gaze is used 'to see, to isolate features, to recognize those that are identical and those that are different, to regroup them, to classify them by species or families' (89).

In the chapter "Seeing and Knowing", Foucault further reflects on the importance of the 'clinical' gaze. The gaze 'refrains from intervening', is 'silent and gestureless', it is 'bound up with a certain silence that enables him [the clinician] to listen', 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'. Foucault distinguishes a hearing gaze and a speaking gaze, between which a balance must be sought. In the end, 'disease, like the word, is deprived of being, but, like the word, it is endowed with a configuration' (119). Thus, Foucault 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. But, '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', which is 'the 'verbal representation of visual representation' (Mitchell 152). On the one hand, 'words can "cite", but never "sight"' (152), on the other hand writers can 'make us see' (152). For Mitchell ekphrasis 'begins to seem paradigmatic of a fundamental tendency in all linguistic expression' (153), and he argues that:

> the moral here is that, from the *semantic* point of view, from the standpoint of referring, expressing intentions and producing effects in a viewer/listener, there is no essential difference between texts and images and thus no gap between the media to be overcome by any special ekphrastic strategies. Language can stand in for depiction and depiction can stand in for language because communicative, expressive acts, narration, argument, description, exposition, and other so-called "speech acts" are not medium-specific, are not "proper" to some medium or other. (160; emphasis in the original)

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. As may be said, 'the text can function in the absence of the image' (Shapiro 2007; 17). Deborah Padfield elaborates this further 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 someone else's mind' (242). One of the dangers of language – she argues – is 'that participants 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. She proposes a 'generic iconography for pain' based on Barthes' denotation (description) and connotation (imposing a second or inferred meaning).

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 relationship carries a 'power disparity between the parties' (82), which is difficult to overcome as no patient would favor 'the help of relatively powerless physicians' (82). Pither (2002) calls it an 'unequal struggle' (570), and according to Mintz (1992), medical language frequently creates a distance between doctors and patients, enhanced by special forms and metaphors. Medical language about a patient 'paints a picture which is a mere phantasm of the person described' (225). 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'. The main reason for the separation is that doctors define the problem in

terms of physiological disease and the patients through illness experiences. 'Rather than representing a shared "reality", illness represents in effect 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:

> Embedded is such discursive features as turn-taking, interrupting, asking questions with the "right" answers implied by them, or speaking in technical jargon, doctors were systematically usurping authority, withholding critical information and thereby deceiving patients about their medical conditions, ignoring what patients brought to the conversations, and controlling 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.

> Hence, what are fundamental characteristics of literature, the use of poetic devices and fiction, are also present in persuasive speech, i.e., speech whose purpose is to making the speaker's points of view accepted by the audience by working on its feelings as well as on its reasoning powers
>
> Jørgen Dines Johansen, 2010

> The telling of events may be just as artful in non-fiction as in fiction – I do not privilege the 'truth' of one genre over another – but it matters to me that the non-fiction work is signed as the author's own experience, while in fiction what may be even truer to the author's personal observation is nevertheless held at a distance, recreated in the life of a 'character'
>
> Arthur W. Frank, *Illness* 1997

## *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. Or, as Rousseau (1986) puts it:

> doctors *must* imagine a fictive world, in addition to a real one, if they are to perform their work. Novelists imagine characters they will invent by empathizing with them; the resulting degree of verisimilitude depends upon this psychological leap more than on stylistic bravura or technical craft. (160; emphasis in the original)[8]

He also asks the question: '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; emphasis in the original). 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 thesis (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 him or her [the reader], there would be no literary text at all' (64). Within reception theory, reading is more important than writing. According to Jean Paul Sartre, 'a work's reception is never just an "external" fact about it', and 'every literary text is built out of a sense of its potential audience, includes an image of whom it is written *for*' (cited in Eagleton 72; emphasis in the original). There is an 'implied reader', and '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'. The latter aspect will be a prominent part of the analyses of novels in Part II of this thesis.

Indeed, Sharf (1990) uses the term 'interpersonal rhetoric' for the contributions of doctor and patient to the clinical encounter, as 'both participants possess essential and complementary forms of information, the doctor being knowledgeable about diagnosis and therapeutics and the patient being

[8] Verisimilitude means similar to the truth. The term means being believable, or having the appearance of being true.

knowledgeable about the self' (219). She uses the word 'rhetoric' as both parties in the encounter possess 'intentionality', although their different priorities run the risk to result in 'distinct, concurrent, and conflicting story lines' (227).

In her article "Illness as Argumentation: A Prolegomenon to the Rhetorical Study of Contestable Complaints", Judy Z. Segal gives an introduction to the 'rhetoric' of the 'exchange of arguments' (229) 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). Indeed, it has been argued that 'even in Aristotle's day, the term "rhetoric" had acquired unsavory connotations, and Aristotle himself castigates popular treatises on the subject for focusing entirely on how to avoid addressing "the facts" of a case' (London 291). Anyhow, where diagnostic doubt exists, it should not come to rest on the shoulders of the patients. Important is that 'the parties to practical deliberation must make an effort to present reasons to one another in a way that is accessible and enhances their understanding of the issue at hand' (291). What Aristotle calls an 'argument from past facts' is that a patient who expresses pain should be believed (Segal 237). Indeed, when patients with pain end up feeling disbelieved, 'they soon start to doubt the doctor and end up doubting themselves' (Pither 570).

According to the philosopher Hans-Georg Gadamer (1979), 'Aristotle offers us a better understanding of human life than can modern science' (77). He has this opinion as in his view Aristotle 'tried to describe what happens in human life' (79). For Gadamer, Aristotle took distance from a too much 'technical' reading of words, as 'this inner tendency of our reason towards theorizing in surpassing our practical situations of action is deeply rooted in our capacity to distantiate everything linguistically' (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'. As expressed by Moscoso (2012) 'as concerns its dramatic nature, 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.[9] 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. Poetry 'tends to express the universal' (Aristotle, cited in Davis and Finke 67), and 'what is possible is credible' (67). Here, we are dealing with 'how language works', what it does to the reader, but without any influence of the reader on the 'work'. In Aristotle' theory,

[9] 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.

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). They incorporate several aspects of philosophy by ‘conveying the discursive aspects through the arguments, and presenting the existential aspect through the characters, their actions and interactions’ (36). 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). Neither, however, teach what to craft (221). For Aristotle, ‘the legitimate use of reason is not limited to this pure realm of unchanging principles, but functions as well within the arena of the concrete reality of the world as we find it’ (Gatens-Robinson 173-174). *Phronesis*, on the other hand, is the opposite of acting on technology and universal laws (scripts and protocols). Erich Frank (1940) explains it as the situation in which:

> the phases of knowing [..] are “rubbed” against one another and refuted by arguments friendly to the opponent, through the use of question and answer, free from jealousy, then *phronesis* [..] flairs up in the soul about every subject for him who makes as much effort as is humanely possible’. (40; emphasis in the original)

*Phronesis* depends on experience and is also called 'practical wisdom', or 'the habit of practical reasoning' (Gadamer 81). It is 'just the application of more or less vague ideals of virtues and attitudes to the concrete demands of the situation' (82). It is 'an ability to apply general or universal knowledge to particular situations' (Gatens-Robinson 174) and has a strong association with empathy (Svenaeus 2014). According to Gadamer, 'with respect to the practical philosophy of Aristotle, it is important to underline one of the qualities of theory, namely, that a certain distantiation is helpful for overcoming a too one-sided commitment of the individual subject' (Gadamer 83-84). As patients are often approached as a 'puzzle' (Gatens-Robinson 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) critically discussed the option of reading the patient as a text in light of Gadamer's hermeneutics (which was influenced by Aristotle, as shown above). He emphasizes that the meeting of patient and doctor must be a dialogue, and that Gadamer's hermeneutic is 'not a methodology of text reading, but an ontological, phenomenological hermeneutics in which understanding is a necessary feature of the being-together of human beings in the world' (171). As the clinical encounter is characterized by an 'asymmetrical estrangement', the goal must be that 'the fixation in writing [of the patient] makes it possible for the text, not only to reveal a hidden world (the world of the author), but also to open up new worlds in the encounter with its reader [the doctor]' (176). The meeting must lead to 'a shared language in the sense that both parties understand what the other is saying' (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. This 'merging' or 'fusing' of horizons, however, is 'not synonymous with reaching the *same* understanding of that of the person who wrote it' (180; emphasis in the original). Both parties will understand the 'document' (or 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 also 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. For him:

> clinical reasoning can involve much of what Aristotle termed “cleverness,” but enlightened *phronetic* insight is not a built-in feature of acquired medical acumen. The moral sensitivity of conscientious physicians is one means by which bioethical issues are recognized’. (148; emphasis in the original)

So, 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’, in which the end cannot be other than the act itself (Widdershoven-Heerding 182). Consequently, excellent 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, ‘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 ‘medical skill is, for Aristotle, in a sense a *techne* that is very similar to *phronesis*’ (411; emphasis in the original). He then goes one step further, referring to the point that Gadamer has also made in arguing that ‘medical practice [..] never “makes” anything in the sense of a *techne*, but rather helps to *re-establish* a healthy balance which has been lost. Medical practice therefore is closer to *phronesis* than to *techne*’ (420-421; emphasis in the original).

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?

> A traditional view holds that language functions as a kind of mirror of reality. In this view, the proper function of language is to refer to some external reality. It is becoming increasingly apparent, however, that language is, at best, a very distorting mirror
>
> David Mintz, 1992

## *Epistemology, hermeneutics and semiotics*

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 thesis. 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 is Pain?", practically immediately thereafter answering '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). The expressions in the latter category 'make use of expressions in the symbolic field and in the deictic field'[10] (183), and 'are closest to the traditional categories of linguistic analysis'. Ehlich turns to Wittgenstein's assumption that 'all language use is to be seen as an instance of making *assertions*' (185; emphasis in the original), but in the end concludes that 'the vagueness or even absence of words hinder a clear verbalization; the underdevelopment of the semantic field of expression for pain forces [..] to speak with unclear metaphors' (185).

As said, it is mainly the task of the doctor to bring the two realities of the world of the patient and that of him- or herself as close to one another as possible to come to a diagnosis. In doing so, the doctor (mostly unknowingly) uses overlapping analytic literary approaches, such as 'epistemology', 'hermeneutics' and 'semiotics'. Here, I will summarize the value of these different approaches in the context of pain.

*Epistemology*

The word 'epistemology' is derived from the Greek words 'epistēmē' (knowledge) and 'logos' (speech or word). This analytical method focuses on knowledge, based on propositions which express a fact or a state of affairs. It also tries to determine the criteria for what may be known and what cannot be known. In a medical context, epistemology denotes codified knowledge of a disease or illness. According to Epstein (1992), 'clinical diagnosis, in fact, contains a narrative epistemology in its effort to encapsulate particular kinds of knowledge about the body' (32). For her, the task of the doctor (who she calls 'physician-historian') is to 'synthesize meaning from an assemblage of these serial moments' (33) and to translate the patient's experience into a clinical text. She argues that as soon as the told is detached from the telling, new epistemological questions are opened (34). An important issue for her is that one may question whether the disease does derive from the life of an individual, or whether the individual life is constructed by disease (35). In other words, does a diagnosis see 'through' a given situation or does it shape part of reality? Seen as such, epistemology is not only a 'pure' observation of facts, but also touches on ontological issues. In this interpretation, a diagnosis is more than only a literary association or representation, but also contains traces of the reality of patients with pain, whatever that reality may be, or how that may be expressed or defined. The problem is that 'acts of interpretation – literary, cultural, or diagnostic – always raise distinctions

[10] Deictic refers to words that can only be understood in their context. Examples are: 'me', or 'here'.

between description and explanation' (37). Anyhow, a patient – doctor encounter is clearly primarily an epistemological one, in the sense of acquiring (one-sided) knowledge.

*Hermeneutics*

The term 'hermeneutics' is an eponym of the Greek god Hermes, son of Zeus and Maia, and brother of Apollo. He is the messenger god, associated with saying, explaining and translating, which may be summarized as 'to interpret' (Bowman 271). Hermeneutics mainly refer to the interpretation of texts. So, simply said, epistemology is translation and hermeneutics interpretation. Hermeneutics is a practice with a long history. At first, it referred to the (allegorical) explanation of biblical texts. Then – in the romantic period – Friedrich Schleiermacher made hermeneutics independent of dogmatic certainty and emphasized the value of language in history. Subsequently, Wilhelm Dilthey pointed at the relativeness of interpretation, and placed the psychology of the author of a text in the center of interpretation. Subsequent theories, however, in their turn placed the autonomy of the text in the center. In a reaction to Dilthey's theory, Martin Heidegger, for example, introduced the concept of 'Vorverständnis'.[11] Before the interpretation of a given text, the reader has an opinion of the themes of the text, based on already perceived knowledge or experience. Understanding of a text then uses the incorporation of Vorverständnis. Gadamer accepted the concept of Vorverständnis, but emphasized that not only the interpreter, but also the text that was going to be interpreted had a history (Gadamer and Risser 83). In his view, the reader starts a dialogue with the text and after a so called 'hermeneutical circle' (reading and re-reading again and again) an interpretation evolves. His ideas may be easily applied to medicine.

Dekkers (1998) explains the difference between hermeneutic analysis and simple interpretation (epistemology) as follows: 'If an interpretation proceeds without difficulty – either in daily life or in the clinical encounter – the act of interpretation is usually not called a hermeneutical act. But if the meaning of a literary text, a piece of music, or a work of art is not obvious, a hermeneutical act is indicated' (278). He also explains that 'in phenomenology, one focuses primarily on what one can "immediately see"', whereas 'in hermeneutics, on the other hand, it is explicitly recognized that every meaning is the result of an interpretation process, of a textual reading' (279). Hermeneutics, to summarize, includes an interpretation which depends on 1) the information obtained, and 2) the skills of the interpreter. This mechanism resembles that of interpreting the patient as text, and that of Aristotelean *phronesis*.

Heelan writes in his article "Natural Science as a Hermeneutic of Instrumentation" that 'a person who is trying to understand a text is always performing an act of projecting' (183). For him, the essential point of hermeneutics is to find a deeper meaning that implies or embodies truth. Going one step further, he states that 'all knowledge is *in some way* a reading of some text or text-like material' (184; emphasis in the original). He refers to Heidegger's terms 'Vorhabe, Vorsicht, Vorgriff', which are all part of Vorverständnis. Based on Heidegger's philosophy he concludes that 'in the case of perception, it is through a text-like sign or "text" that one "has" or "holds" the object in anticipation of recognizing or naming it as something in one's World' (185). In other words, when hearing the

[11] 'Vorverständnis' is variously translated as 'preliminary understanding', 'fore-knowledge', 'preconception', 'fore-conception', or 'pre-understanding'. Here, the original German word will be used. In a negative sense, it can also be seen as 'bias', when the Vorverständnis is used to in- or exclude, or remain attached to a pre-conceived idea.

words of someone with pain, or reading about pain, one has a 'pre-notion' (or bias): a set of conditions antecedent to and necessary for interpretative meaning. Think of the pain of a hit of the hammer on your thumb. The 'known' pain serves as an understanding of the pain of others, conform the beetle in the box. Interpretative understanding is based on a double relation to reality, that of oneself and that of another, or that of 'embodied subjects' expressed in real bodies and in real texts.

The French philosopher Paul Ricoeur – whose thoughts are for the purpose of the present analysis of the utmost importance – considered a text not as a closed universe of signs, but as having a connection to reality, the so-called 'référence'. He proposes the following working definition of hermeneutics: 'Hermeneutics is the theory of the operation of understanding in its relation to the interpretation of texts' (Ricoeur *Task* 112). He proposes to see 'the text as a projection of a world' (Ricoeur *Function* 130), but 'the world of the text of which we are speaking is not therefore the world of everyday language. In this sense it constitutes a new kind of distanciation which we call a distanciation of the real from itself. It is this distanciation that fiction introduces into our apprehension of reality' (141). He argues that a story, fairy tale or poem do *not* lack a referent. They open up new possibilities of being-in-the world within everyday reality. In short, fictional texts may also have an association with reality. The same may be said for 'diagnostic texts', for example on headache, which obviously have a content that may be compared with 'fiction' (subjective symptoms without objective signs), but also with 'reality' (we all know that pain can be real).

So, as emphasized by Ricoeur, literature has a relation to reality, which seems an obvious conclusion. This 'reality' may be used for the status of 'the patient as text', but also for 'the text as patient', in which a possible opposite diagnostic relation exists, that of reader (doctor) and text (patient). This will be worked out in Part II of this thesis. For now, I am concerned with hermeneutics and medicine.

*Hermeneutics and medicine*

Medicine is fundamentally an epistemological and hermeneutical process, but more hermeneutical, as it does not only observe but also interpret. This is especially true for the medical diagnosis, which according to Daniel (1990) is a 'mixture of science and art' (Daniel *Interpretation*). He proposes to distinguish a separate discipline called 'medical or clinical hermeneutics' (5). In doing so, for him one needs to 'bring medicine to the hermeneutical turn by regarding the patient – medicine's primary subject – as a kind of text to be interpreted' (6). As described above, the 'kind of' remains important. Nevertheless, the concept of 'the patient as text' (with all its caveats) remains fundamental for the present analysis. For Daniel there is a need to 'validation of the cognitive role of metaphors (e.g., "text") in biomedicine' (8). These 'texts' may be texts, or human subjects with complaints. Leder (1990) argues that medicine is essentially a hermeneutic enterprise as the physician interprets the 'text' of the ill person (*Interpretation* 9). The practice of medicine, however, produces several texts, and Leder – as said – recognizes four separate varieties: the experiential (illness as lived out by the patient), the narrative (as constituted during the questioning of the patient by the doctor), the physical (the patient's body examined), and the instrumental (constructed by diagnostic technologies). The third and fourth variety (body examined and results of ancillary tests) will be discussed later under semiotics; the first two are important here as they reflect the complex associations between illness, patient, narrative and doctor. Translating this to a doctor – patient encounter makes clear that also in that situation several genres may be distinguished and often patients 'seek to reconstruct a comprehensive plot' (12). In the 'experiental text', mentioned above,

the task of the doctor is to 'help the text into being' (12). The 'narrative text' is the product of three different authors: the diseased body, the patient with a narrative voice and the doctor as 'channeling discourse' (13). Baron (1990), however, criticizes Leder's distinctions, as in his opinion 'the metaphor of clinical work as textual explication creates the expectation that there is a text somewhere to be found' (*Hermeneutics* 25). As said, one may indeed be afraid that patients seen as a text will be seen more static than they are in reality. When one is considering a patient as a text, one must also take into account the mutual and shifting dynamic nature of the encounter of patient and doctor.

As illustration of several aspects of hermeneutics, including the abovementioned critique, Albert Howard Carter III (1986) presents in his article "Esthetics and Anesthetics: Mimesis, Hermeneutics, and Treatment in Literature and Medicine" a patient who is going to a doctor after twisting his ankle. Although it is a simple medical problem, many complex issues arise. The protagonist is interrogated, examined, x-rayed, and operated upon. He also receives drugs to relieve him of his pain. When entering the hospital, he changes from a 'normal' human being with pain in the ankle into a 'sick role' and seeks a 'medicalization' of his state. In this process, he even hands over his whole being (even his consciousness) to his caregivers. His wife – a writer – intends to write a short story about his experiences, thereby in addition producing a 'literature-ization' of the events. So, the patient is driven into a sick-role and his wife is artificially entering the world of the sick. Both of their acts contain (traces of) reality. In this case, reality is represented in a technological way. An x-ray of his ankle makes reality 'visible', which may be considered as a mimetic imitation of reality (more in the direct Aristotelean than in the indirect Platonic sense). His wife, the journalist, uses hermeneutics, making a diagnosis based on perceived facts. She considers her husband's pain/x-ray/body as texts that are to be interpreted. She turns her husband's problem into language, thereby making it fictional. In the meantime, her husband's life is ontologically altered. He is not only turned into a patient, but also into (the subject of) a literary text.

As repeatedly mentioned, Daniel (1986) proposes to see the patient as text. In his model of 'clinical hermeneutics', four levels of interpretation of the patient/text are warranted: 1) the literal facts (of the patient's body and story); 2) the diagnostic meaning of these facts; 3) the consequences of the diagnosis; 4) the changes in the life-worlds of patients and clinicians after 1–3. Levels 3 and 4 will not further be discussed here as they concern the results of the diagnosis, and not the process of making a diagnosis. Daniel refers to Karl Jaspers' remark that 'all knowledge is matter of interpretation, and therefore the study of being is like the study of texts'. Daniel gives a comprehensive overview of the history of hermeneutics in medicine, concluding that the parallel and difference between fact (medicine) and fiction is illustrated as 'the practice of each discipline involves a double interpretation of meaning: the reader of a poem or a short story interprets the work which itself is an interpretation of the world, while the doctor interprets the patient's story or interpretation of "dis-ease" ' (201).

Thus, whereas fiction has a doubly distant relation to reality, the same is true for the diagnosis of a doctor. Important, however, is that both have some relation to reality, as fiction as well as medical diagnosis refer to something 'real'. Daniel adds another layer:

> If we think about it, we realize that the text in medicine is actually a triple text. The primary text is the patient, a physical thing embodying a mysterious self. That text can be read only with the aid of two secondary texts – one spoken and the other written. The first of these is the patient's story of dis-ease or health [..]. This is literally a fiction in the root sense of a

> “making,” and it is the physician’s job to determine whether the story is an accurate or even helpful interpretation of the story-teller. The other secondary text is the physician’s documentation of the clinical event, including the case summary, diagnosis, treatment plan, and progress notes in the patient’s record. (202)

Thus, the physician has the double task of interpreting both the patient and the patient’s story, and, as such, the whole dossier becomes a text for other phycisians also.

Gogel and Terry (1987) propose ‘some of the minimum possible conditions for medicine as a hermeneutic or interpretive field’, in an attempt to ‘make explicit many of the implicit aspects of any clinical encounter that have become second nature to the experienced clinician’ (211). They emphasize that no two patients will be exactly alike (in parallel with e.g. poems), and paraphrase Gatens-Robinson (1986) that ‘a medical fact isn’t a fact without a clinician reading it into a coherent story in a particular way, that is, into the case or story of the actual patient at hand’. The interpretation of ‘facts’, and the ‘reading’ of the patient are not mathematically fixed but depend on many variables of the patient and his or her circumstances. Interpretation also depends on the investigative technique chosen. When dealing with, for instance, internal diseases, this technique will be a laboratory test, but for pain without visible lesion, the choice necessarily will be the words that form the history of the patient. The authors also extensively describe other issues that must be taken into account in interpretation in medicine: prejudgment (also referred to as ‘tentative diagnosis’), which resembles Heidegger’s ‘Vorverständnis’, the influence of a potential consequence of a given interpretation (a diagnosis of a potentially treatable disease is preferred over that of an untreatable one), the need to re-evaluate an interpretation when new information comes available, which resembles Gadamer’s hermeneutical circle, the possibility of multiple interpretations (this is especially so in a patient with pain or headache), the need to reconcile incommensurable subtexts (for example, when the history of the patient points at one diagnosis and the examination at another), and the importance of validating an interpretation through open discourse with the right community (colleagues, patients, family-members of the patient, etc).

As a final point of importance it is stressed that ‘the only way to learn fully how to interpret particulars is through an apprenticeship’ (213). Although this topic does not lie within the scope of this thesis, it is mentioned here, as in their article Gogel and Terry give a remarkable example of a teacher – student situation. The famous British doctor William Osler apparently took his medical students on the wards and ‘made explicit analogies to reading skills and *the patient as text*’ (213; my emphasis). This insight, expressed in 1903, may be seen as ‘avant-garde’ and fundamental for the present thesis. So, historically, the patient was already seen as a text and the neurological examination may be read likewise. Gogel and Terry end their text with some warnings, of which the most important in the present context is that patients are not ‘passive “texts”’ (214). Any model must incorporate that patients must also be allowed to personally read their own body. Also, the model of ‘the patient as text’ must never claim that a patient is ‘merely or always’ a text. Rather, the patient as a text may create a wholeness which is greater than the sum of its parts. Anyhow, for the majority of patients with pain, the only available ‘text’ is a verbal one, and despite the advantages and disadvantages of this ‘reality’, one has to do with it.

James D. Lock, realizing that ‘medical knowledge [..] takes a linguistic form’ and that ‘the body [..] can only be known through language’ (42), focuses in his article “Some Aspects of Medical Hermeneutics:

The Role of Dialectic and Narrative” on the interaction between doctor (in his case a psychiatrist[12]) and patient. He mainly bases his argumentation on that of Siegler (1981), who discerns four moments of this encounter. First, the patient decides that he is ill and for that visits a doctor. Second, the doctor determines – by using clinical methods – whether the patient has ‘a disease that can be named or treated or not’ (44). In the third stage, the doctor and patient negotiate about a decision, which ‘involves evaluation and consideration of the individual characteristics brought to by the relationship by both the physician and the patient’ (44). The fourth moment is ‘an extension of the terms of the accommodation through the development of trust and long-term bonds between patient and physician’. These bonds result in a relation with ‘reality’, acknowledging that ‘the body, disease entities, and physiologies which may indeed have an objective reference can only be known through language’ (42). Lock concludes that ‘a medical case can be thought of as a struggle between an explanation of the real event of the disease process and the significance and meaning of these events in the broader context of the patient’s life’ (47-48). This is not only true for psychiatric patients, but also for those with pain.

*Semiotics*

The study of signs and symbols as elements of communicative behavior and the analysis of systems of communication, such as language, gestures, or clothing all fall under the definition of semiotics. According to Kathryn Vance Staiano semiotics offer ‘a metalanguage useful in the analysis of the production, relation, and manipulation of signs and for the transformation of one sort of sign into another, or for the recognition of analogous signs expressed in different idioms’ (*Redefining* 341). ‘Medical semiotics’ may be seen as ‘a straight path from physiological events, through bodily sensations to symptom reports. Hence, sensations are taken as a direct index of understanding pathophysiological processes that may be verbally described by a reliable patient’ (Kirmayer *Culture* 319).

To illustrate the importance of signs and symbols, and thus that of semiotics, I can give a personal experience. At the end of the last century, I had the tradition of going to the hospital on Christmas day with one of my colleagues and our daughters to visit the hospitalized patients, wish them a happy Christmas and bring a little gift. On one of these occasions our daughters (aged between 5 and 12) saw a lady who had had an accident and because of that carried a bandage around her head. Because of the bandage the lady was considered by our daughters as the most severely ill patient on the ward. Other patients with ‘invisible’ diseases such as a stroke or brain tumor were considered less ‘ill’. The lady with the bandage was dismissed the next day, whereas many of the other patients stayed much longer, or even never went home. The bandage was interpreted by our young daughters as a sign of serious disease. The patients without externally visible signs were considered much less affected. As young as they were, they used semiotics to come to an interpretation of reality.

Obviously, there is a great overlap between hermeneutics and semiotics (Daniel *Interpretation* 5; 8), mainly because both involve the interpretative act. Berger (1987) states that ‘both the communicative and semiotic powers of the body [..] are logocentric’ (148), stressing the importance of words for semiotics also. Here, the difference between ‘sign’ and ’symptom’ (see above) in making

[12] Virtually all psychiatric diagnoses strongly depend on the words (and sometimes the behavior) of the patient, just like those of pain without a visible lesion.

a diagnosis seems important. As defined in medical studies, a sign may be seen as objective and a symptom as subjective knowledge. A sign then leads to 'an implicit assumption that what the patient notices about his own state is somewhat less "objective" than what the doctor notices about the patient's state' (Kahn 88). In such a situation, complaints such as pain, numbness or nausea get a lesser meaning than a broken bone, thick thumb (sorry) or abnormal reflex. It has even been proposed to avoid the term 'symptom' entirely, since 'the doctor can only gain access to the patient's "symptoms" through general code signs' (88), i.e. words. The idea here is that one must consider signs and symptoms as equal.

In the light of represented or produced meaning, a recent article published by Fox (2016) is helpful. He gives an overview of the development of 'structuralism' (mainly the thoughts of Ferdinand De Saussure) to 'post-structuralism' in health sociology, which is of great importance for the present discussion. His starting point is that 'although concepts supposedly refer to "real" objects, these may only be signified through symbols such as words or other notations, which are necessarily constituted through reference to other signifiers' (*Health Sociology* 64). This seems a rather straightforward summary of the theory of De Saussure. Fox, however, continues with a critique by stating that 'because signifiers can only refer to other signifiers, definition offers not reality but a further approximation that, regardless of the effort to make it more "real", is always already deferred and irrecoverable' (64). It is mportant to realize the impossibility of direct knowledge of reality and the logocentric nature of all propositions to know the truth, also referred to as the 'linguistic turn' in post-structuralism.

Spolski (2002) explains the 'deferred and irrecoverable' nature of signifiers in similar terms, arguing that:

> Saussure's original observation, namely that meaning was in the relationship between words and not in the words themselves, was slowly understood to have destabilizing implications for the study of just about everything. Since the study of about everything is conducted in words, these inherent instabilities or ambiguities, previously described as "literary" phenomena parasitic on "normal" language [..] were now understood as a general condition of language use, including language to conduct scholarly debate. (50)

In his book *The Language of Pain* (2010), Biro summarizes the thoughts of the American philosopher Charles Sanders Peirce on this topic:[13]

> Implicit in the creation of a sign, whereby something signified (pain) becomes linked to a signifier (object), is its functionality. The sign is a signal that calls for a response, that requires what the philosopher C.S. Peirce once called an "interpretant"; it creates meaning, inasmuch as one can act on that meaning. (136)

Biro realizes that 'pain is difficult to express because it isn't necessarily connected to objects or referents in the shared outer world' (206). Nevertheless, the 'sign' (in Saussurean terms: the signified plus signifier) needs to be interpreted. Meaning must be given or made. In my assessment, De Saussure's proposition is too simple, here, and Peirce's alternative is essential, as it is useful in medical differential diagnosing.

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[13] Peirce (1839-1914) was specifically interested in pain, and even once remarked 'I was born in the century of pain' (cited in Moscoso 79), referring to the poor quality of the treatment of pain in the 19th century.

In their article “The Logic of Medical Diagnosis” (2013), Stanley and Campos work out Peirce’s theories and describe Peirce’s ordering in signs, symptoms, and tests. First, there is the ‘abductive’ stage in the differential diagnosis in which the most appropriate possibilities are selected. In this stage a ‘reach for simplicity’ and ‘intelligent guessing’ are important, so that an explanatory hypothesis is generated. In ‘habitual abduction’, the inquirer already has knowledge of general rules and laws and makes a choice. It often depends on ‘pattern recognition’ based on the classification of disease and signs and symptoms. In ‘creative abduction’, the inquirer must conceive the explanation itself. A further stage is ‘deduction’, ‘deriving the testable consequences of the hypothesis so that experimental tests can be conducted’ (302). Then follows ‘induction’, which is ‘testing the consequences of the hypothesis’.

In a similar argumentation, in her article “A Semiotic Definition of Illness”, Staiano argues that often signs are ‘symptomized’, because they do not stand on their own or have a fixed value, but also depend on a culturally mediated code. Expressed through language, signs are fitted into existing categories and according to expectations and in that way intersubjectively evaluated by individuals who are themselves social constructs (*Semiotics* 112). The diagnostician and doctor are also sign-producers, as they are also social beings. She quotes Einstein’s ‘it is the theory which decides what we can observe’ (113). In a following article “Medical Semiotics: Redefining an Ancient Craft”, she adds that ‘diagnoses are not based solely on signs and symptoms but derive from a process in which other knowledge is employed to arrive at a decision’ (320). Meanings are thus susceptible to negotiation. Furthermore:

> symptoms, both intersubjective (‘clinical signs’, organic, physical, objective signs, etc.) and introspective (symptoms, the ‘signs’ presented by the patient, the subjective signs), may be indexical – that is, nonarbitrarily related to their object – or they may be symbolic – that is, arbitrarily related to their object. (335)

She quotes Peirce, who calls a medical symptom an example of an index, which is defined as a ‘sign determined by its dynamic object by virtue of being in a real relation to it’ (331), and Barthes who states that ‘the symptom emerges as a sign only through “the organizing consciousness of the doctor” and through the “mediation of language” ’ (332). The symptom becomes a sign only under the gaze of the doctor and is a substitution, a metaphor, for what is absent (333). Rousseau (1986) further works this out, by stating that ‘no one doubts that contemporary physicians who interpret signs, diagnose symptoms, read clues – are semioticians of a type’ (159). Doctors may envision an imagined world.

According to Kathryn Vance Staiano, the ‘representamen’[14] proposed by Peirce:

> is awkward but allows greater precision than that of Saussure. Determination of meaning becomes dependent of the inclusion in a system of signs, and is not only dependent on the signified (object/image) – signifier relation. A third aspect, that of interpretation, is of utmost importance and determination of “meaning” for such a sign then becomes dependent upon its inclusion within a system of signs (*syndrome*, *symptom complex*) (*Definition* 108; emphasis in the original).

[14] A sign or signifier, whether physical or otherwise, which points to an object.

Kugelmann (2003) in his article “Pain as Symptom, Pain as Sign” also goes beyond De Saussure and discusses the semiotics of Peirce specifically in relation to pain, with a remarkable outcome. First, he contests the difference between symptoms and signs, by arguing that ‘symptoms signify’ (30). He follows Peirce’s theory that both the medical symptom and the medical sign are types of signs, because ‘they both signify something to someone’ (31). Peirce distinguishes three types of signs in relation to an object: the icon, the index and the symbol. In the icon the relation between sign and meaning is ‘motivated’ on resemblance (a picture of a person – for example – has things in common with that person). The index is motivated by contiguity (as smoke borders on fire). The symbol – finally – is not motivated, but its meaning is arbitrary; it depends on an agreement. Kugelmann calls pain iconic ‘insofar as it is not an object of my perception but rather as who and what I am, pre-objectively’ (35). A felt bodily sense, such as pain, taken as medical symptom to make a diagnosis may be seen as index (eg. pointing at gout or a brain tumor). Pain also becomes a symbol by calling it ‘pain’ (or ‘dolor’, ‘pijn’, ‘mal’, ’Schmerz’, etc.). So, the same sign or complaint (‘pain’) may have iconic, indexical and symbolic aspects. Kugelmann goes a step further by stating that ‘pain is an interpretation, not only that wath is interpreted’ (36). For the interpretation of, or the giving of meaning to a certain sign (or the diagnosis in case of pain), Peirce introduced the interaction of three elements of the ‘sign triad’: an object, a representamen (signifier) and an interpretant. Of the relation between the first two may be said that ‘if the relation between object and representamen is nonarbitrary, the sign exists as an index or an icon. If, however, the representamen could as easily be replaced by another sign, the relationship is arbitrary and the sign exists as a symbol’ (Staiano *Semiotics* 338).

The place of the interpretant has to be determined. Kugelmann argues that pain can be all three. Pain is an object ‘insofar as the pain is the disease and not pointing at some else’ (38). Pain is a representamen, as it ‘means something’, is a ‘type of communication’, and ‘produces consequences’ (38-39). If pain is seen as standing for something (‘punishment’, ‘cancer’, or maybe ‘migraine’ – see later), its significance is iconic as it ‘participates in the reality it represents’ (39). Finally, Kugelmann argues that pain may also be seen as an interpretant (39-40). As one of the examples he describes a patient whose headache worsens when told that he has a brain tumor. Here, ‘the pain interprets the sign’ (39). Another example is that of a child tripping and hitting a knee on the floor. During the fall, ‘the child’s eye catches mother’s eye’. The pain of the child will be influenced by how the mother reacts. If the mother grimaces, the child will have more pain than when the mother reacts matter-of-factly. Here the ‘objective’ pain serves as ‘interpretant’ based on the context, as ‘there is no one-to-one correlation between tissue damage and pain’ (40).

A situation may be ‘read’ through the ‘lens of pain’ (40). In this context, the third ‘layer’ in giving meaning (the first two are partly analogous to De Saussures signifier and signified) is the interpretation of the sign according to Peirce. ‘If something signifies, it has rhetorical effect; it produces an interpretant’ (44). This is one aspect that distinguishes Peirce from De Saussure, or that discriminates between their theories. As Kugelmann concludes, ‘pain occurs in a complex semiotic web, takes place structurally as a situation and exists through the agents who embody it in a variety of ways. Pain may be ‘my private, my unknown’, but it is at the same time a medium within which we share a common life’ (46). Like already said, pain as a ‘signifier without signified’ is a beetle in the box.

In this thesis, I will aim at further elaborations of this issue from the perspective of migraine – first in its ‘real’ and later its ‘fictional’ form.