Migraine as text – text as migraine: Diagnosis and literature
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Preface

> The majority of those who suffer, even if in solitude, consider their pain this way: in a transitory form, which sooner or later should stop or be remedied. Here experience takes on its most dramatic and literal sense, which implies displacement and peril. For both those who suffer and those who look on, pain – if it must be considered as such – is a drama that situates us in a borderland
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> Javier Moscoso, 2012

The interdisciplinary field of medicine and literary studies has in the last decades received much attention from both sides. This is – for example – illustrated by the existence of several devoted journals, such as *Literature and Medicine,* the *Journal of Medical Humanities* and *Medical Humanities*. In The Netherlands, there are several academic groups working in this field, of which the best known is that of the Free University in Amsterdam, which has expressed its work in many publications on the topic.[1] A subspeciality of the 'medicine-literary studies field' is pain, which has also received much scholarly attention. As a result, there are several books (written in or translated into English) that specifically address the association of pain-syndromes and literary studies, such as *The History of Pain* by Roselyne Rey (1993; English translation 1995), *The Culture of Pain* by David B. Morris (1991), *The Language of Pain* by David Biro (2010), *Pain. A Cultural History* by Javier Moscoso (2012), and *The Story of Pain: From Prayers to Painkillers* by Joanna Bourke (2014). There is also a contribution from the aforementioned group of the Free University, called *Pijn: Over Literatuur en Lijden (Pain. On Literature and Suffering)* (Oderwald et al., 2004).

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

The first major question posed in this thesis is fundamental: what is the relation between pain and language? Clearly, this question finds itself on the interstice between medicine (neurology) and literary studies. Sub-questions posed are how people with pain may make their pain 'readable' and how fictional texts about pain 'perform' the pain instead of only describing it. Yet in all instances the main question is how pain is or can be expressed. For possible answers to the central question and the subquestions mentioned above, I will first focus on pain in general, to set the stage for my addressing these questions in relation to migraine. I will compare medical thoughts on pain and migraine with those provoked by literary works in their being paradigms of expression, and try to bring these together.

[1] http://literatuurengeneeskunde.nl/publications/ last visited 8/11/2019

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

Why do I focus on migraine? One reason is that there is, as mentioned above, hardly any knowledge from the side of literary studies about this pain-syndrome that comes in attacks and has a double potential in relation to language, both destructive and creative. Gilles Deleuze has remarked that 'the encounter between two disciplines doesn't take place where one begins to reflect on the other but when one discipline realizes that it has to resolve for itself and by its own means a problem similar to the one confronted by the other' (cited in Century et al 10). He was right, so such a confrontation is what I intend to study and enact, in line with Stephen L. Daniel's thought that 'it is inevitable that we come to apply hermeneutics to medicine, since medicine is, [..] "the most humane of the sciences, the most scientific of the humanities" '(1986, 196).

The answer to the question what pain is seems easy, as almost everyone knows pain. The 'almost' refers to the >99% of living beings who may feel and express pain, including fetuses, babies and demented, intellectually disabled and unconscious people. There are, however, some individuals who (apparently) are incapable of feeling pain at all. This exception is present in a very rare genetic abnormality called congenital or inborn indifference of insensitivity to pain (Van Ness Dearborn 1932; McMurray 1950; Sternbach 1963; Critchley *Divine Banquet*; Danziger et al., 2006; Levy Erez et al., 2010; Nahorski et al., 2015; Staudt et al., 2017).[2] In the general view, not feeling pain seems wonderful, but in practice the condition places a heavy burden on its sufferers. First, those who claim not to feel pain are seen as hysterics, mental defectives or psychotics (Sternbach 252). Second, not feeling pain may be dangerous, as the body does not warn for possible external dangers, which may lead to burns, unrecognized tumors, etc. In this way, not feeling pain may even be lethal. It seems, therefore, that the ability to feel pain is a necessary condition for any human being.

Thus, except for the 'congenital insensitivity', everyone probably knows the feeling of pain. Remember for example the intestinal cramps as an infant, the humiliating pain when hit on the buttocks after a mischief, the pain of the scratch on your knee after falling of your bike, the pain of gout in your great toe, the hangover, or the invalidating pain of arthrosis in the hip. Clearly, pain is ubiquitously present in all life-stages, in numerous forms, disguises and situations. But, in fact, the

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

answer to the question how to express or represent what pain is in reality, still turns out to be extremely difficult to give. Why is this?

First, there is the complex origin of the word 'pain'. In their article "A Philological Study on Some Words Concerning Pain", Procacci and Maresca (1985) explain that the Greek words *algos*, *odynia* and *angina* were used for different kinds of pain. The word 'pain', however, was derived from *poena*, which meant 'punishment'. This association pointed at the ascription of pain and suffering to prior transgressions of sin (Loeser *Pain and Suffering* 5). Procacci and Maresca also point at the complex significations of the English words 'ache' and 'pain', and the Italian and French difficulties to separate dolor, douleur and dolore. And what to think about the German word Schmerz? So, what we are talking about is a sort of Babylonian confusion about pain-related terms (Bonica 247; Loeser *Pain and Suffering* 3).

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

However, thirdly, there is the difficulty patients experience when attempting to express their pain in words, as well as the difficult interpretation of these words. This interpretational crux will be the main focus of this thesis. Here, we are talking about words, referents and reality where so-called signifiers and signifieds are important. If we use the word 'pain' we somehow expect it to mean something, to refer to something. Yet was is that 'something'? If we say 'tree' pointing at a tree or 'horse' pointing at a horse, there is a word that relates to a referent. But what can be the referent of the word 'pain'? In a translation of what a patient feels or says, the verbal expression and thus the comprehension of or diagnosis by 'third' parties, such as a doctor, of the word 'pain', will be at least somewhat unreliable, as there is not only a difficult process of expression, but also one of translation and interpretation. In terms of diagnosing and (attempting to) cure someone, at least this unreliability of the words used for diagnosis and cure have to be overcome. I intend to do this for migraine, but there are many pitfalls on the road.

Since almost everyone knows what pain is, it seems obvious that pain is part of 'reality'. As hinted at, it may, however, be disputable what 'reality' is. Some have even claimed that all humans have their own reality and that our perception of the world only is 'a fantasy that coincides with reality' (Frith 111). Without a doubt, language is extremely important here, not only to describe this imaged reality, but also – as especially postmodern thinkers have emphasized – to create reality (see chapter 3). As Stenner and Eccleston state in their article "On the Textuality of Being" (1994), 'we understand language to be more like a set of tools (for local and contingent use) than as a set of representations of some *really real reality*' (my emphasis). This raises the question the more: what about the really real reality of the paroxysmal pain of migraine? What is its relation to language? These are the questions I hope to answer in the next chapters, first by taking the text of the migraine patient as starting point and thereafter focusing on literary texts about migraine, in this way bringing medicine and literary studies together, in the hope that both fields will benefit from it.

Build-up and ultimate aim of this thesis

In **chapter 1** I will argue that patients with pain may be read as a (literary) text. I describe which methods can be used to do so and which issues are important in this process, such as the distinction between symptom and sign, between illness and disease, and the importance of *phronesis* – Aristotle's practical wisdom. I will also introduce De Saussure's and Peirce's theories about words and 'reality'. These considerations form the basis for the following chapters and the final goal of this thesis. In **chapter 2**, I will discuss how to read a specific form of pain, migraine, as a (literary) text. I will show how words contribute to the 'reality' of migraine, and will thereby focus on the differences between chronic pain and migraine, a disease or illness that comes in attacks. In **chapter 3** I will describe that, as there are no biological tests for migraine, the diagnosis depends on criteria which are artificially agreed upon. These criteria are mainly based on the words of the patients themselves. There are thousands of scientific articles that use the current criteria and these articles together may be seen as a discourse, of which it is known that it often leads to in- and exclusion and hierarchy. I will explore the consequences of the discourse of migraine also for some types of non-migraine headache. **Chapter 4** addresses the question: 'Does migraine destroy language?' The destruction of language by pain is one of the most important topics of Scarry's landmark publication *The Body in Pain*. Indeed, many patients with migraine stay silent due to their affliction. They may be silent when they do not have headache (because then there is no reason to complain), but also at the time they have a headache (because then the pain often is too severe to utter their complaints). As such, migraine seems to result in a situation of 'double destruction' of words. I will compare the 'destruction of language' as described by Scarry for chronic pain with the paroxysmal situation of migraine. This will bring me to conclude that migraine has an enormous creative potential, especially when patients are outside of their attack and find the words and metaphors to describe their experiences. As time seems to play an important role in migraine, in terms of frequency and rhythm and in terms of being in- or outside an attack, I will address questions about the 'temporality' of migraine in the context of philosophical theories about time in **chapter 5**. I will compare studies of time-perception of migraine patients in- and outside attacks. This perception – in which memory and language both play an important role – might give a notion of the 'subjectivity' or call it the feeling of self of patients with migraine.

After this, the issues raised in the first 5 chapters will be used in **Part II** of this thesis as themes for the analysis of selected novels that include migraine and that are all in some way concerned with the notion of self. In relation to language, the question is not so much how migraine is being described, but how it is performed in and through these texts. This is the 'text as patient' part.

In **Chapter 6** the rationale for the selection and analysis of four selected novels that include migraine is described. The analyses partially use the issues discussed in the first 5 chapters, but the question of how the words of migraine-patients relate to their pain will be turned around in an analysis of how fictional texts that include descriptions of migraine describe, or rather, 'perform' migraine. The possibility of a construction or modelling of a migraine subject on these interpretations towards a 'migraine self' is introduced, to be worked-out in the following chapters. In **chapter 7** two works of Siri Hustvedt are analyzed: *The Blindfold* and *The Shaking Woman*. The first is a work of fiction, the second a non-fiction essay. In both, migraine is an important topic, which in the novel can be recognized as the migraine of the author. Therefore, *The Blindfold* is analyzed as an example of a work of fiction in which author and narrator cannot be completely separated. **Chapter 8** deals with

James Lasdun's novel *The Horned Man* which is built up as a thriller, with strong 'who's done it?' aspects and cliffhangers. The role of the narrator's migraine will be analyzed in relation to the issue of epistemological uncertainty. The issue is how someone suffering from migraine has an ability to know. The novel analyzed in **chapter 9**, Rivka Galchen's novel *Atmospheric Disturbances*, starts in the middle of a migraine attack and from that point on poses questions of ontology. The narrator – a psychiatrist – suffers from Capgras' syndrome, a so-called delusional misidentification syndrome, in which patients see persons in their surroundings as impostors, replacing loved ones. This disturbance of perception is analyzed in the context of the ontological situation of a migraine-patient. Irvin Yalom's novel *When Nietzsche Wept*, analyzed in **chapter 10,** seems to contain a mix of fiction and non-fiction. An important feature of the fictional Nietzsche presented is how he deals with his migraine. It is analyzed whether this affliction was also important for the 'real' Nietzsche and whether his migraine was of importance for some of the core-ideas of his philosophy: eternal recurrence, amor fati and suffering. If in the previous chapters epistemology and ontology were the key, here the notion of self is of utmost importance.

In **chapter 11** 'Conclusion', Part I: 'the patient as text' (chapters 1-5) and Part II: 'the text as patient' (chapters 6-10) are put in perspective and combined to come to a conclusion about the performative strength of texts about migraine and notions of a 'migraine self'.

One initial question is how the words of migraine-patients relate to their pain in a lived reality. As said, the goal of my thesis is to come to a better understanding of the relation between migraine and language. By analyzing this relation, in the end, I hope to be able to better understand or diagnose my patients, in terms of their disease and in terms of their selves, and thus be a better doctor for them. In the context of literary studies migraine is of relevance for its potential to destroy and create language, especially metaphorical language, such as in relation with the signifiers used. Yet this study also hopes to offer new insights to a more general audience, whether having migraine or not. It is through literature that we can get, such is my contention, a better socio-cultural understanding and diagnosis of what this chimaeric disease that affects millions 'is' and what it means to the constitution of the selves that suffer from it. Important is that migraine can on the one side be called 'chimaeric', but on the other side is also 'real'. In both senses, its recognition heavily depends on language.