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Migraine as text - text as migraine: Diagnosis and literature

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Chapter 4

Does migraine destroy language?

Anyone who has suffered severe pain and tried to describe the experience to a friend or doctor may find himself or herself at a loss of words

Joel Katz and Ronald Melzack, 1999

How much I suffered last night, in my heel and in my ribs. Sheer torture ... There are no words to express it, only howls of pain could do so

Alphonse Daudet, (1930/2002)

Some scholars have argued that pain destroys words. The major propagator of this thought is Elaine Scarry, a professor of English at the university of Pennsylvania. Her book *The Body in Pain. The Making and Unmaking of the World* (1985) has become a classic on this topic and was even called 'canonical' and 'seminal'. Scarry describes the effects of pain on the 'unmaking' of the world, with as starting points that physical pain has no voice (3) and that there is an inexpressibility of physical pain (3). For her, 'physical pain does not simply resist language but actively destroys it, bringing out an immediate reversion to a state anterior of language, to the sounds and cries a human being makes before language is learned' (4). In her opinion, there is 'ordinarily no language for pain' (13) and 'before destroying language, it [pain] first monopolizes language, becoming its only subject' (54). In addition, for her physical pain is 'consistent in its assault on language, so the verbal strategies for overcoming that assault are very small in number' (13). In other words, 'the person in pain is ordinarily bereft of the resources of speech' (6), because 'intense pain is language-destroying' (35). In her book, she mainly focuses on the effects of the pain of physical torture on speech, but her thoughts on pain have also been read in a much broader sense by many scholars.³¹ In the discussion of either having pain (for instance in the case of someone being tortured) or producing it (as a torturer), in this thesis, I will for obvious reasons focus on the 'having' instead of the 'producing' of pain, as it is not known who or what 'produces' the pain of migraine.

The concept of a destroying effect of pain on language has been accepted, or at least strongly considered, by many other scholars. Kugelmann, for example, accepts that 'pain afflicts and can disable any activity, including walking, grasping, swallowing, remembering, and thinking' (*Vernacular* 308), and elsewhere adds that pain 'reduces one to moans, groans and screams; pain is often verbally inexpressible' (*Symptom* 37). The inexpressibility of pain is the starting point for David Biro's book *The Language of Pain* (14). In his opinion, 'pain has the elusive quality of an absence, an absence not only of words to describe it (that is, a linguistic absence) but also of ways to think about

³¹ Scarry's words have – for example – influenced the thoughts of Morris (*The Culture of Pain*), Biro (*The Language of Pain*) and Thernstrom (*The Pain Chronicles*).

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

A slightly other standpoint in this matter is taken by Fredrik Svenaeus (2014), who argues that 'pain can surely stop me from doing what I want to do or becoming who I want to be' (*Hermeneutics* 411), but emphasizes that this destroying effect of pain 'is only *one* of the potential relationships between pain and mental suffering' (411; emphasis in the original). There are other things than pain that can make a person suffer. He adds that he does not want to introduce 'some kind of dualist philosophy' (411), where pain (body) is seen separate from mind (e.g. words or language). In his opinion, 'medicine has been too preoccupied with the *causes* of pain and other bodily symptoms and too ignorant of the way the symptoms attain *meaning* for the person suffering from them' (411-412; emphasis in the original). So, translating this to Scarry's emphasis on the destroying of words by pain, he considers her standpoint too simple. The interaction between the bodily sensation of pain and the mental action of language is much more complex than the 'one way' destructive one. So, possibly, pain can destroy language in its semantic sense in certain circumstances, but it probably does not destroy the sense of meaning and it even also can have other effects on it, including the production of meaning. There may even be a creative vision on what accompanies the experience of pain (Engdahl Coates 243). It seems that illness can thwart creativity (243) and that pain 'enables one to "toy" with language and even to "coin" new words' (244).

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

Still, Scarry finds support from others. For instance, Arthur W. Frank has worked out the effects of illness (including pain) on language in his book *The Wounded Storyteller* (1995). He describes how a

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

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

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

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

A more productive position is taken by Butler (1997). She acknowledges that pain can be a threat to language and can shatter language, but also that language can 'wield *its own violence*' (6; emphasis in the original). She points at the fact that there is a 'specific kind of injury that language itself performs' (6). The thought that words can damage is one of the pillars of her book *Excitable Speech: A Politics of the Performative*. I will discuss the performative use of language by patients, but also in works of fiction, in Part II of this thesis.

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

The writer experiences the hunger to tell, often
finding in poetic diction the means of expressing that
which otherwise remains unsaid and therefore
unknown

Rita Charon, 1996

Pain can create

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

The present thesis, however, does not deal with music or painting, but with words. The main reason for this is that words are of utmost importance in the patient-doctor encounter (as can be read in chapters 1 and 2), are crucial to make a diagnosis and to 'perform'. Pain may destroy words, but possibly also create language, for example by the creation of a narrative by the patient in pain, expressed by Rey as 'pain always has a specific language' (4). For Siri Hustvedt, 'every illness has an alien quality, a feeling of invasion and loss of control that is evident in the language that we use about it' (*Shaking* 6). In her case, headache did not make language dry but created a quality (more on this in chapter 7). Indeed, Scarry herself does not only refer to the destructive power of pain on language, but also states that 'physical pain has no voice, but when it at last finds a voice, it begins to tell a story' (*Body* 3). In the second part of her book she describes the 'making' of the world in opposite to the 'unmaking' worked out in the first part. Comparable with Frank's creative restitution and quest narratives, which are in opposite to the chaos narratives that mute, she also sees some creative function of pain. So, it can be argued that pain destroys language, but at the same time leads to an increase in creativity. Here, Woolf's "On Being Ill" cited above is also of importance. After writing that pain makes language run dry, she describes the other side: that pain may create. After crushing the words of pain together, 'a brand- new word in the end drops out' (7) and in 'illness words seem to possess a mystic quality' (21). In addition to Svenaeus and Frank, cited above,

Kirmayer (1992), for example, states that ‘through the pain and suffering that foreshadow its own mortality, the body drives us to seek meaning’ (325). Morris sees pain as something ‘that ennobles even as it destroys’ (*How to Read* 199) and quotes the surgeon/writer Richard Selzer who has written that ‘pain invents its own language’ (222). So, it seems that in many instances, words are created by pain instead of being destroyed by it.

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

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

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

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

No general theory about pain. Each patient discovers
his own, and the nature of pain varies, like a singer’s
voice, according to the acoustics of the hall

Alphonse Daudet, 2002/1930

Ego-documents of pain and literature

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

By the way, the separation of ‘fiction’ and ‘reality’ in the context of ego-documents can be challenged, as it can never be trusted that what is narrated by an ‘ego’ really happened. It is clear that in first-person ego-documents the borders of truth and fiction are blurred and therefore notoriously uncertain. Why do patients write about their own illness? Do they want to regain control over their life? Do they seek attention for their illness and a correct diagnosis? Do they seek the potential to share? Other beetles? Probably it is a combination of these. Not far from autobiography there is the so-called autofiction (see also chapter 6), in which author, protagonist and narrator are the same. Of this, I will give some examples.

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

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

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

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

Isolation necessarily characterizes pain, given that pain is one of the few experiences it is impossible to share with another human being

A. Elisabeth McKim, 2005

Does migraine destroy or create? Or both?

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

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

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

This 'twisted correspondence to imaginary worlds' strongly suggest the parallel worlds a migraine sufferer lives in or experiences (see also described in chapter 9).

Giving an example from another 'art', Morris mentions how the painter Georgia O'Keeffe was inspired by her headache to paint (*How to Read* 196), and even calls her headache 'a possible source of beauty' (*Culture* 197). Her headache can be seen as something 'that ennobles even as it destroys' (*How to Read* 199). Also, it has been argued that the Italian painter Giorgio de Chirico (1888-1978) painted some of his paintings under the influence of his migraine (Piechowski-Jozwiak and Bogousslavsky 2013). Of Pablo Picasso it was first argued that migraine was an inspiration for some of his cubist paintings (Ferrari and Haan, 2000), but later this opinion was retracted (Haan and

Ferrari, 2011). As said, however, this thesis does not deal with the association between visual representations and pain, but with the relation of pain with words.

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

The actual having of migraine, on the other hand, often has direct destructive powers on language (Schwedt et al., 2019). This can be due to the pain, but also due to the so-called aura (see chapter 2, note 9). Up to one third of migraine patients suffer from at least some attacks with aura, the prodromes of the headache, that most frequently consist of visual or sensory disturbances. Disturbances of speech, in the form of aphasia³², dysarthria³³ and as a component of confusion, however, may occur also (Bruyn 1968, Ardilla and Sanchez, 1988; Kelman 2004; Petrusic et al., 2013). Aphasia can also be the result of a large number of other brain diseases, for example a stroke or a tumor. The aphasia of migraine, however, is described as being different from that of other causes, as many patients with aphasia as a part of a migraine attack describe that they knew perfectly well what to say but were unable, due to some sort of block, to express verbally what they thought of (Bruyn 63). A consequence of this is that the migraine aura *temporarily* destroys language in these cases. In addition, inability to write (‘agraphia’), read (‘alexia’) and difficulty in writing text messages (‘dystextia’) have also been described as part of the migraine aura (Bigley and Sharp, 1983; Fleischman et al., 1983; Evers et al., 1996; Whitfield and Jayathissa 2011).

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

³² The term aphasia is used for an inability to comprehend and/or formulate language due to a dysfunction in certain brain regions (the so-called speech areas of Broca and Wernicke). The words of the patient can become incomprehensible and/or the patient cannot understand what is said to him or her.

³³ Dysarthria can be described as spluttering over words with a thick tongue. Often, bystanders think that the patient is drunk. So, whereas aphasia affects the contents of speech, dysarthria affects its form. Both, however, can affect language considerably.

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

On the other hand, Kirmayer (1992) illustrates how migraine can also produce meaning: 'When a patient with a life-long history of migraine headaches spontaneously remarks, "My head is made of glass," she is simultaneously revealing something about her body image, her model of migraine, and the way she wishes to be handled by the physician' (*Insistence* 340). Whatever the intended meaning, the metaphor of a 'head made of glass' can be considered creative. Likewise, in the headache poems of Jane Cave Winscom (see above) there are plenty of similar metaphors, such as: 'But pain within my frame its scepter rears!' (94), or 'Through ev'ry particle the torture flies' (94). In her case the headache seems to destroy speech, but not the ability to write down these words, and to create her poem. Her poems are an illustration of the idea of Svenaeus, that pain 'gives room for positive transformation' (*Hermeneutics* 416).

In the chapter "The Inscrutability of Pain" of his book *The Citadel of Senses*, MacDonald Critchley (1986) argues that 'the head pains in migraine offer an opportunity for mulling over the nature and meaning of painful experiences in general' (*Citadel* 180). He sees the head as '*locus minoris resistentiae*' ('weak spot') in headache patients, and refers to Nietzsche, who has said that 'all pain is per se, and especially when in excess, destructive [...]. Mere pain can destroy life' (181). But on this point MacDonald Critchley makes an exception for migraine, as it also 'may fulfill some purpose or bring about some cryptic benefit to the victim' (181). He describes the benefits of a migraine attack as: 'when stress of an emotional, mental, or physical kind reaches a critical level, an attack of migraine might intervene and bring a temporary halt to such a potentially noxious influence' (181). Here, migraine resembles a cathartic experience. For this experience, see also chapter 10.

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

So much that I cannot write today

So painfully the migraine does disable me

Piercing my brow just like an arrow

That I can scarcely look at the light

That this is an attack of (pre-IHS) migraine is likely. The pain is disabling, probably one-sided ('brow', not brows) and with photophobia. Remarkable is that the author writes that he 'cannot write today', though he is clearly writing words, probably with hindsight (on this dual temporality see chapter 5). Yet even in his painful and disabled state, he produces a metaphor: the piercing just like an arrow.

So, although his migraine seems to destroy words ('cannot write today'), it also seems to create ('like an arrow').

Roland Barthes (1915-1980), a French linguist, philosopher, semiotician, structuralist and post-structuralist, suffered from migraine. He described the effects of his affliction in detail in his autobiographic book *Roland Barthes by Roland Barthes* (1977). In the book Barthes (or the 'I' called 'Roland Barthes') interrogates himself as a text (and in that sense he is a 'patient as text', but maybe also a 'text as patient'). He often talks about himself as 'he' instead of 'I', possibly because he fears 'the labyrinth of levels in which anyone who speaks about himself gets lost' (119-120). He states that he 'had no other solution than to *rewrite myself*' (142; emphasis in the original), and this rewriting also includes his thoughts on migraine:

*Mon corps n' existe ... ~ My body exists ...*³⁴

My body exists for myself only in two general forms: migraine and sensuality. These states are not unheard of, but on the contrary quite temperate, accessible, remediable, as if in either one it had been decided to reduce the glorious or accursed images of the body. Migraine is merely the very first degree of physical pain, and sensuality is for the most part considered only as a kind of reject-version of active pleasure.

In other words, my body is not a hero. The light, diffused character of pain or of pleasure (migraine too *caresses* some of my days) keeps the body from constituting itself as an alien, hallucinated site, seat of intense transgressions; migraine (as I am rather carelessly calling a simple headache) and sensual pleasure are merely coenesthesias, whose function is to individuate my own body, without it being able to glorify itself with any danger: my body is theatrical to itself only to a mild degree. (60; emphasis in the original)

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

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

this unsuitable word [migraine] (for it is not only half of my head which gives me pain) is a socially accurate one: mythological attribute of bourgeois woman and of the man of letters, the migraine is a class phenomenon: who ever heard of the proletarian or the small businessman with migraines? The social division occurs within my body: my body itself is social. (124)

³⁴ This is in the original translation, though the French states: 'My body does not exist...'

Here, one can think of the stigmatization of migraine, as well as that of the disease hierarchy (see chapter 2). Although the prejudice can be criticized (there are many ‘proletarians’ and ‘small businessmen’ with migraine), Barthes writes about migraine in a ‘positive’ way, and not as something that destroys.

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

So different from Michelet's migraines, “amalgams of bewilderment and nausea,” my migraines are matte. To have a (never very strong) headache is for me a way of rendering my body opaque, stubborn, thick, *fallen*, which is to say, ultimately (back to the major theme) *neutral*. Absence of migraine, the insignificant vigilance of the body, coenesthesia degree zero – I should read these in short as the *theater* of health; in order to assure myself that my body is not healthy in a hysterical fashion, I should occasionally need to take away its *signs* of transparence and experience it as a kind of glaucous organ, rather than a triumphant figure. Hence migraine would be a psychosomatic (and no longer a neurotic) affliction by which I should agree to enter – though *just a little way* (for the migraine is a tenuous thing) – into man's mortal disease: insolvency of symbolization. (125; emphasis in the original)³⁵

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

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

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

those strange drugged days, punctuated by the visits of young men in white coats who would held up pencils for me to identify, asked me the day and the year and the name of the

³⁵ ‘Glaucous’ means a pale grey or bluish-green appearance of the surface.

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

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

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

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

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

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

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

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

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

The 'Humpty Dumpty' in Hustvedt's quotation about her hospital stay, cited above, of course, refers to Lewis Carroll's novel *Alice in Wonderland*. Indeed, there is a clear association between that novel and migraine. The novels *Alice in Wonderland* and *Through the Looking Glass* contain much descriptions of hallucinations and illusions³⁶. An example of a hallucination is the 'Cheshire Cat', seen by Alice in a tree; examples of illusions are the episodes in which Alice feels as if her neck is very long or where she feels bigger than her surroundings. The latter subjective disturbances of the perception of one's own body or the surroundings have been labeled 'metamorphopsia', a type of distorted vision. These are very common in children with migraine and occasionally occur in adults also and have led to the eponymous diagnosis of the 'Alice in Wonderland Syndrome' (Fine 2013; Blom 2016). There has been a debate about whether Lewis Carroll (synonym for Charles Ludwidge Dodgson) based these descriptions on his own suffering of migraine or not (the debate is summarized in Haan and Meulenberg *Muze* 66-74). If these were Carroll's own experiences, it can be argued that they caused destruction (in the sense of deformation of visual images) or creation (in the sense of reviving them in his works of fiction). In both cases, a discussion of these would not be relevant for the present thesis as the distortion concerned visual and not verbal qualities. Jill Gordon Klee (1991), however, also associates some aspects of Carroll's text with disturbances of speech. She argues that 'what more perfect description of a fluent aphasia can be imagined in the poem, "Jabberwocky"³⁷, which only becomes understandable when explained by Humpty Dumpty' (30). Next to this, Alice displays signs of 'pure nominative aphasia' when she is unable to name familiar things such as a tree or a fawn and even herself (30). Klee refers to Carroll's own (migraine-related?) stuttering as a possible reason for his including of these disturbances of language in his fictional text, but here

³⁶ Respectively: perceptions of something that is not present; and distortion of something that is present.

³⁷ For example, the first lines of the Jabberwocky poem are:

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

maybe confuses the author with the narrator. Presuming that Carroll indeed had migraine, the disease did not destroy, but led to an inspired creation.

Conclusion

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

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

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

destroy +, create –

Outside of an attack it is:

destroy –, create +

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

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

As final part of part I, I will discuss the relation of migraine and time. In my opinion, this topic emerges directly from the previous chapters. In migraine, time plays a very important role as patients are either in- or outside an attack. This influences their perception of time considerably, as I will show, but – as I have already argued – also their use of language and maybe even their 'selves'. During attacks, language is destroyed, in between attacks it is created. It is important to realize that Jane Cave Winscom used the present tense to describe her experiences during her attacks, although she wrote her poems outside the attacks. Here the aspects 'destroy', and 'time' are strongly connected. This results in (at least) four topics that all are associated with destruction, creation of language and time: 1) the destruction of language during the attack; 2) the creative representation of migraine in between attacks; 3) the rhythmic nature of migraine as a way to form ones identity (as described by Barthes), and 4) migraine approaching 'the sublime', combining the forming of identity with that of great emotional intensity, as described by Hustvedt in *The Shaking Woman*. These topics will be analyzed further in the next chapter and in part II.