Migraine as text – text as migraine: Diagnosis and literature

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Chapter 7

Narrator and author with migraine: Defining a self

The Blindfold and *The Shaking Woman* by Siri Hustvedt

All literary texts are woven out of other literary texts
Terry Eagleton, 2010

The question of why those who study literature and medicine should attend to nonfiction first-person accounts of illness could have been answered directly: because what is told really happened
Arthur W. Frank, 1994

Introduction

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

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

Authors who write fiction in the first-person remain especially at risk to be confused with their protagonists. Heinze (2008) gives an additional reason for a confusion of author and narrator in this situation. He argues that in fact:

> the term first-person tends to underline the misunderstanding of equating "narrator" with "human-being." Proclamations about the death of the narrator argue exactly this: the "I" of first-person narrative is merely a signifier, a semiotic sign to which readers during the reading process attribute certain propositions and descriptions that also occur in the narrative. (281)[43]

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

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

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

On the other hand, authors evidently need to use their personal thoughts, experiences and lives when giving voices to the protagonists of their 'fictional' texts. They cannot deny their own voice. Because of this, in the nineteenth century, Wilhelm Dilthey placed the psychology of the author in the center of interpretation of their texts (see chapter 1). His standpoint can be described as 'the attempt to enter into the mind of an historical author' (Heelan 182). Subsequent theories, however, placed the autonomy of the text in the center, and thus the author was indeed, in a way, declared dead. As said, an influence of the mind of the author on a text can, however, hardly be denied. Therefore, there are many works of fiction in which obvious traces of the life and the thoughts of the author can be found. The case here is that for authors who suffer from the disease they write about the disease can form an important source of inspiration. There are numerous examples of such disease-based fiction, e.g. Guy de Maupassant and Alphonse Daudet who depicted the venereal disease syphilis in their novels (see chapter 4) and Fjodor Dostojevski who suffered from epilepsy and imbued several of his protagonists with this disease (Vein 2006). In these cases, the author was not (yet) dead, but had a disease that obviously influenced the 'fiction'. Because of this, as said, one must be very cautious to see the narrator and the author of works of fiction as the same, even if they had a disease in 'real' life that was depicted in their fiction.

An exception, however, might be an author who repeatedly mentions in non-fiction texts that the disease was a source of inspiration for the fictional work. It can be argued that the narrators of such 'fictional' works may be seen as referring to an external framework, including not only their mind, fantasies, body and life, but also their extradiegetic disease.[44] By writing fiction about their own disease, in a sense, they 'define' a self in their fiction that depends on their self outside the fiction. One of such authors is the American writer Siri Hustvedt who has claimed to suffer from severe

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

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

migraine in numerous texts. Her diagnosis can be read in various entries on the internet, in her non-fiction autobiographic essay *The Shaking Woman* (2010) and in a number of articles in scientific journals (Hustvedt *Philosophy*; Century et al.; Hustvedt *Wept*). She acknowledged that she began to try to make sense of these migraine experiences by letting neuroscience enter into her fiction (Century et al., 12), remarking that:

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

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

First, I will compare *The Blindfold* with Hustvedt's non-fiction work *The Shaking Woman*, focusing on the question what the relation is between narrator and author. Of these two books, Hustvedt has said in a literary discussion panel that:

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

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

For my analysis of fact and fiction in Hustvedt's work, I have chosen to first address the 'fiction' and then the 'fact'. My first argument for this is that *The Blindfold* was published in 1992 and *The Shaking Woman* in 2010. An important question therefore is how the 'fiction' that came first influenced the 'fact', and if so, how much 'fact' is in the 'fiction' and how much 'fiction' in the 'fact'. Or, in the light of this thesis, has the text influenced the patient or the patient the text? This seems to contain the pitfall of Nietzsche's pin-pain confusion (see chapter 1): an interpretation of cause and effect. So, both texts must be interpreted with caution. Besides, it can be of importance to investigate how the writer Hustvedt is formed by her texts. It might be that these texts have played an important role in the forming of her 'self'. Are we dealing with autobiography, autofiction (see chapter 6), or fiction? Hereafter, I will argue that in these texts not only the protagonist/narrator becomes a 'real' self but also the author.

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

I felt a Cleaving in my Mind-
As if my Brain had split-
I tried to match it – Seam by Seam –
But could not make it fit

Emily Dickinson (cited by Hustvedt *Shaking*)

The narrator: The story of Iris

The Blindfold is the story of Iris Vegan, a student of literature in New York, told in the first-person. It includes four separate chapters, but one can wonder whether they must be seen as one whole or as separate short stories. Indeed, Jameson (2010) sees them as 'four separate, non-chronologically recounted yet thematically connected mini-narratives' (421). The fourth chapter seems to give a summary of the first three, puts them in some sort of chronological order and unites the text as a whole. For Jameson, 'since each section of the novel relates an experience that threatens to unsettle or annihilate Iris's sense of self, viewing the fragmented text as a survival narrative ties the episodes together' (424). So, it seems that the 'self' is fragmented and must be put together. The novel can thus be seen as a quest for something: putting together the fragments of a self. The question can be asked what the 'role' or importance of migraine is in the threat, the tying and the quest of reconstructing this self. I will discuss these topics in the light of the processes of 'destroy' and 'create' (see chapter 4), but will first give a summary of the narrative (-s), which is told by a so-called 'character bound narrator', one who takes part in the occurrences described (Bal 21).

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

The second chapter introduces Stephen, Iris' boyfriend, with whom she has a difficult relationship. She secretly likes Stephen's friend the photographer George better and a sort of triadic relationship develops. At the end of a photo-session with George she runs away because she is afraid of the expression on his face, which is 'like a person who has just eaten well' (55). Then she gets a migraine-attack in Stephens room when she discovers one of the photos made by George. First, she gets 'a slight sensation of nausea' (66) and then:

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

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

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

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

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

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

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

She starts to feel guilty, not only because the other patients have more serious neurological diseases than she has (see the so-called 'prestige hierarchy' of diseases of Album and Westin (2008) described in chapter 3), but also because 'I had made the headache, created the monster myself, and just because I couldn't get rid of the damned thing didn't mean I wasn't to blame' (91). Here, the feeling of guilt which many migraine sufferers have is described. A new headache attack is always their own fault. They drank too much wine, ate chocolate, went to bed too late or had too much pleasure. After the double, triple or call it quadruple negation of the last quote, Iris makes a remark that is one of the most important in the light of this thesis. She says: 'The distance between the place were the words originated – somewhere deep within the headache – and where they had to go – out into the room – seemed impassable' (91-92). Here, she describes the impossibility of translating pain/headache into words – or call it the signifiers – that are important to give substance to the feeling of pain, their signified. The pain makes it impossible to create the right words. She clearly is a 'patient as text' but doubts whether her text can or will be read as a patient, as it is destroyed by the impossibility to translate the pain into words. On top of this problem, a confusion of words develops between her as a patient (text) and the reader of that text (doctor), as she notices that 'my doctor told me that I was improving when I was not' (92). The doctor translates her words wrongly in what Iris calls 'a ferocious editing' (93). Then she realizes that she 'had tried to tell my story to six less famous physicians, and each time, I had lost my tongue. I felt that if only I could articulate my illness in all its aspects, I might give a trained ear the clue that would make me well, but my words were always inadequate' (93). Here, again she feels guilty, as her language is inadequate. In a way it seems 'destroyed'. She feels like a person going to pieces, whose head was in the way, and whose pain was becoming an obsession (94).

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

The fourth chapter deals with how Iris is asked by a professor of literary studies to translate a German novel. During that work, she identifies herself with Klaus, the protagonist of the novel and tries to bring him to life by wearing men's clothes and acting as uncanny as he. The professor finds

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

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

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

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

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

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

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

> Intellectual curiosity about one's own illness is certainly born out of a desire for mastery
>
> Siri Hustvedt *Shaking*

The author: The story of Siri

It has been argued that one of the consequences of 'the death of the author' is a transformation of the author into 'a literary subject, or a function of the text' (Johnson *Author* 5). Maybe this is true for Hustvedt as well. Her essay *The Shaking Woman or a History of my Nerves* (2010) is about her own disease. In that sense, it can be called a 'biography', or maybe more accurate 'pathography'. The

latter is defined as 'the memoir of illness experience' (Wiltshire *Biography* 409) and can be called 'a critical patient narrative' (412). A 'pathography' might be written 'as an act of protest, as a recall to the fact that one is not only a body, and to rescue the whole experience of illness and medicalization from the narrower definitions of the clinic' (412).

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

In *The Shaking Woman*, she describes her search for the cause of the trembling and how she consulted many neurologists and psychiatrists. First, epilepsy is considered. Uncontrollable shaking can occur in some seizures, but there is something strange the matter with her attacks, as she realizes that 'my shaking was on both sides of my body – and I had talked throughout the fit. How many talk through a seizure?' (9). Because she did not become unconscious during the attack, the diagnosis of epilepsy is rejected. In her further quest she considers and explores other possible disorders, such as hysteria, panic disorder, conversion disorder, stage fright and dissociation.[45] In the end, however, the most likely cause for her symptoms is considered to be migraine, and for her the symptoms belong to her status as 'migraineur'.

She describes her first experiences in the hospital in detail:

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

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

> alas, my life is lived in the borderland of Headache. Most days I wake up with headache, which subsides after coffee, but nearly every day includes some pain, some clouds in the head, heightened sensitivities to light, sounds, moisture in the air. Most afternoons I lie down

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

> to do my biofeedback exercises, which calm my nervous system. The headache is me, and understanding this has been my salvation. (174)

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

Stigma can be divided in 'enacted' and 'felt' stigma (Scambler and Hopkins 33). Enacted refers to the discrimination against patients on grounds of their perceived inferiority. Felt stigma refers to the fear of enacted stigma, but also encompasses a feeling of shame associated with the disease (33). It seems that Siri introduces a third category: the stigma 'migraineur' as self-description. She uses for herself the stigmatizing and negative term with which migraine patients are confronted (see also chapters 2 and 3), being called a 'word', or being placed in a disease category. Mostly, the disease migraine and the word 'migraineur' connote something negative. Indeed, although migraine is the third most disabling disease (Disease and Injury Incidence and Prevalence Collaborators 2016) it is still not seen as a serious disease by many. Using the term 'migraineur' is a synechdoche standing for the patient as a whole and thus can also be described as a 'morbus pro toto'. It is argued that the term should be avoided, just as – for example – the designations 'an epileptic' for a patient with epilepsy, 'a schizophrenic', or 'a retard' (Scambler and Hopkins; Young *De-Stigmatizing* 320). It is not right to define a patient with a disease 'as' that disease. For Butler (1997), 'to be called a name is one of the first forms of linguistic injuries that one learns' (2). It can, however, be considered more injuring to be called a name based on a disease or another incapability. Indeed, as Butler says, 'to be addressed is not merely to be recognized for what one already is, but to have the very term conferred by which the recognition of existence becomes possible' (5). So, for the term 'migraineur' it can be said that 'the word not only signifies a thing, but that this signification will also be an enactment of the thing' (44). When one calls oneself 'a migraineur', one also 'is' headache and through this 'performative' an escape from hell indeed seems very far away.

Unfortunately for Siri, the MRI-scan, ordered to investigate the presence of a structural lesion to support a diagnosis of epilepsy, triggered a migraine attack. For her, the MRI 'has knocked that poor organ into familiar territory – the land of Headache. The irony makes me smile. I don't fight migraine anymore. I embrace it, and by doing that, I am also, strangely, able to feel less pain' (176). Her 'land of headache' reminds one of Susan Sontag's kingdom of the sick, or of Daudet's land of pain. The 'embracing' resembles the 'amor fati' of Friedrich Nietzsche (see chapter 10). Important for Siri is that she knows that the pain of the migraine attack will end (as otherwise it would not be called an attack), which makes it (somewhat) more bearable. Only during her periods of 'status migrainosus', one of which lasted a year, it was difficult for her to 'embrace' the pain. The migraine 'betrayed' her as it did not end and violated the definition of an attack. She writes, 'I continually checked my pain: Was it lighter? A bit. Hope waved a victorious flag inside me. Soon it will disappear and go away forever! Was it worse? Yes, it was definitely worse. I lowered the flag and returned to battle' (179).

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

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

> Literary studies will also need to pay new attention to various writer's attempts, through history, to imagine, understand, and represent their own cognitive processes
>
> Mary Thomas Crane and
> Alan Richardson, 1999

> True stories can't be told forward, only backward. We invent them from the vantage point of an ever-changing present and tell ourselves how they unfolded
>
> Siri Hustvedt *Shaking*

Is Siri Iris and/or Iris Siri?

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

In the terms of Frank (1994, *Reclaiming*) Iris's story seems a chaos narrative. Being fiction, it can be said that it is not important whether the occurrences are past, present or future. Their importance are the creation of new dimensions and new ontologies, the creation of new worlds and selves out of nothing. Adventures of a protagonist of fiction may contain historical aspects, but most of it is imaginary, and the temporal order often is deliberately disturbed (Bal 8, 79-88). Likewise, illness alters the temporal and hence narrative orientation of the story of a patient (Woods 75). I have argued in chapter 5 that migraine causes a fragmentation and thereby a disturbed perception of time. As examples I gave variants of 'achrony', such as 'anticipation-within-retroversion' (Bal 96) in which a migraine patient describes how in the past he or she thought about a future attack. A second form I described was 'retroversion-within-anticipation' which describes how the 'present' will be remembered (re-presented) in the future (97). These mechanisms are important for a 'real' patient, but of course can also be important for a narrator in a fictional work. In *The Blindfold*, which is told backwards, many examples of 'achrony' can be found. As illustration of this, here are some quotes from one of the first pages: 'Sometimes even now I think I see him in the street or standing in a

window or bent over a book in a coffee shop', 'I met him eight years ago', 'On a day in July, not long before I met Mr. Morning', 'That was two months after Stephen left me', 'In June I had done work for a medical historian' (all on page 9). A consequence of these five time-indications in a row is that the readers will be puzzled and 'lost in time'. In addition, the temporal crisscross also illustrates the confusion of the narrator herself. This is a confusion of ontology, of not knowing on what '(time-) level' one is. In a way, Iris 'defines' herself here by means of these temporal disturbances, and she clearly illustrates the loss of self of a migraine patient, as it is also described in chapter 5.

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

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

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

Indeed, *The Blindfold* contains many distorted facts, including the course of time, the (non-) vision of reality, and the issue of disturbed seeing and to be seen. It 'defines' a separate person or self. The migraine and being a 'migraineur' seem fixed 'realities' in this chaotic lifeworld. They are a fixation to the extradiegetic migraine of its historical author, who once called her protagonist 'a heroine' (Century 12), probably because she has experienced the (heroic) suffering of migraine herself.

When it was published in 1992 *The Blindfold* had to be seen as an entirely fictional work. Many years later, however, it appeared to be partially based on the 'real' experiences of the author. So, the author was 'dead' for about 18 years and then became 'alive'. When one accepts this, *The Blindfold*, however, still does not describe the 'truth', as its own 'Internal Field of Reference' remains unchanged. Jameson (2010) has written about *The Blindfold* that 'the multifaceted nature of power causes the protagonist to experience nothing less than *self-shattering*, a dangerous destabilization of any sense of personal identity' (422; my emphasis). Is this the 'heroine' the author is referring to? It is clear that Iris's migraine contributes to the shattering of her world and to her loss of control. As a

'migraineur', she falls apart in symptoms and signs and has to endure opinions and prejudices. What else could be the fate of 'a migraineur'? The same *self-shattering* and destabilization are almost eponymous for *The Shaking Woman* in which Hustvedt describes her quest to regain her sense of personal identity. Unfortunately, however, as pointed out by Tougaw (2012), when a patient finds herself in a world of contradicting physicians and still is without a firm diagnosis 'metaphors mask the limitations of science' (*Memoirs* 182). He concludes that 'Hustvedt becomes the shaking woman through writing' (189). She defines herself indeed as such in the last sentence of her text (Hustvedt *Shaking* 199), stating that 'I am the shaking woman' (199). As is said, 'suffering must be embedded in language to be conceptualized' (Rousseau 164), and 'the record of suffering constitutes a gold mine waiting to be quarried, if we will only learn to decode its signs and languages' (171). This is especially true for migraine, as I have argued in chapter 2 and which is clearly illustrated by Hustvedt in both texts.

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

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

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

Now Siri, who describes that:

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

This is a clear example of how patients and their doctors can be in completely 'different worlds', as described in chapter 1. After this experience, Siri decides to write a novel of which she says that 'I would have to impersonate a psychiatrist and psychoanalyst, a man I came to think of as my imaginary brother' (5). The novel, *The Sorrows of an American* (2008), is written in the third-person point of view. From a distance, the narrator observes his sister's 'arcs of energetic production that

were followed by migraines and the blues, what she referred to as her "neurological crashes"' (55). He also realizes that 'there are times, however, when fantasy, delusion, or outright lies parade as autobiography, and it's necessary to make some nominal distinction between fact and fiction' (86). The distinction between fact and fiction is not specifically worked out further in this novel, but a 'fact' is that Hustvedt's 'imaginary brother' tells about the migraines (and apparently also about the epilepsy) of his sister Inga. He says, 'I'm convinced now that Inga was suffering from absences, what used to be called petit mal seizures, which resolved themselves spontaneously as she grew older. What has remained with her are migraine and their auras and something fragile in her personality' (25).

Migraine is a joint quality of Siri, Iris and Inga. The narrator of *The Sorrows of an American*, Siri's 'imaginary brother', seems also to refer to Siri's quest for her 'shaking', and he apparently describes part of the biography of 'his' author and creator. In this process, he seems to associate her migraine with epilepsy. Also in this novel reality and fiction seem to interact and it looks like some 'autobiography in the third-person'.

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

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

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

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

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

Nielsen (2004) discusses the issue of who it is that narrates in first-person (or homodiegetic) fiction. He argues that 'in literary fiction, as opposed to oral narrative, one cannot be certain that it is the person referred to as 'I' who speaks or narrates' (133). So, we need to posit an impersonal voice of the narrative. Maybe, this is reflected by Bal's theory that 'I' and 'he' in fiction are the same (20). When a narrator says, 'I have a headache' or 'he has a headache', this can also be translated to '(I say) I have a headache' and '(I say) he has a headache' (21). So, both sentences are uttered by a speaking subject, an 'I', but in one the speaker talks about himself and in the other about someone else. Nielsen further points at the fact that some narrators ('narrating-I's') narrate about things of which they cannot possibly know, or in such a quantity of detail that is impossible for any real person to remember (135). This resembles the so-called 'paralepsis', as it describes the situation of a narrator who assumes or pretends to have a competence he/she cannot not properly have (Heinze 280).[46] Thus, 'a paraleptic human consciousness [..] will almost inevitably be judged according to what we as readers know from experience human beings could or should not know or be able to do under the specific circumstances of a fictional situation' (283). One way out would be to label a paraleptic first-person narrator unreliable, based on the anthropomorphic argument that no first-person narrator can have privileged knowledge (283). A subtype is 'illusory paralepsis', where paralepsis seems to be present, but where 'delayed disclosure reveals that there are natural, realistic sources of the character narrator's unusual knowledge' (285). *The Shaking Woman* can be seen as such a 'delayed disclosure' for Iris's migraine as it is based on detailed descriptions of Siri's migraine.

So, on the one hand there are 'sentences about something that only exist by virtue of the sentences' (Nielsen 134-135), but there can also be things that exists independent of the narration, which existed prior to the narration. These intra- and extradiegetic issues then represent different ontologies of the same situation, such as is true for *The Blindfold* and *The Shaking Woman*. It can even be claimed that for these two texts, the fictional first-person narrative does not belong to the domain of true fiction, as it approximates the narration of the third-person narrative. On top of this, 'a story told from the *limited* point of view of a single protagonist may highlight the utter unpredictability of what happens: since we don't know what other characters are thinking or what else is going on, everything that occurs to this character may be a surprise' (Culler *Literary Theory* 91; emphasis in the original). There is no doubt that *The Blindfold* is based on 'real' (extradiegetic) experience, so one can wonder to what category of literature it belongs.

Thinking about real or 'virtual' pain, in her article about 'autofiction' (see chapter 6), Marie Darrieussecq states that pain cannot be imitated (76). One of her arguments is that of Plato who called fiction 'a copy of a copy' or a 'simulacrum'. In line with this thought, the question emerges how pain can be copied or represented in fiction or – more in general – in words. This is the main question of this thesis, but here one can ask whether *The Blindfold* is pure fiction, autobiography (a copy of a copy) or autofiction. And – more important in the light of this thesis – is the migraine imaginary or part of (some sort of) reality? Darrieussecq also warns to confuse the author with the

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

narrator in fiction in the first person, but maybe we should not to be reserved about this in case of *The Blindfold*. Concerning the *The Shaking Woman* it can, in my opinion, not be ignored that Iris clearly is a reflection (or mirror, or copy, or simulacrum) of Siri. Note that this sentence contains a double negation (not, ignored), which at least expresses some doubt about the issue at hand.

In chapter 6, I have described another category of fiction called 'neuronovel', which includes novels of 'consciousness, interiority, linguistic play and estranging description' (Roth 7). It is clear that *The Blindfold* can be seen as such a 'neuronovel', as its stream-of-consciousness narration is dominated by an 'anthropological figure of the cerebral subject [and] a character attributed to a cerebral lobe' (Burn *Neuroscience* 213). The cerebral lobe in question is suffering from migraine, as can be read on many of the pages.

Another issue related to neuronovels is discussed by Burn who points at the theory that so-called 'confabulation'[47] (…) is 'emblematic of what it is to be human' (36). In other words, we all fill in the gaps in our perception of reality. In line with this he argues that 'postmodern fiction has found in the centrality of confabulation an answer to the great question of where fiction could go after the realistic novel' (36). This could be one of the reasons for postmodern fiction's engagement with neuroscience and the publication of numerous 'neuronovels' (Brindley 2013). Furthermore, it could be that 'the simple fact of having a first-person narrator with a neurological disability is a positive thing, in that it forces the reader to question the structures of normativity that usually prevail' (Peacock 81). One must, however, be careful to overestimate medical conditions for their symbolic value as this detracts from real illness and suffering. It is therefore important that the symbolic function of migraine in *The Blindfold* is put in perspective in *The Shaking Woman*, which is a story of personal and 'real' suffering.

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

Conclusion

It can be concluded that Iris is not Siri. This would of course be impossible, as Siri is someone of flesh and blood and Iris consists of words on a white page. Iris produces a chaos-narrative of loss, pain, and incoherence of storytelling and time. Her language 'cannot re-socialize what has happened'

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

(Frank *Reclaiming* 7). The story of Siri is a quest, including a call, road of trials, and return. After her quest she is renamed and her name is 'migraineur', which in Frank's terms can be seen as 'another layer in the sedimentation of identity' (11). Likewise, 'the boom at the end of this quest is not restoration of health but renewal of subjectivity, including the recognition that much of the previously "healthy" identity was imaginary' (12). In short this is the defining of a new self.

The Blindfold illustrates what Lamarque (1990) in his article "The Death of the Author: An Analytical Autopsy" states as 'the author function is distinct from the author-as-person' (325). He adds that 'it is a convention of some kinds of fiction that they draw attention to their own fictional status, that they point inward rather than outward, that they teasingly conceal their origin, and so forth' (329). This seems also true for the majority of the contents of *The Blindfold*, but with an important exception. The question 'is Iris Siri?' is not important, but rather that of 'is the migraine of Iris the migraine of Siri?' After my comparison of *The Blindfold* with *The Shaking Woman*, the answer seems to be 'yes'. In both instances the migraine consists of words and although the persons using those words are different and in different 'ontologies', the words are the same. This makes their 'selves' also 'the same'. So, the author of *The Blindfold* is not dead in all aspects, as part of her is alive and this part is called 'migraine'. As Frank puts it: 'the value of this voice is not its assurance of truth, but simply that these narratives are signed in the name of an ill person' (*Reclaiming* 17). The death of the author, however, is mainly about the loss of the authorial voice, and not about the eclipse of the real person. Nevertheless, the way in which the 'real' author infiltrates characters and narrators remain important. The complex relation between the authorial voice and the voice of a real person will be further worked-out in chapter 10 (about Irvin Yalom's *When Nietzsche Wept*), where it will emerge in a double form.