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## **Migraine as text - text as migraine: Diagnosis and literature**

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## Chapter 5

### *Migraine and the representation of time*

Time cannot be explained without assuming time

J. Ellis McTaggart, 1908

The future is always coming nearer, while yet remaining future. The past is always going farther away, while yet remaining past. The present, however, while it remains present, does not change in this way

J. Ellis McTaggart, 1909

In our culture, time is most often presented as linear, an “arrow” with a forward direction. This implies that time is irreversible. Time can also be described as cyclic, mirrored in the course of nature – day and night, the lunar month, the changing of generations and the life cycle of man – birth, aging, ageing and death

Christina Hellström and  
Sven G. Carlsson, 1996

### *Time, illness and pain*

Modern scientific medicine is focused on objective, quantifiable data. For patients, however, what they feel and perceive counts more than what can be measured. So, a consequence of modern medicine is that doctors and patients often talk about different things, and that whereas ‘the patient conceives his illness in terms of lived experience, the physician conceptualizes it as a disease state’ (Toombs *Temporality* 228). In chapters 1 and 2, I have discussed the different view of patients and doctors. The gap between what patients feel and what doctors can measure also seems to be reflected in different viewpoints on time, as I will show in this chapter.

Indeed, for Gilmore (2012) there are in disease ‘different temporalities’ (94). And according to the neurologist William Gooddy:

[first] we need to study the mechanisms by which, normally, the sense of time is provided; second, the defects in the perceptions of time which arise from disorders of the innumerable mechanisms from which any time sense is achieved; and third, perhaps most important of all, the stresses arising from incompatibilities between different time systems which use quite separate methods of computation for their creation. (*Outside* 240)

Everybody knows and feels what time is; at any moment one has the perception of the passage of time. In spite of this, however, it appears very difficult to define time. In the *Encyclopaedia Britannica* (1963; Volume 22; p. 224) it is defined as 'a basic concept which deals with the occurrence of events. There is a definite order in which any two non-simultaneous events occur'. This sounds logical, but at the moment one starts to think about time several dilemmas emerge. Consider, for example, a chair. One can take a step back and describe it in words or gestures. When thinking about time, however, it appears that one cannot take a step back, as at the moment one starts to think about time or takes the step, it is already in the past. Or, as Dingle (1958) has phrased it: 'time is so deeply rooted in consciousness itself that it is impossible for the normal human being to contemplate a state of existence apart from it' (231). Put in another way: 'the principal reason why we are troubled to accommodate our experience of time to the intellectual theory of time goes very deep in the philosophy of philosophy' (Williams 466).

What most philosophical theories about time tell us is that there is an important distinction between 'objective' and 'subjective' time. In his article "Disorders of Orientation in Space-Time" (1966), Gooddy remarks that 'physicists have, by a superb exercise of intellect and imagination [...] discovered that the human being needs to escape from that rigid form of absolute time, inherited from Galileo and Newton, into a flexible, personal, relativistic form' (*Disorders* 662). And in his article "Outside Time and Inside Time" (1969) he adds that 'relative, apparent, and common time is a perceptible, external form of measurements of some sort of duration derived from movements, either regular or uneven, which the layman uses instead of real time' (*Outside* 239). For him, technological chronometry ("outside time") has increasingly invaded private chronometry ("inside time").

A radical distinction between objective and subjective time also forms the major part of Husserl's phenomenological theory about temporality. For the subjective experience of duration Husserl uses the word 'retention', which is close to memory. Indeed, 'past temporal phases of the object are retained in primary memory as a part of the present consciousness of the object' (Toombs *Temporality* 229). This differs from recollection, in which the object is no longer actually perceived. Recollection is re-presented (and not presented). In retention, a temporal unity is unfolding, whereas in recollection there is an 'as-if' presentation. The consequence of retention is that also a protention (anticipation) of future temporal phases develops. In this way, past, present and future become an inseparable unit. Said in other words, the present can only be seen in a continuum with past and future. Consequently, there is a radical distinction between lived time and objective time (229). According to Husserl, temporal objects are experienced not in terms of isolated, discrete, now-points along a given timeline, but rather [...] as 'temporal wholes' (230), a theory I will later return to.

Furthermore, in the continuum of the 'reality' of the patient probably a navigation between subjective and objective experiences of time is important. Indeed, as Mellor writes in his article "I and Now" (1988-1989), 'what makes this belief [in time] true is just that everyone shares my habit of using those words to do this' (92). Seen as such, time is another Wittgensteinian beetle in the box. All persons perceive time, but no one knows exactly how the other perceives it. Gooddy phrases this as follows: 'The "now-point" is a personal and present state of awareness [...] which serves to distinguish our individual past from our future' and adds that we have also a kind of communal 'now-point' (*Directions* 86). It thus seems that the box of the patient contains at least two beetles, one called 'pain' and another called 'time'.

In their article “Disturbances of Time Consciousness From a Phenomenological and a Neuroscientific Perspective” (2007), Vogeley and Kupke emphasize that the subjective experience of time is a fundamental constituent of human consciousness, and they mention Husserl’s *Lectures on the Phenomenology of the Consciousness of Internal Time* as an essential work on this topic (157). In that text, Husserl argues that the intuitive experience of ‘now,’ is always an extended now in a continuing perception. So, ‘now’ is something relative, and – I would like to add – it gets its meaning because others also have a ‘now’ and can represent this ‘now’ in words (and deeds).

When translating Husserl’s ideas to states of illness, it can be said that in illness the character of lived temporality changes (Toombs *Illness* 212). Future possibilities change and suddenly appear irrelevant or out of reach (212). In illness there is a focus on the demands of the here and now. Whereas ‘few people live their lives solely in terms of the present, most act in the present in the light of specific goals that relate to future possibilities. Illness truncates the experiencing of the individual. It imprisons him within the present moment’ (234). The sense of a temporal whole becomes less and can even disintegrate, maybe also because ‘the next moment can always be the last’ (Svenaesus *Illness* 338). Temporality is the ultimate horizon of meaning, as everything can and will end. This is not only true for ‘normal’ life, but even more so for life with an illness. Svenaesus (2011) even states that the temporal structure of illness can be conceptualized as an alienation of past and future (333). In illness, the time of the body no longer fits into the time of the self, and therefore illness necessitates ‘a retelling of the past and a re-visioning of the future’ (333). Indeed, illness causes an accentuated focus on the present, amidst a shrinking away of the past and the future (339).

The thoughts about the relation of time and illness can be further narrowed when one considers painful illnesses. According to Toombs (1990), ‘the immediate sensation of pain is constituted as a temporal object (i.e. as a unity which is extended durationally) through the synthezizing activity of inner time-consciousness’ (*Temporality* 231). The person in pain experiences pain as a continuum in which ‘pain just-past’ and ‘now-pain’ are retained in consciousness, and future pains are anticipated. It has been found out that this often makes it difficult for patients to report about the duration of their pain in terms of objective timescales (a topic I will later return to). It appears that, in general, pain is felt in subjective time and therefore difficult to translate into objective time.

For the relation between time and pain an essential distinction must be made between chronic and acute pain; both terms by themselves refer to time. ‘Chronic’ contains the Greek word for time (χρόνιος) and ‘acute’ (οξύς) expresses the moment the pain began. Nevertheless, there is an important other difference between the two types. Acute pain almost always leads to withdrawal followed by immobilization and avoidance, which are important aspects of protection against injury (Kirmayer *Culture* 329). For this reaction the ability to remember previous acute pain is of utmost importance, as ‘pain and memory are linked in multiple ways: pain cements memory, pain evokes memory, and memory in turn can re-evoked pain’ (331). It can thus be said that ‘our first response to pain, then, is an act of imagination that shapes all future actions’ (Stoddard Holmes and Chambers 135). When having pain for the first time, one looks forward. When having (many) more acute pain episodes, one looks both backward (to the previous pain) and forward (to expected or feared pain).

Of chronic pain Loftus (2011) contends that ‘patients with chronic pain come to believe that the “damage” they think must be causing their pain is continuing to do them more and more harm because this is what happens in machines that malfunction and are not repaired properly – the

damage gets worse' (220). He argues that chronic pain has a connotation with a machine metaphor and progressive damage. Also with respect to chronic pain, Hellström and Carlsson state that 'a changed experience of temporality is revealed in that the long-standing pain-patient creates the experience of "*a long standing now*", that is a "viscous" present, a slowly fleeting time' (421; emphasis in the original). Leder (2016) also focuses on chronic pain, 'rather than on modes of brief, acute, and perhaps medically resolvable pain' (*Experiental* 444). In his description of how patients can react to chronic pain, he includes his own experiences as a patient with pain in the leg. He visited an orthopedist, vascular surgeon, neurologist, pain specialist and acupuncturist and searched on many Web pages, before discovering that 'with each new interpretive perspective, the sensed pain changed in quality, intensity, meaning, and affective content' (446). Thus, the pain itself partook in referentiality and interpretation depending on the context. Importantly, the pain was seizing him back to the here and now and it was 'very difficult [...] to project beyond it – that is, use one's own powers of recollection, imagination, or positive anticipation, to escape its grasp' (449). So, past (recollection) and future (anticipation) disappeared in the present.

To summarize, as illness in general, pain appears to influence time perception, the perception of past, now and future, and leads to a focus on the 'now'. This is wonderfully expressed in one of Emily Dickinson's poems:

Pain – has an element of blank –

It cannot recollect

When it began – or if there were

A time when it was not –

It has no future – but itself –

Its infinite contain

Its Past – enlightened to perceive

New periods of Pain.

(Dickinson 323-324).

In the poem, it seems that there is a fracturing of time. Written from a 'now', the words refer to the past ('when it began', 'a time when it was not'), the future ('new periods of pain') and a present (when it was written). But past and future disappear ('cannot recollect'; 'no future'). The pain is fixed in the present. Besides, the fracturing seems to refer to a paroxysmal pain-disorder, such as migraine. This defining feature of migraine in relation to time will be the topic of the next paragraphs.

Through repetition, the character of time as stretching-along is rooted in the deep unity of time as future, past, and present, the backward movement toward the past is retrieved in the anticipation of a

project, and the endlessness of historical time is grafted on the finite structure of being-toward-death  
Paul Ricoeur, 1980

Patients with long-lasting pain present a new understanding of lived time and temporality, characterized by a broken past, a fragmented future and “a long-lasting now”  
Marja-Liisa Honkasalo, 2000

### *Why migraine and time?*

It appears that issues of time are extremely important in the understanding of many aspects of pain, especially that of the temporal ‘reality’ of pain from the patient’s view. What I will now argue is that migraine encompasses many more aspects of time than any other chronic or acute pain-syndrome. All issues mentioned above about the relation of time with illness and pain are also true for migraine, but being as well chronic, acute, transient and paroxysmal (coming in attacks), the perception and representation of past, present and future of a patient with migraine must be seen in this light.

There are several philosophical aspects of time that I will use in my argument: the already mentioned distinction between objective and subjective time, including the importance of the counting of numbers; the ‘passage of time’ versus ‘flowing present’ and the definition of ‘now’.

First, there is the distinction between objective and subjective time, as already mentioned above when I discussed Husserl’s thoughts in the section on *Time, Illness and Pain*. In this context, however, it must first be remembered that our so-called ‘objective’ time, the Greenwich Mean Time (GMT), was adopted by a convention in 1884 and since then determines terrestrial time (Goody *Disorders* 664). Later, in 1952, the International Astronomical Union recommended to cease to take the day as our standard of constancy and substitute the year (Dingle 236). A particular year (1900) was chosen as the fundamental unit of time. Based on this choice, a second was defined as 1/31,556,925.9747 of the year 1900 and time reckoned in the new units was called Ephemeris Time (237). Nevertheless, GMT and Ephemeris time permit local time and that personal chronometers are altered in relation to longitude. We can look at our watches, but the time indicated can be wrong (e.g. as I am forgotten to adjust it to ‘summertime’ or the longitude I am in). Watches all over the world indicate different times. So, what about ‘objective time’? Both the so called ‘objective’ and ‘subjective’ time can be divided into past, present and future, but there is ‘a fundamental distinction between the *concept* of time and the *experience* of time’ (Dingle 233; emphasis in the original). Or, to speak with Aristotle, ‘time is the product of the soul that counts and measures changes against one another’ (cited in Marina and Mason 192).

When dealing with migraine, one can speak of an ‘episodic dimension’, which is defined by Ricoeur as ‘made out of events’ (*Narrative Time* 178). At one time, the future may be perceived as a threat, the remembered past may be threatening and perceived as close in time, the here and now may be preoccupied with the actual demands (Toombs *Illness* 213). During another ‘event’, this perception of past, present and future may change.

According to Goody (1966), many other neurological disorders lead to disturbances of time (*Disorders* 667-668). Examples are Alzheimer's disease in which often a day-night reversal occurs, and Parkinson's disease in which characteristically a slowing of thought and movement occurs. Goody further argues that in many neurological disorders 'chronometric and navigational performance will fail', which will lead to 'disorders of chronological sequences' (667). This may be true for many neurological diseases, but in my opinion not for migraine, as this in contrast will lead to an increased sense of time and chronometry.

In the representation of migraine several aspects of time are very important. For example, for migraine patients it is not only important since when they had the complaints, but also how long the attacks lasted, how long the pain-free periods between the attacks were, when the last attack occurred, when the next is to be expected, how fast attack-medication works, etc. In addition, in the representation of migraine, also the counting of numbers plays a role. Aristotle already said that 'time is that which is counted and not that by which we count' (cited in Marina and Mason 189) and called time 'motion that admits of numeration' (cited in Russell 229). There seems indeed to be a fundamental relationship between counting and time, which I will explain in the next paragraph.

The way in which the counting of numbers is important for migraine can be illustrated with several examples. First, there is the frequency of the attacks. As defined by the current criteria, a diagnosis of migraine without aura can be made when someone has had at least five attacks in his or her lifetime (see chapter 3), and a diagnosis of migraine with aura after two characteristic attacks. Most patients, by the way, have a much higher attack-frequency, in some up to 6 attacks per month. As described in chapter 3, migraine can be separated into an 'episodic' and a 'chronic' form, a distinction which is based on counting, as – according to the criteria – migraine is episodic when a patient has migraine-headache on less than 15 days per month, whereas a diagnosis of 'chronic migraine' can be made when there are more than 15 headache days per month, of which at least 8 have the accompanying features of migraine, such as nausea, phonophobia or photophobia (International Classification of Headache Disorders 2018). However, the use of the word 'chronic' for the number of headache days per month has been criticized, as the word also refers to the fact that the patient has had attacks during a certain period, in pain-syndromes mostly defined as 'more than 6 months' (Lavie-Ajayi et al., 193; see chapter 1). Migraine is in most patients a life-long disease and therefore the term 'chronic migraine' for the number of headache days per month is confusing and even seems a pleonasm (Headache Classification Committee 2006). The counting of hours is also important as according to the criteria in the episodic form migraine headache attacks must have a duration between 4 and 72 hours and auras between 4 and 60 minutes (see chapter 3). So, the counting and keeping of time are important for the diagnosis.

Counting can also be used to determine the burden of migraine, which is not only expressed in the number of attacks and / or headache-days per month, but also measured ('calculated') in its intensity by the so called 'migraine disability assessment' (MIDAS)-score (Stewart et al., 2001), which calculates the burden of migraine in individual sufferers. In addition, the severity of the separate pain episodes can be translated into scores, for example on the VAS scale (see chapter 1), or on a scale called the Headache Impact Test (HIT-6) (Yang et al., 2011). A last example of the importance of time and counting numbers is the so-called menstrual migraine. For female patients the rhythmicity of migraine often parallels that of their hormonal fluctuations, which are often 'clock-like', and menstrual migraine is a special type in which attacks only occur during menstruation and therefore



by definition once per month. These attacks can literally ‘set the clock’ for these women during the largest part of their life.

Time, numbers and counting are also very important when the patient encounters a doctor (Blau *Diagnosing* 1250), as – for example – one of the first questions the doctor will ask is: ‘Since when did you have these complaints?’, and one of the last questions the patient will ask or at least wonder (after being further interrogated, investigated and having received a diagnosis): ‘What does my future look like?’ It has been said that one’s ‘world’ can be defined as ‘a general communal three-dimensional space, into which an individual introduces his feelings of time’ (Goody *Disorders* 662). So, time can be considered the fourth dimension. In line with this, an essential part of the representation of migraine is the thinking and expressing of temporal issues of past, present and future. How do migraine patients experience time and how important is the perception of time for the representation of migraine?

In many ways migraine therefore can be seen as a disease that is ‘subject to mathematical analysis’ (Leder *Medicine* 30). It fulfills ‘the mathematical ideal’ (Leder *Interpretation* 20) and fulfills ‘another epistemological ideal: that represented by quantitative data’ (20). It seems that migraine can be measured and calculated. The future of this would be that migraine can be ‘proven’ by means of mathematical, biological or genetic tests (Schytz and Olesen, 2016). This is, however, not (yet) the case, as now words and the application of artificial criteria are important (see chapter 3). In the meantime, what must not be forgotten is the subjective experience of migraine patients. Are these tests, numbers and figures also as important for them individually? In a way yes, but there is more.

After the importance of counting and numbers, a second aspect of time that can be important for the perception of time in migraine is the distinction between the so-called ‘passage of time’ versus that of the ‘flowing present’. St. Augustine already distinguished the three aspects of time: the past, the present and the future, of which the first is associated with memory and the latter with expectation. Heidegger saw temporality as the plural unity of future, past and present (cited in Ricoeur *Narrative Time* 171) and defined ‘within-time-ness’. For him, there is no representation of time as a linear series of ‘now’s’. There are indeed many perspectives of time in which the ‘objective’ linearity of time is abandoned, for example in expressions such as ‘taking time to’, ‘wasting time’, ‘having time to’, ‘how time flies’ or ‘stretching time’. Importantly, we emerge as subjects from inside a reality which we can never objectify. Time is the very structure of human life itself. The distinction between temporal passage and flowing present made J. Ellis McTaggart even conclude that ‘time is unreal’, which I will try to explain.

When describing time, McTaggart (1908) proposed an ‘A-series’, ‘B-series’ and finally also a ‘C-series’. The A-series is the passage of time in which events undergo change merely in virtue of the fact that they have progressed from the future, through the present, into the past. So, time is here understood in terms of static relations between ‘being past’, ‘being present’, and ‘being future’ rather than in terms of temporal flow. He argued that this series is self-contradictory, as it may be that the distinction of past, present and future is simply a constant illusion of our minds, and that the real nature of time only contains the distinction of the B-series, the distinction of earlier and later (*Unreality* 458-459). McTaggart argues that neither time as a whole, nor the A-series and B-series, really exist, as ‘the A and B-series are equally essential to time, which must be distinguished as past, present and future, and must likewise be distinguished as earlier and later. But the two series are not

equally fundamental' (463). This makes it possible that 'a C-series does really exist' (473), as there may be several independent time-series in reality (466). McTaggart's ideas have led to a separation between 'A-theorists', who believe that the present is objectively distinct from the past and the future, and 'B-theorists', who deny such objectivity and take temporal relations between earlier and later as most important. The possible existence of a C-series, however, makes several independent time series possible in (the representation and perception of) reality, a possibility on which I will come back later. The importance of McTaggart's thoughts is summarized by A.W. Moore (1987), who states that if McTaggart's ideas are true, 'it does indeed follow that time is not a feature of reality; it is, rather, a feature of certain ways of representing reality' (7).

A third issue that is important for the understanding of time is the definition of the 'present', or the 'now'. Marina and Mason (2001) describe that according to Aristotle 'the now cannot always be the same' (177), as for him there are 'different now's'. Indeed, Aristotle argues that 'we recognize time when we distinguish the before and after in change of motion, and we do this when we recognize *two now's*' (cited in Annas 108; emphasis in the original). Conform McTaggart's C-series, independent time series can cause different realities, but I think that it may also be the other way around: that different realities can lead to different time series. Aristotle noted that time 'turns out to be always different before and after, because the now's are different' (Marina and Mason 189). As such, a person in different places or situations can have different 'now's', which are the now's depending on the context, and that is exactly what is the matter in migraine, as I will argue.

As said, in many (neurological and psychiatric) diseases, time is considered to be out of balance, as the 'normal' temporal order is disturbed (Goody *Outside* 251). So, certain diseases lead to 'alterations in the behavior of our inner clock forms' (251), of which I gave the examples of Alzheimer's disease and Parkinson's disease. There is experimental evidence from a mouse model with a migraine mutation that in migraine there is an inadequate adaptation mechanism to phase advance time shifts, such as during eastbound versus westbound time zone transitions (van Oosterhout et al., 2008). So, there might be an intrinsic altered time-perception in migraine. On top of this, migraine is extra special, as there is the double situation of either being inside or outside an attack. In my opinion, these factors may make the relation of migraine with time unique, as the perception and representation of past, present and future must be seen from two different temporal perspectives and within a special intrinsic situation. In line with the thought of two now's or presents, the present, past and future in migraine can be seen from the perspective of the two possible situations leading to six instead of three 'times' to be considered. This is in line with Goody's idea that different circumstances will produce great personal changes in the time sense, with the production of a number of different time senses (*Directions* 86). It also follows Ricoeur's 'episodic dimension', made out of events (*Narrative Time* 178) and Aristotle's idea that 'now' depends on context.

To acknowledge this special situation, I will discuss the circumstances/dimensions/events in an order adjusted to migraine: from the perspective of the two possible presents: of having pain / not having pain.

Pain restructures and dictates the sufferer's perception of time

### *Time perception during migraine seen from the two 'possible presents'*

- a) Perception of present, past and future during a migraine attack.

*Present:* The question here is how patients experience time when their reality is that of severe pain, feeling horrible, being nauseated and bothered by light, sound and smell. This question is difficult to answer, as most studies so far performed only addressed time perception outside attacks (see below). There is one (older) study that compared the time perception of patients who at the moment of investigation suffered from headache with that of subjects without headache (Isler et al., 1987). The investigators hypothesized that during headache automatic responses would be directed toward avoiding stress in general and sensory stimulation in particular, and that this reduction of information-processing would lead to underestimation of the duration of the headache. They guessed that, on the other hand, when the subjects were headache free their estimates of duration should increase. These hypotheses were tested in three experiments.<sup>38</sup> First, 38 patients with primary headache (migraine, 'muscle contraction headache', or 'mixed headaches') were asked to estimate the duration of a respiratory biofeedback session. Patients with headache at the time of the session indeed gave significantly lower estimates of the duration of the session than patients without headache. The second experiment resembled the first but used electromyographic biofeedback in 44 patients. Patients with headache again tended to underestimate the duration. The third experiment will be described below, as it only dealt with the situation outside an attack. In short, the two 'attack experiments' suggested that during headache, migraine patients had the perception that the surroundings were going faster, and thus consequently that their own time seemed to go slower. They seemed to be 'trapped' in slower time. The pain extended their perception of their now.

This finding is in line with some anecdotal descriptions of altered time perception during migraine-attacks. In 1979, Golden described two children with recurrent attacks of impairment of time sense. The first child described that she initially felt to go too fast herself and later that 'things were going too fast' (this seems to reflect 'two now's'). The second child related that 'everyone was talking too fast and that he was moving too fast'. He felt that 'everything moved too rapidly'. It seems that both children had the perception of going slower than their environment. Dooley et al. (1990) reported on 9 children who had recurrent episodes during which they perceived a distortion of time. For example, one boy felt that both he and everything in his environment moved very quickly and one of the girls thought that only her surroundings moved too quickly. The authors called this phenomenon 'the rushes'. Ebersbach and Poewe (1996) reported on a 26-year-old male who was 'lost in time' during his migraine-attacks as he was unable to judge the duration of current events. Importantly, in most of these descriptions, patients had the subjective experience that the environment was moving too fast, and that they themselves – consequently – were slower.

It can be concluded from these reports that time perception of migraine-patients during their attacks has not been extensively studied and is only known from a few studies and some described individual cases, but also that all of the sparse 'evidence' suggests that in the perception of the patient time

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<sup>38</sup> A weakness of the publication (and thus possibly also of the study) is that it is not made clear whether patients with headache were compared with other patients without headache (inter-individual) or whether the same patient was compared with himself with and without headache (intra-individual).

goes slower during attacks. This is line with studies that showed slowing down of recollected time during a frightening event (Stetson et al.; Moreira Ferreira et al., 301).

Taking my cue from Heidegger's ideas, the pain of migraine seems to consist of 'things which our concern counts on more than utensils offered to one's manipulation' (cited in Ricoeur *Narrative Time* 172). In other words, the acute concern caused by pain counts more than 'rational' manipulation, such as expressing pain in a 'pain-score' or the measurement of time. The pain of migraine may also lead to Heidegger's 'within-time-ness', as the here-and-now is most important. Referring to the notion that the present is more 'real' than the past or the future, the situation of a migraine-patient during an attack can also be compared with that of so-called 'presentism'. According to this theory 'the way things are is the way things presently are' (Savitt S563). The only things that in presentism exist are things that presently exist (S563), or to say it short: 'Only the present exists' (S564). This seems too logical or even nonsense, but it reflects that for a sense of 'reality' at a given moment past and future are less important than the here-and-now. This seems to be the case during a migraine attack.

As in illness in general, headache can cause an accentuated focus on the present and make the past and the future shrink away. Williams (1951) phrases it as, 'the totality of being consists of the set of events which are simultaneous with the utterance "now"' (458; emphasis in the original). In her article "Suffering over Time. Six Varieties of Pain" (1989), Lana Hartman Landon writes that 'pain is the *now* from which there is no escape except death' (75-76; emphasis in the original). In her opinion, 'the sufferer is trapped in the *now* of the pain' (76; emphasis in the original), and 'there is no time for the most human activities: recollection, anticipation, and reflection' (76). So, past and future disappear in the present. When migraine patients are in the middle of an attack, the pain obviously is the dominating part of their reality. The character of their lived temporality changes into an emphasis on now, but what about their past and future?

As said, it is very likely that during a headache attack the past will disappear in the present. The patient will not think about the previous days, weeks or months, but about today. Important for the patient is the present attack and not the previous ones. It is possible that he or she will think about the time shortly before the onset of the present attack to search for a possible explanation for its occurrence, like a for example a lack of sleep, stress, certain food or menstruation. This human tendency to perceive events that are close in space and time more likely to be causally related than events further apart was already described by the English philosopher Hume in the eighteenth century (Muller and Nobre 63). Often, this tendency will lead to Nietzsche's 'pin-pain' confusion, replacing cause and effect (see chapter 1). Moreover, as Lord Brain has put it in a presidential address in 1962: 'Our vocabulary for the description of pain is relatively poor and we tend to fall back on terms which describe a pain by describing the way in which it might have been produced, even though in the particular instance it has not been so produced' (cited in Merskey *Psychological* 302). For Nietzsche, it is the model of linear mechanistic time which introduces such 'causal and teleological logic' (cited in Hartog 136). By thinking of such 'reasons', patients sometimes get the idea that they had caused the attack themselves, which even can lead to a feeling of guilt. Here, another of Nietzsche's thoughts comes into mind, namely that 'we cannot bear meaningless suffering and so we give it meaning' (cited in Kain *Horror* 59). For Nietzsche, suffering, however, must not be seen as punishment or admittance of guilt (59). For him it is *amor fati*: love of one's fate (see chapter 10).

During a migraine-attack the patient will think of only one thing: the end (of the attack), and this time-point lies in the future. Especially at this time, however, the future is uncertain, and some patients even doubt whether there will be a future at all. The idea that 'the next moment can always be the last' (Svenaeus *Illness* 338), can come into their minds. As illness in general, the temporal structure of migraine can lead to an alienation of the future and necessitates 'a re-visioning of the future' (333). Indeed, in this way, an accentuated focus on the present will probably lead to a shrinking away of the future.

b) Perception of present, past and future from outside an attack.

Hartman Landon (1989) has compared intervals of relief in pain with a pause in music (76). One of the six types of pain in her categorization is 'dependable' pain, in which the pain can be anticipated and be expected at a predictable time. The interval between the pain, 'allows the patient to move from inside the *now* of the pain to a stance outside and independent of it' (76; emphasis in the original). Although her description of dependable pain resembles aspects of migraine, she categorizes migraine under 'unreliable' pain (77). This is pain that cannot be predicted on the basis of past experience (77). It is unreliable, because the time between attacks is irregular and arrhythmic.<sup>39</sup> A feature of unreliable pain is that it is defined by anxiety (77), in the case of migraine this is the anxiety for the next attack, also called cephalalgiphobia (Peres et al., 2007; Giannini et al., 2013). Time is measured by the length of time between attacks and 'the longer since the last attack, the more likely one is near' (77).

When a migraine patient visits a doctor, it is almost always in between attacks. The previous attack has ended and the next one will probably come. The end of the last attack marks the 'road' to the beginning of the next. Further, it counts that: 'repetition is constitutive of the temporal form itself' (Ricoeur *Narrative Time* 186). At the appointment not much will be spoken about the present, as the patient will almost always be symptom-free, but much attention will be given to the past and the future. Was the headache splitting, hammering or something else? How long did it last? The patient may hesitate to answer, wavering between trying to recall the sensation itself and choosing the words to describe it from a distance. This is different from the situation during an attack, as described above. The present, however, is always regarded as having more reality than the past or the future (McTaggart *Relation* 348). And – to quote Ricoeur again – 'thanks to repetition as fate, retrospection is reconnected to anticipation, and anticipation is rooted in retrospection' (*Narrative Time* 182). Thus, the present of the patient with migraine outside an attack is rooted in retrospection and anticipation.

As above for the time perception during an attack, I will now describe present, past and future from the perspective of the periods between the attacks.

In their study of illness-perception of patients with migraine, Radat et al. (2013) found that most migraine patients perceived their illness as successive crises and not as a pathogen process outside the crises (394). They used this as explanation of why many patients resented treatments that must be taken in the long run (so-called preventives) and preferred treatments with a chance of immediate efficacy at the moment the pain is present (attack-treatment). So, migraine was perceived as consisting of successive, separate crises but not as a progressive disease. Its cause and

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<sup>39</sup> An exception is menstrual migraine, which is regular and rhythmic (see above).

consequences were attributed to the separate attacks, but the notion to have a permanent, chronic disease was absent from the discourse. This probably reflected the on-off occurrence of the attack. Rimmon-Kenan (2006) describes an illustrative comparable situation when she cites the words of a patient with breast cancer: 'When you have cancer, you have a new body each day, a body that may or may not have a relationship with the body you had the day before' (242). Without any intention to suggest that having cancer is comparable with having migraine, this sentence is also true with respect to time when 'cancer' is replaced by 'migraine'. When you have migraine, each day your head is 'new'<sup>40</sup>. It can be a day with or one without headache.

As already said, most studies of time perception in migraine-patients were performed outside attacks, when the patient was pain-free. Anagnostou and Mitsikostas (2004) found no evidence that patients with migraine did generally over- or underestimate temporal events. Zhang et al. (2012), on the other hand, found that patients with migraine significantly overestimated the duration of a visual stimulus when compared with healthy subjects. They explained the different outcome of their study with that of Anagnostou and Mitsikostas by the different study-parameters used, as they used a visual stimulus themselves and Anagnostou and Mitsikostas used auditory stimuli. Vicario et al. (2014) studied time perception in children with migraine and found that these also tended to overestimate temporal intervals. They explain this finding biologically, by pointing at changes in the functions of dopaminergic and serotonergic receptors in migraine (552). Zhang et al. conclude that 'migraine can be regarded as an information-processing disorder, both during migraines and during the interictal period' (1495), but – as said – they did not investigate this during attacks. The already mentioned third experiment of Isler et al. (1987) showed that primary headache patients tended to overestimate the duration of a reading task when they were headache free.

Taken together, also outside attacks the time perception of migraine patients seems altered for one reason or another. In most studies signals from the outside seemed to last longer, which is in contrast with the perception during attacks as described above. Outside attacks, time seems to go faster for the patients, while during attacks time was slower.

In general, we all seem to experience difficulties in estimating time, but in patients with headache this seems more pronounced (Blau *Diagnosing* 22). It has also been shown that there is a considerable difference between retrospectively (without prior warning) and prospectively (forewarned) estimating time (Macar et al., 1993). The ability to accurately estimate time seems to depend on the amount of attention devoted to the passage of time at the actual moment (673).

Past migraine attacks seen from the (pain-free) present, which is the usual situation in a patient – doctor encounter, must be recalled from memory, and 'for memory to exist at all, the sense of time must be intact' (Goody *Directions* 83). Past headache has a past-oriented property, in the sense of having been painful. It is still an event, which counts for the patient, but it isn't painful anymore. One could suggest that the physical pain has ended, but that the mental pain still lasts. As Toombs (1990) has said: 'the patient is obliged to recollect past events and relive his illness, not in its immediacy, but in an 'as-if' presentation (*Temporality* 234). For this recollection, of course memory is important. Memory, however, is not a static repository of knowledge and experience but 'an active arena of reconstruction – remembering, embodying, and extending experience as it unfolds' (Kirmayer *Culture* 331). Memory is also selective; '*events of importance are chosen because of their usefulness in*

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<sup>40</sup> This can be a description of episodic as well as chronic migraine (see chapter 3).

*directing future conduct* (Goody *Directions* 84; emphasis in the original). It has been questioned whether a 'pain-memory' exists. As described before, Hunter and colleagues (1979) demonstrated in pain-sufferers a remarkable ability to remember the intensity and quality of pain, but it was likely that the recalling referred to the words used to describe the pain instead of the pain itself. Previous studies of the recall of chronic and acute pain gave variable results (summarized in Babel 2015), as every outcome was possible. Pain could be overestimated, underestimated, or recalled accurately. Factors that could possibly explain these different outcomes were pain-intensity and the length of time between the pain episode and its recall.

There are no studies about the remembering of the duration or intensity of migraine. A systematic analysis of headache diaries and calendars could probably answer some of the questions, but such studies have not been performed (Nappi et al., 2006). This lack of controlled studies can be seen as remarkable, as the diagnosis and treatment of migraine almost fully depend on these variables.

There is, however, another type of short-lasting (but not regularly recurring) pain that has extensively been studied in the context of 'memory': the pain of labor (Erskine et al., 1990; Niven and Brodie 1995; Niven and Murphy-Black 2000). Most of the studies addressed the memory for the severity of pain, but a few also included the memory for the duration of pain. For example, Niven and Brodie (1995) found that only 26% of women accurately recollected the duration of their labor pain. For many women in that study, time 'stood still', as exemplified by one of the participants who said: 'I remember just thinking 'My God how much longer will I be in labor.' I kept looking at the clock, it seemed to stay still' (389). Recent systematic studies on the recall of labor pain have discovered two important phenomena. First, there is the so-called 'peak-and-end rule' which indicates that the most intensive state of pain and the final state are best remembered and that these are assessed according to their average (Chajut et al., 2014; Harari 344). Second, the duration of the pain is often hardly remembered, and often even largely neglected, a phenomenon which is therefore called the 'duration neglect' (Fredrickson and Kahneman 1993). The writer Milan Kundera once remarked that 'memory does not make films, it makes photographs' (Kundera 1991). This is in line with the 'peak' rule, which refers to a moment (or 'snapshot' according to Fredrickson and Kahneman 1993), but also to the 'duration neglect', as the memory of pain is not as a film.

It can be imagined that aversive experiences (such as labor pain or a migraine-attack) would be preferred to be shorter retained in memory. However, time is cumulative and this extending of the duration of an aversive experience adds to the negative affect. On the opposite, one can imagine that pleasurable experiences are remembered to be of a longer duration than they actually were, but in general this is not the case. For example, in a study of the memory for pleasant meals also a duration neglect was demonstrated (Rode et al., 2007). So, the memory for both aversive and pleasurable events is less dependent on the duration than on the peak intensity of the experience. Interestingly, Miron-Shatz (2009) evaluated the peak-and-end rule and duration neglect in the memory of multi-episode events and found that the peak-and-end were less important than 'normative' factors (including duration). There was a duration neglect, but the participants based the time-ratings of the occurrences of the previous days mainly on two selected 'fixed' time points and they ignored the rest. Most migraine patients seem to do the same: they focus on the peak of the last attack or couple of attacks, and not on the long-lasting chronic course of their disease, or on the duration of individual attacks. This tendency is called 'recall-bias' and is a characteristic of many other diseases.

*Future*: The past and present are (by definition) 'real', whereas the future is not more than a possibility. No one knows his or her future. When I have no pain today, will I also have no pain tomorrow? It has been said that 'the uncertainty of the future intensifies the *now*' (Hartman Landon 81; emphasis in the original). Dingle's notion that 'our concept of time enables us to foretell events and to know at what reading of our clock they will occur' (235) seems especially true for migraine. According to Levison (1987), the thought that events are carried from the future towards the present and then recede further and further into the past seems to be deeply embedded in our common-sense way of looking at the world (341). This 'temporal passage' can be easily understood as being important for migraine patients, as the next attack is already waiting for them in the future. Indeed, 'in the process of planning, we make use of memory, by applying our present memory to a future set of imaginary, but likely circumstances. [...] From what we recall of the past, under the labels of memory and experience, we calculate the probabilities of future events' (Goody *Directions* 86-87).

Although criticized for the general notion of time, this passage seems true for migraine where some prediction of the future (the next attack) is possible. If one accepts that when one is born at  $t_1$  and will die at  $t_2$ ,  $t_1$  will move further away and  $t_2$  will approach. In the same way, one can accept that the next migraine attack (say  $t_3$ ) will also approach. Thus, to (mis-)use Heidegger's term 'existence towards death', which refers to one's own personal history as 'authentically meaningful when I accept responsibility for my own existence, seize my own future possibilities and live in enduring awareness of my own future death' (cited by Eagleton 56-57), it can be said that the enduring awareness of one's own future death can also be translated to the awareness of one's future (and unfortunately almost unavoidable) migraine-attack, as a sort of 'existence towards the next attack'. Frank (2004) describes chaos stories as antinarratives 'that are told from within *dehumanized* time' (*Asking* 213; emphasis in the original). This dehumanization seems a consequence of the transient, paroxysmal and unpredictable nature of migraine. Here the words of a famous migraine-sufferer (Friedrich Nietzsche) come into mind, who wrote about 'eternal recurrence' in *The Gay Science*:

This life as you now live it and have lived it, but every pain and every joy and every thought and sigh and everything unutterably small or great in your life will have to return to you, all in the same succession and sequence. [...] Do you desire this once more and innumerable times more? (cited in Kain *Horror* 53)

According to Nietzsche, this 'eternal recurrence' shows one the horror of existence but is also a part of *amor fati* (both are further worked-out in chapter 10).

It has been said that 'the defining criterion for evaluating the healthiness of past experiences is whether or not past experiences are considered closed and distant [...], or whether they are actualized in current affairs and future plans' (Sools 104). In schizophrenics, for example, the difficulty in coping with the future makes it hard for the patient to plan and make decisions (Hellström and Carlsson 422). It can be argued that in them intentional time is disturbed. Thus, it has been suggested that in schizophrenia 'the implicit or automatic temporal synthesis necessary for the constitution of reality is disturbed, and that this leads to fragmentation' (Fuchs 230). Likewise, it has been said about pain that it 'registers a lot like foreshadowing. It is as much as an immediate, present-tense phenomenon as it is the anticipation, anxiety, and uncertainty of what the future holds; it involves having pain as much as it does the threat of having pain' (Biro 103). One can argue that in migraine the fragmentation caused by the disease causes a disturbance of the constitution of



reality through a disturbed perception of time both in- and outside attacks. It can therefore even be said that disturbed variants of so-called 'achrony' (a term I borrow from narratology) occur. One form of achrony is 'anticipation-within-retroversion', in which someone is referring forward within a back-reference (Bal 96). In other words, a migraine patient describes how in the past he or she thought about a future attack. As I have argued above, this will probably not have taken place during a migraine attack, as the patient will not think about the future then. It can be imagined that during a previous attack-free period the patient has thought about the future. Another form of achrony is 'retroversion-within-anticipation', which is the exact opposite of 'anticipation-within-retroversion'. Here, on beforehand, it is told how circumstances in the 'present' will be re-presented (remembered) in the future (Bal 97). This will not apply to a future migraine-attack, as then the 'present' will not be remembered, but one can form an idea of how in the future will be looked back at the (pleasant) situation of 'not-being-in-an-attack'.

In migraine, the end of the pain is the herald of the beginning of the next pain to come. This temporal repetition again can be referred to Nietzsche, who describes in Zarathustra three notions of repetition, being 'the repetition of the past, that is, the notion that the past will repeat itself in the future; the repetition of the present, that is, the notion that there is an omnipresent "now," or present moment, that is repeatedly present in all times, places and things; and the repetition of the possibility of a future that interrupts the reproduction and repetition of the past' (cited in Loeb, 2007). The future of migraine-patients consists of their expectation, which is in most instances the fear for the next attack, the cephalalgiphobia. This fear of what is coming is, obviously, also influenced by the reminiscence of past experiences as, in general, it is impossible to expect or be afraid of something one does not know (Babel 865). It has been shown that in migraine so-called 'rumination' occurs, mainly reflected in the tendency to perseverative thoughts (Kokonyei et al., 2016). The cause of this is thought to be 'the discrepancy between one's current state and desired state' (e.g. 'Why do I have migraine?'). So, recurring acute pain 'is planted in memory, and may even exert enduring effects when not present' (Kirmayer *Culture* 330; Freitag 2007). In line with this, Rachman and Eyrl (1989) found in recurrent pain (not specifically migraine) a relation between memory and expectation. Remarkably, in their study patients tended to remember the pain they had expected more than the pain they actually experienced, as there was a closer correspondence between predicted pain and the recall of pain, than between actual pain and recalled pain. There was what the authors call 'an erroneous magnification of prediction'. Gedney and Logan (2006) also found that pain is remembered inaccurately and becomes exaggerated over time. Past pain modulates the expectation of future pain. Likewise, Noel et al. (2012) found that children developed greater pain expectations prior to a subsequent pain experience. There is a remarkable parallel between these misjudgments of past pain and the duration neglect and peak-and-end rule described above.

However, not the reworking of previous pain (which can never be alleviated anymore) is the most important, but how a patient deals with the expectation of future pains. There is no doubt that in migraine interictal burden exists (Lampl et al., 2016), as patients tend to worry about the next episode (cephalalgiphobia). To borrow a term from narratology again, one can speak of 'iterative anticipation', in which an event is presented as the first in an anticipated series (Bal 94). The anticipation of something that is likely to occur repeatedly often leads, unfortunately, but understandingly, to fear (Hursey and Jack 1992; Asmundson et al., 1999; Freitag 2007; Brandes 2007; Rutberg and Öhrling 2012; Black et al., 2015). It has even been said that fear of pain can even be

more disabling than the pain itself (Black et al., 670). Leder writes of this 'not-being-in-pain' that it is 'perhaps startling, inducing both hope and fear given its precarious nature', and uses this to adjust Emily Dickinson's poem to:

*Not-Being-in-Pain* – has an Element of Blank –

It cannot recollect

When it began – or if there were

A time when it was not –

(Leder *Experiential* 450; emphasis in the original).

The double negation (not-being-in-pain, when it was not) could refer to the paroxysmal nature of migraine, as the not-not points at the presence of pain. Chronic pain can 'simultaneous seem both never- and ever-changing' (450), and that is exactly what is the matter with migraine. About chronic pain Leder concludes that it is 'truly the pain of time itself (*khronos*), unless the sufferer can make peace with the three-faced god of past, present, and future' (451; emphasis in the original). But also that "'Chronic" pain (the pain of *khronos*, time) is also the pain of *topos* (place), changing our place in the world' (454; emphasis in the original). And this is also what is the matter with migraine, but then in an 'on-off' manner. The perception of time changes during an attack and the 'place in the world' literally changes also (as patients tend to lay still in a dark and silent room to avoid light and sound), and with their change of place their 'now' also changes, as argued by Aristotle.

Of a migraine attack, it can be said that, 'It began by being a future event. It became every moment an event in the nearer future. At last it was present. Then it became past, and will always remain so, though every moment it becomes further and further past' (McTaggart *Unreality* 460).

To which I can add that in migraine this must be multiplied by  $n=x$ , as this description can be applied to each past, present or future attack, and its 'eternal' recurrence.

Man, the still-unconquered eternal-futurist who finds no rest from the force that propels him, so that his future mercilessly digs into the flesh of every present like a spur – how could such a courageous and rich animal not be the most endangered as well, of all sick animals the one most profoundly sick, and for longest?

Friedrich Nietzsche, cited in McNeill 2015

## Conclusion

In my doctor's office I am talking with a migraine patient. We are in the same space, but maybe not in the same time. We both have (at least) two beetles in our boxes: the one is called 'pain' and the other 'time'. I try to understand and envisage the patient's beetles, but this is very difficult. As I have argued, the time perception of migraine patients is different during and outside attacks, so this

particular patient maybe even has two beetles which can be called 'two perceptions of time'. This makes my task even harder. I must realize that maybe for a migraine patient during an attack time seems to go slower, whereas outside an attack (and consequently at the actual moment) it goes faster. According to Kant space and time are *a priori* forms that determine our world. He questions whether both time and space are constructs of the mind. As the patient may have different perceptions of time, which I have called 'different presents' – but which can also be called 'different now's' in the Aristotelian sense – he or she will consequently be in McTaggart's C-series in which (at least) two different times exist.

For the patient in my office, the last attack is the most important one. For me, the pattern of attacks over time is much more important, as this is needed for making a diagnosis and to give (preventive) advice. Also, these different viewpoints can lead to two different ontologies: for the patient the acute perspective and for me the chronic one. We have different three-faced gods of past, present, and future. As phrased by Toombs (1987) from the perspective of a patient (she suffered from multiple sclerosis): 'Rather than representing a shared reality between us, illness represents in effect two quite distinct realities' (*Meaning* 219). These different ontologies / realities are also different realities of time and in migraine must be at least multiplied by two.

Nevertheless, to help my patients, I must try to understand their words and their worlds, including their perception(-s) of time. For this, I must leave my own notion of so-called objective time and try to imagine the subjective time of the patient, or at least combine it with my own subjective time. First, I must explain to the patient that his or her migraine attacks must be seen in the context of time. It is not the last attack that is most important, but the composite of many attacks, which form Heidegger's 'plural unity of future, past, and present' and Bergson's 'duration': the organic whole of past and present which gnaws into the future, and which swells as it advances. Indeed, whatever past and present were and are, for both me and my patient the future is the most important of all: what is coming and what is to do about it?

Kierkegaard described life as 'lived forwards while understood backwards' (cited in Lerner 1998, 556). In my opinion, this is not wholly true for migraine, as then life should be 'understood forwards'. The understanding of time is an important aspect of this understanding, as I must realize that the 'now' of the patient in my office is much different from the 'now' he or she experiences during attacks. At those moments, a timeless state might occur in which past, present, and future are merged into a single instant, call it presentism. During attacks there appears to be a focus on the 'now' and time perception changes, probably even leading to a duration neglect. To realize the existence of this and other neglects – and to overcome it, together with my patient – is one of my main tasks as doctor.