

Oliver Sacks and migraine

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Abstract

Background: Oliver Sacks (1933–2015) published a large number of books on a variety of neurological topics. Of these, numerous copies have been sold and they probably serve as the only or main source of information on neurological diseases for many persons without a medical background. His first book was on migraine and in his subsequent books many descriptions of migraine can be found, mainly those of auras.

Methods: We explored the descriptions of migraine in Sacks' work in order to evaluate the image of migraine offered to the readers.

Conclusion: Oliver Sacks gave wonderful descriptions of migraine auras, but hardly any of migraine headache. Furthermore, he described rare auras such as 'amusia' and olfactory auras. Overall, this makes his descriptions of migraine not very useful to serve as medical information for laypersons. Oliver Sacks, however, wrote great literature.

Keywords

Oliver Sacks, migraine, aura, images of illness, narrative review

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Introduction

The British born, American-trained neurologist Oliver Sacks (1933–2015) was probably one of the best-known neurologists worldwide (1). He became particularly famous for books like *The Man who Mistook his Wife for a Hat* (1985), *Awakenings* (1973) and *Musicophilia* (2007), and for the film version of *Awakenings*. A complete overview of his work can be found online at <http://www.oliversacks.com/>. Being read across the globe by millions without a medical background (his books have been translated into over 25 languages), Sacks' texts probably serve as the only or main source of information on neurological diseases for many. Mergenthaler (1) points at the contradiction that: 'Conversely to his vast popular celebrity, Sacks' books have attracted relatively few genuine scientific and medical interest. The secondary literature dealing with Sacks in a scientific sense is very rare and diverse in journals for philosophy, literature, culture and only rarely for medicine. The main part of Sacks' reception can be picked up in the daily press.' She concludes that 'while usually underestimated by his colleagues, Sacks has caused an enormous positive feedback among non-professionals' (1).

Sacks' first book was titled *Migraine* (1970), and in his subsequent books many descriptions of migraine can be found. Here, we explore the descriptions of migraine in Sacks' work in chronological order to evaluate which picture of migraine emerges to serve

as information for 'non-doctors'. This is of particular interest currently, as physicians, including headache specialists, are increasingly confronted with patients who have informed themselves through non-medical sources, including the internet, prior to their (headache) consultation. Our main research questions will therefore be: 'What do the works of Oliver Sacks teach the general public about migraine?'

Migraine (1970)

The first book published by Sacks, *Migraine*, is set up as a traditional monograph on a medical subject (2). It starts with a 'Historical Introduction', in which Sacks describes the development of ideas about migraine from

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Greek and Roman times to the present. In the following part called 'The Experience of Migraine', he gives a state of the art description of 'common migraine', 'migraine equivalents', 'migraine aura and classical migraine' and 'hemiplegic migraine'. 'The Occurrence of Migraine' deals with 'predisposition' (incidence, inheritance, age, provocation, etc.), 'The Basis of Migraine' with pathophysiology (physiological, biological, psychological), followed by 'Therapeutic Approaches'. The final part (co-authored by the neuroscientist Ralph M. Siegel) carries the enigmatic title 'Migraine as a Universal' and gives an overview of Sacks' ideas about visual auras, which he divided in 'phosphenes', 'scotoma' and 'geometrical patterns'. The 'Universal' in the title refers to Sacks' hypothesis that visual hallucinations similar to those in a migraine aura can also be caused by mescaline, cannabis, hypoglycaemia, fever, cerebral ischaemia, epilepsy and flickering or rotating visual stimuli. He argues that 'complex neuronal events and integrations are determined less by local considerations of microanatomy and nuclei and columns and centers than by global considerations of wave actions and interactive in an alive, spontaneous active, enormous complex neuronal medium'. Thus, Sacks proposes as the cause for visual symptoms such as in migraine a universal reaction to an aspecific stimulus. He based this theory mainly on that of the physiologist and psychologist Heinrich Klüver, who regarded almost all forms of primitive visual hallucinations as 'form constants' (3,4). In his books, Klüver included several descriptions of his own hallucinations after the use of mescaline, and considered them identical to those found in migraine.

Scattered through the different parts of *Migraine* are many case descriptions, some on headache (there are 21 pages on 'Common Migraine', with 10 cases) and much more on auras (the chapter on 'Migraine Aura and Classical Migraine' includes 48 pages with 14 cases). In the Preface, Sacks wrote: 'When I saw my first migraine patient, I thought of migraine as a peculiar type of headache, no more and no less. [...] I delved into the literature of the subject, submerged, and then re-emerged, more knowledgeable in some ways but more confused in others. I returned to my patients whom I found more instructive than any book' and 'Every patient with classical migraine opened out, as it were, into an entire encyclopaedia of neurology' (2). In the Acknowledgement, he thanks his patients, as they 'have provided me with the clinical reality from which all observations were derived, and against which every idea has had to be tested.' *Migraine* was written in the descriptive, pre-ICHD classification era and as such had its limitations; nevertheless, it remains an impressive text on a fascinating topic.

A Leg to Stand on (1984)

After *Migraine* and *Awakenings* (1973), the latter being on post-encephalitic patients, Sacks turned to a different kind of narrative, which he has called 'a neurological novel' (5). In *A Leg to Stand on*, he does not deal with patients, but he is the patient himself (6). It is described as 'an account of Sacks' descent into the underworld of patienthood' (7). When making a trip in the Norwegian mountains Sacks falls and injures his leg. He is taken to a local doctor ('himself a red-faced son of the soil'), brought to the small local hospital at Odda ('a cottage hospital, with only a dozen beds or so'), and from there transferred to London for an operation. 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. 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'. Here, his ideas about 'scotoma' (see below) emerge. The book has been subjected to many scholarly studies (7–11), mainly because of Sacks' 'holistic' reflections on the body-mind relationships. Most recently, the deficits, as he described them in the book, have been diagnosed as a 'functional paralysis' (11), a diagnosis Sacks did not agree with (12). He saw the problems with his leg as 'normal brain response to a peripheral injury' (12).

Of great importance for the present analysis is that in *A Leg to Stand on* Sacks also described a migraine attack he has had himself when in the hospital. The attack starts during a dream. Parts of the familiar pear-tree and garden wall appear to be missing and his mother (who was already deceased at that time) seems bisected. Then Sacks wakes up at the moment nurse Sulu enters his room. Sacks: 'Oh...ummm...its's nothing. I just had a bad dream'. He doesn't dare to tell the nurse that she is bisected also. Sacks realizes he has 'one of my migraines', of which the visual scotoma had come during sleep. Now he finds the 'half-vision, the hemianopia, [...] rather funny'. He 'giggles' and asks the nurse for a breakfast after 'my stomach and eyesight has settled'. Before that, he asks her to walk across the room to notice that she transforms into a mosaic, to 'become inorganic'. Then 'the mosaic, the flickering, were gone in an instant. "That's it", I said with delight. "I think you helped to chase the aura away! And the nausea is all gone. Now – yes, *now* – I would like those kippers I smelt earlier' (emphasis in the original). Shortly thereafter, Sacks is able to eat 'an enormous, a most sumptuous breakfast', being 'reborn after my night of horrors and migraine'. After this, he develops ideas about 'scotoma' and 'being-scotomized',

to conclude that ‘a scotoma is a hole in reality’, and that this is also going on with his ‘missing leg’: ‘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.’

In the following chapter, called ‘Limbo’, he philosophizes about the (migrainous) scotoma: ‘The word “hell” supposedly is cognate with “hole” – and the hole of a *scotoma* is indeed a sort of hell [...] and ‘a *scotoma* is a hole in reality itself’ (emphases in the original). Sacks felt himself sinking, engulfed in an abyss. He associates the lack of understanding of his doctors to this abyss and quotes Nietzsche: ‘If you stare into the abyss, it will stare back at you’, to decide 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.’ He turns to art and religion (‘not to science’) for comfort. Wiltshire describes this episode as ‘the horror of migrainous “scotoma” [...] may be felt not just as failure of sight, but as a failure of reality itself’, an uncanny ‘hole in the world’ (7). Diedrich (10) goes one step further: ‘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’.

The Man who Mistook his Wife for a Hat (1985)

This is one of Sacks’ most famous books, with many intriguing case descriptions (13). It is the book that made Sacks also very popular among the general public. There are no cases with migraine, but one of the appendices deals with ‘The Visions of Hildegard’ (which was first published as appendix in *Migraine*). Hildegard von Bingen was a German abbess, mystic and composer of church music, who lived from 1098 to 1179, and who left several texts with descriptions of her visions (*Scivias, Liber divinorum operum simplicis hominis*) and several drawings of her visions. According to Sacks, these represent her migraine: ‘A careful consideration of these accounts and figures leaves no room for doubt concerning their nature: they were indisputably migrainous.’ This opinion had already been expressed in 1917 by Charles Singer, a British physician and first President of the British Society for the History of Science, who suggested that concerning ‘the more typical of these [Hildegard’s] visions, in which the medical reader or the sufferer from migraine will, we think, easily recognize the symptoms of “scintillating scotoma”’ (14). Singer’s publication was neglected by the scientific community, except for a Lieut.-Col. R.H. Elliot who gave a lecture at the Medical Society of London in 1932 on ‘Migraine and

Mysticism’, claiming that ‘several of my patients, looking at her [Hildegard’s] graphic illustrations, have recognized in them without hesitation features of their migraine attacks’ (15). Elliot adds: ‘Let me remind you that some of our patients are much richer in migraine symptoms than others. This richness is, I think, more often observed in clever intellectual people endowed with the creative type of mind’ (15).

Since Sacks’ revival of Singers (and Elliot’s) theory, a debate developed between scholars who agreed with Singer’s/Elliot’s/Sacks’ idea that Hildegard offered a clear example of migraine (e.g. (16,17)), and others who suggested that her drawings are not at all typical for a migraine aura, thereby refuting the suggestion that Hildegard suffered from migraine (18–20). Recently, Foxhall (21) pointed at the unreliability of ‘interdisciplinary borrowing’ and ‘disease biographies’ when reconstructing the life of a diseased. Her careful analysis of the process by which Singer came to the theory of Hildegard as migraine-sufferer shows that the diagnosis is – to say the least – dubious. She also mentions Sacks’ role in the survival of the theory and specifically points at his ‘emphasis on migraine aura’ in *Migraine* and that ‘the narrow definition of migraine that the Hildegard imagery represents ([...] revived in part by Oliver Sacks [...]), excludes a large proportion of migraine sufferers who do not see their own experiences in these images.’

Based on his careful analysis of many drawings by migraine patients, Schott (22) concluded that ‘Hildegard’s “fortification figures” resemble the castellated tops of battlements, which are depicted together with human figures, but not the scotoma of migraine’. He argues: ‘To the present writer neither Hildegard’s illustrations, nor her descriptions, are at all suggestive of migraine aura’, and concludes that here, ‘illustration has been instrumental in discriminating fact from fiction.’ The question remains why Sacks recognized his own visual auras in Hildegard’s drawings, that must be at least considered atypical for migraine (at present, most neurologist would favour some form of visual epilepsy to explain her descriptions, but one can never know for sure without an EEG). Nevertheless, also for the auras of Sacks it is true – to quote Schott again – that ‘the visual aura of migraine is a subjective phenomenon. What the migraineur experiences is necessarily inaccessible to others.’

Introduction of Liveing’s On Megrin (1993)

The English physician Edward Liveing (1832–1919) published his famous monograph on migraine called *On Megrin, Sick Headache and Some Allied Disorders* in 1873 (23). In it, he unfolds his theory on the pathogenesis of migraine and ‘brain storms’, much of which

still stands today. The 1993 reprint of the text includes an 18 pages introduction by Sacks, starting as follows (24):

I am going to introduce this book on a personal note. I started seeing patients with migraine in a clinic in New York in 1966. If I had first thought of migraine as a simple headache, or a “sick-headache,” or even a “blind-headache,” I was soon to be disabused – migraine-attacks, I rapidly realized, could be of a complexity and a diversity none of my previous readings had prepared for me. My patients described every conceivable cerebral disorder: not only the classical scintillating scotomas and visual field defects, but strange metamorphopsias and achromatopsias, Lilliputian hallucinations, palinopsias; not only the “classical” paresthesiae of arms, legs and mouth (so like Jacksonian “sensory fits” in slow motion), but bizarre disorders of body-image of every kind. I heard descriptions of strange olfactory hallucinations [...].

Sacks highly praises Liveing:

[...] All that had fascinated and puzzled me with my patients – their huge range of symptoms, their often inarticulate distresses, the odd “metamorphoses” of their attacks – all these were discussed, as with an old friend, in the ample pages of Liveing.

Sacks ‘arranged to get the whole book photocopied’ and it became his ‘closest companion for a year.’ He calls *On Megrim* ‘a treasure of clinical observations’, which was ‘crucial for the generation of my own thoughts and book’ (referring to *Migraine*). Liveing’s depiction of migraine defines for Sacks ‘a strange land’.

After reading this introduction, it is confirmed that Sacks has learned a lot from talking to his migraine patients, an experience he had already described in *Migraine*, but it is not clear why he does not mention his own migraine (described for the first time in 1984) at all in this lengthy text, which even starts with a ‘personal’ note. His fascination for Liveing’s text will make an extensive comeback in *Hallucinations* (2012), see below.

Uncle Tungsten: Memories of a Chemical Boyhood (2001)

This autobiography covers only the first 15 years of the life of the author and mainly focuses on his fascination for chemistry (25). Migraine is only mentioned once:

The other side to all of this, I came to realize – a sort of deconstruction or decomposition – could occur when I

had migraines, in which there were often strange visual alterations. [...] I was terrified when I got attacks like this – they started when I was four or five, before the war – but when I told my mother about them, she said she had similar attacks, and that they did not harm and lasted only a few minutes. With this, I started to look forward to my occasional attacks, wondering what might happen in the next one.

The young Oliver Sacks is a migraine patient who looks forward to the next attack. This is in contradiction with the experience of most other migraine patients who not only suffer during, but also between attacks, as they then have considerable fear of the next attack (26). The main fear is of pain, but there is fear of the aura also. There has, however, not yet been a study of interictal fear in patients who suffer exclusively from auras without headache.

Musicophilia (2007)

Writing *Musicophilia*, as Sacks stated in the foreword of the book, was inspired by the selection of essays called *Music and the Brain* published by McDonald Critchley (27). Sacks’ own migraine appears in *Musicophilia* in the description of two attacks with so-called amusia (one of the chapters in McDonald Critchley’s book also deals with this topic). In the first attack, Sacks ‘was driving along the Bronx River Parkway, listening to a Chopin ballade on the radio, when a strange alteration of the music occurred.’ The music changed to a sort of toneless banging and Sacks lost all sense of melody as part of a migraine aura (without headache). The second attack occurred two weeks later when Sacks was playing Mozart on the piano. He experienced a loss of tone and unpleasant metallic reverberations. This time, however, he also had a scotoma, for which he realized that the amusia was part of his migraine attack (again without headache): ‘My experience, like most of those described in the neurological literature, was of an *acquired* amusia’ (emphasis in the text).

Amusia is a very rare symptom associated with migraine, with no hits in PubMed (May 2016) with the search terms ‘amusia and migraine’ and one with ‘music and loss and migraine’, the latter being a personal account of losing the ability to read music and play the piano after a right angular stroke ‘in the setting of migraine’ (28).

Hallucinations (2012)

This book contains wonderfully written chapters on the Charles Bonnet syndrome, parkinsonism and narcolepsy, among other topics (29). The chapter called

'Patterns: Visual Migraines' deals with (visual) migrainous auras. Sacks starts the chapter with a description of his own migraine: 'I have had migraines for most of my life; the first attack I remember occurred when I was three or four years old.' He again describes being terrified by the experience and the relief after hearing the explanation of his mother (who was also a doctor and 'a migraineur'). His mother described it as a 'zigzag shape [...], so it was called a fortification pattern.' Later she would tell him that auras resemble 'medieval forts'. Sacks realized that 'I was lucky to be one of those people who got only the aura without the headache.' His auras were mostly visual, but in *Hallucinations* he also describes a peculiar variant.

Hallucinations of smell are not uncommon – the smells are often intense, unpleasant, strangely familiar, yet unspecifiable. I myself twice hallucinated a smell before a migraine, but a pleasant one – the smell of buttered toast. The first time it happened, I was at the hospital and went in search of the toast – it did not occur to me that I was having a hallucination until the visual fortifications started up, a few minutes later.

Whereas osmophobia is common during the headache phase of migraine attacks, hallucinations of smell as part of the aura are very rare (30). In addition, when they occur, they are virtually always unpleasant, in contrast to those of Sacks.

Another chapter in *Hallucinations* (called 'Altered States') contains a description of Liveing's *On Megrim*, which Sacks largely bases on his previous 'Foreword' (see above). There are, however, some remarkable new revelations. Sacks describes how he found *On Megrim* in the medical library in 1967 and being fascinated by 'the range of symptoms and phenomena that could occur in migraine attacks.' He felt that 'every attack of migraine opened out into an encyclopaedia of neurology.' After reading a dozen of articles on migraine, Sacks did not find 'the full richness of its phenomenology' in them. Then he started reading *On Megrim* (after 'downing my bitter draft of amphetamine') and came into 'a sort of catatonic concentration'. After many hours of reading, Sacks felt 'almost as if I were becoming Liveing himself, uttering to be 'unsure whether I was reading the book or writing it.' At the height of this ecstasy, he 'saw migraine shining like an archipelago of stars in the neurological heavens.' Then Sacks comes to a decision:

Rousing myself from my reverie of being Liveing or one of his contemporaries, I came to and said to myself, "Now it is the 1960s, not the 1860s. Who could be the Liveing of our time?" A disingenuous clutter of names spoke themselves in my mind. I thought of

Dr. A. and Dr. B. and Dr. C. and Dr. D., all of them good men but none of them with that mix of science and humanism that was so powerful in Liveing. And then a very loud internal voice said, "You silly bugger! You're the man!" (Emphasis in the text.)

On the Move. A Life (2015)

This autobiography reveals much on Sacks' drug-abuse and hidden homosexuality during his younger years, but does not give much new information on (his own) migraine (31). He repeats having learned a lot from his migraine patients ('No two patients with migraine were the same, and all of them were extraordinary') and from reading *On Megrim*. He adds that in 1968 he learned about auras 'by seeing an exhibit on migraine art and in part by discussion with my friend Ralph Siegel, a very good mathematician and neuroscientist.' In the around 400 pages, Sacks mentions his migraine auras only twice: 'How did we make sense of the world, visually? I had developed these interests from an early age through having visual migraines, for besides the brilliant zigzags which heralded an attack, I might, during a migraine aura, lose the sense of colour or depth or movement or even the ability to recognize anything', and 'I found myself referring again to the "cinematographic" sequences of stills described to me by migraine patients and which I myself had on occasion experienced.' To the latter sentences, he adds: '(I had also experienced it very strikingly with other perceptual disorders when I got intoxicated by *sakau* in Micronesia)' (parentheses and emphasis in the original). The remark between parentheses seems to refer to Sacks' opinion, as put forward in *Migraine* (2), that visual hallucinations are an unspecific reaction to various stimuli, but it also emphasizes that Sacks frequently had had hallucinations after using drugs such as amphetamine/chloral hydrate ('a customer paying his bill at the cash register had a huge proboscidean head, like an elephant seal'). As he described in *Hallucinations* (29), he even decided to write his book on migraine while being intoxicated with amphetamine.

In December 2005, Sacks was diagnosed with a melanoma in his right eye, affecting his vision: 'wild topological distortions, the perversions of colour, the clever but automatic filling in of blind spots, the incontinent spread of colour and form, the continued perception of objects and scenes when the eyes were closed, and, not least, the varied hallucinations which now swarmed in my ever-larger blind spots. My brain was clearly as involved as the eye itself.' He wishes to make 'a bargain' with the melanoma: 'take the eye if you must [...] but leave the rest of me alone'.

Around 2009, Sacks was hit by several other mishaps. A haemorrhage in his eye blinded it completely; he had to have a total replacement of a knee and was tortured by sciatica. Now: ‘some of my thinking and reading at this time, indeed, was about pain, a subject I had never really thought about.’ He learned that there are two radically different sorts of pain: ‘local’ and ‘neuralgic’ (non-neuropathic and neuropathic). The latter has ‘an affective component all of its own, which I found difficult to describe, a quality of agony, of anguish, of horror – words which still do not catch its essence’. Here, he seems to describe the pain of migraine.

Various publications in scientific journals

Sacks has also published some articles in scientific journals. A PubMed search with the search terms ‘Oliver Sacks’ discloses 23 hits with him as (co-)author of a scientific publication, a few of which deal with migraine. In a Letter to the Editor in the journal *Neurology* (32), Sacks reacts on an article by Evans et al. (33), who found a high prevalence of migraine in neurologists. In his letter, Sacks asks attention for an article by Alvarez (34), who also describes such a high prevalence. Evans et al. had speculated on the possible reasons for such high prevalence, especially in headache specialists, to which Sacks adds: ‘For myself, with a personal history of classical migraines (and, more often, isolated visual ones) going back to childhood, the extraordinary phenomena of the aura [...] excited an interest in the brain [...] at an early stage’ (32). He mentions migraines as one of the reasons to be attracted to neurology. Evans et al. reply that ‘this anecdote indicates an important previously unrecognized benefit’ of having migraine, and add that their own ‘career choices were independent of our personal medical histories.’ In another publication called ‘Hallucinations of musical notation’, Sacks mentions ‘certain types of migraine’ as possible cause for these hallucinations, but does not go into detail nor give relevant references (35). Migraine is also mentioned as possible cause (without references) in another article, of which Sacks is a co-author, describing one case of so-called prosopmetamorphopsia, in which patients see other people’s faces distorted (36).

Discussion

It is said that from his first book (*Migraine*), Sacks moved further and further away from the position and style of the professional physician addressing other physicians (7). Rather than a scientist, he became a novelist. In Sacks’ own words: ‘In *Migraine* (originally drafted in 1967), there are not tales, or

scarcely any, only brief case histories, sometimes mere pathographies’, whereas he calls the descriptions in *The Man who Mistook his Wife for a Hat* ‘clinical tales’ (5). *Migraine* indeed gives a rather ‘neutral’ state of the art description of the symptoms, causes and treatment of migraine at that time (1970). The text, however, mainly focuses on the aura instead of the headache. In *Migraine*, Sacks emphasises that he had learned a lot from his patients about migraine, but at that time he was suffering from migraine with aura already for years, as known from other sources (*A Leg to Stand on*, *Hallucinations*, interviews etc.). His recognition of Hildegard von Bingen’s descriptions as migraine auras echoes Singer’s hypothesis on the topic and must lead to the conclusion that when Sacks’ auras indeed looked like those of Hildegard they were very unusual. The first reference to his own migraine appears in *A Leg to Stand on* (1984), but that description also contains some peculiarities (6). His aura starts in a dream, which is not very common (37). After recognition of the situation Sacks seems to enjoy it (he even asks the nurse to walk around the room to see her change shape) and shortly after the ‘attack’ he longs for fried fish, which is also not very usual in migraine patients, considering their anxiety, osmophobia, malaise, etc. Amusia as part of an aura (*Musicophilia*) is rare (no description in the neurological literature, see above), and this is true of olfactory sensations (*Hallucinations*) (30). The life-long occurrence of auras without headache is another peculiar aspect of Sacks’ migraine. It is known that many patients with migraine with aura now and then suffer attacks without headache and that especially older subjects can have so-called migraine accompaniments (aura like symptoms without headache), which are then difficult to separate from transient cerebral ischaemia (39). Having exclusively attacks without headache, however, raises doubt on their migrainous nature. Finally, on several occasions Sacks claims to be happy to have an attack or even to look forward to the next attack, which is very unusual in general in migraine patients.

The Russian neuropsychologist Luria (1902–1977) advocated a ‘romantic’ approach to neurological diseases: ‘romantics in science want neither to split into its elementary components nor to represent the wealth of life’s concrete events in abstract models that lose the properties of the phenomena themselves’ (40). His approach found expression in two ‘neurological novels’, *The Mind of a Mnemonist* and *The Man with a Shattered World*. Sacks indicated on several occasions that he was profoundly influenced by Luria (5), e.g. in *The Man who Mistook his Wife for a Hat*; *Musicophilia*, *On the Move*). His book *A Leg to Stand on* is dedicated to Luria. The influence of Luria on Sacks has been the

subject of several studies (1,7,8,16,41). One of Sacks' motives to turn to 'romantic neurology' is that 'I fear for a neurology which forgets his historical roots' (cited in (42)). He has argued that 'in illness we are all thrown into a 'tale' and that 'we find ourselves, playing the central role in a philosophical or symbolic drama' (cited in (43)). Sacks' version of 'romantic neurology' has, however, seriously been criticized. The sociologist and philosopher Tom Shakespeare, for example, ironically changed the title of *The Man who Mistook his Wife for a Hat*, into: 'Oliver Sacks, the man who mistook his patients for a literary career' (44). The depiction of disabled persons was even called 'a freak show', and Sacks' panopticum was compared with the travelling circus of P.T. Barnum (45). Sacks even became a protagonist in a work of fiction himself, being intertextually parodied in Richard Powers' novel *The Echo Maker* as 'cognitive neurologist' Gerald Weber, who calls himself 'the Beau Brummel of brain research' (46). In the story, he is called in for help of a patient with Capgras syndrome (in which the patient sees persons in his vicinity as doubles of themselves), but all he does is write a text called 'The man who doubled his sister', which is not very helpful for the case.

Mergenthaler (1) expresses the criticism on Sacks more mildly, by concluding that:

Because of an overflow of rhetorical elements, his narratives often advance to separate pieces of art that have left their factual basis and do not reach or reflect the patients' feelings. Sacks draws much attention onto the illustrations of the character of the protagonists, but in the end many portraits remain shadowy and even unrealistic. His metaphors 'create not only an atmosphere of consolation, but they also offer the possibility to overlook a personal calamity and even tragedy' (1).

Without doubt, the writings of Oliver Sacks have great importance, otherwise they would not have been so

popular. His work can be put into the context of narrative health psychology: this line of thought explores how people make sense of symptoms and illness labels (47). Illness perceptions (the cognitive and emotional representations of bodily sensations) drive coping behaviour of patients and, therefore, their self-management behaviour (48). These perceptions do not necessarily reflect 'objective' reality. They are, however, very real for the sufferer. Addressing maladaptive illness perceptions and changing them into more constructive ones results in improvements in medical outcome (49). This topic needs exploration in persons with migraine as well.

In 1986, Sacks wrote: 'Thus the *first* act of medicine is to listen to a personal story, extract or abstract from it a (syndromic or etiological) "case", and exclaim "Migraine!", and "Parkinsonism!", with all that this implies' (5) (emphasis in the original). He then goes on by pointing at the importance of Hippocrates' 'insistence that one should not just consider or treat the disease, but consider and treat the diseased *individual*' (emphasis in the original). Couser points at the ethical problem of 'narratives in which the portrayal of aberrant somatic states is *not* autobiographical' (emphasis in the original) and calls the individuals thus described 'doubly vulnerable' (50).

When read as pure fiction, one can wonder why Sacks' descriptions seem to be those of real patients (with initials, dates of birth, biographical information and so on), and why he has written about his own 'clinical tales': 'they have a factual, clinical basis and lend themselves to a clinical or medical analysis' (5). When read as non-fiction then why did he repeatedly put extremely rare phenotypes in the spotlight? Maybe the latter point gives the answer. Oliver Sacks chose for 'positive' imaginative descriptions and not for the 'horror' of 'real' disease and 'real' life. As a variation on Luria's 'romantic neurology', we would propose the term 'romanticized neurology' as basis for an intermediate reading mode for Sacks' works.

Key findings

- Many descriptions of migraine occur in the work of Oliver Sacks.
- In the opinion of the authors, he often did not describe migraine realistically. Many of the descriptions should be labelled 'fiction'.
- His books and articles offer easy reading for the general public, and are not intended for medical doctors or scientists in particular.

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