A behavioural strategy for reducing the symptoms of narcolepsy

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1. Introduction

Narcolepsy [1,2,3] is defined as “a sleep disorder which affects the brains’ ability to regulate the normal sleep-wake cycle”. This can lead to symptoms such as disturbed night-time sleep, excessive daytime sleepiness (EDS), cataplexy or the loss of muscle control, sleep paralysis, and hypnagogic hallucinations.

The cause of narcolepsy, or at least a physiological correlate, is a reduction of a neuropeptide called hypocretin in the hypothalamus. Current thinking is that hypocretin is destroyed by the body's own immune system, and this induces narcolepsy. The peptide is found predominantly in a relatively small number of neurons that connect to various other regions in the brain and spinal cord.

One of the authors, CO, has suffered symptoms of narcolepsy for a number of years. These include loss of motor control accompanied by uncomfortable cooling of the extremities. The cold sensation is followed by instantaneous deep sleep often accompanied by vivid dreams.

CO observed that “there is a lack of motor function that first occurs, but if something can mentally stimulate me, I can be pulled out of the lack of motor function most times. So I know there is a mental thought factor involved”. This comment stimulated WT to adapt a psychological model of the mind-brain attributed to F.W.H. Meyers, and to propose a coping strategy based on the revised model. The suggested strategy was evaluated positively by CO, and may prove to be useful to others.

2. A mind-brain theory of narcolepsy

Some symptoms of narcolepsy are loosely similar to a near death experience (NDE). In both cases, the body loses consciousness and motor control, and there can be unusual, vivid, visual experiences. The narcoleptic person may experience uncontrolled movements of the limbs as well as automatic behaviour such as writing, typing or driving, while the NDE seems to include movement of the body image or the point of awareness. The NDE is associated with a nearly lifeless brain which should not be able to support mental activity. The alternative is that the mind continues to exist in some non-physical domain. Might narcolepsy also involve more than physiological activity in the brain?

An old psychological theory of F.W.H. Myers might help to answer this question. It was first publicized more than a century ago, and reappeared recently in a book called "Irreducible Mind: Toward a Psychology for the 21st Century" by Kelly et al. (2007). The basic idea is that the contents of conscious awareness is a small part of a large sea of mostly unconscious information. The mind implements filters that allow more or less of this information into awareness. So when one becomes hypnotized or has an hallucination or even a dream, it would be because the filter properties have changed.

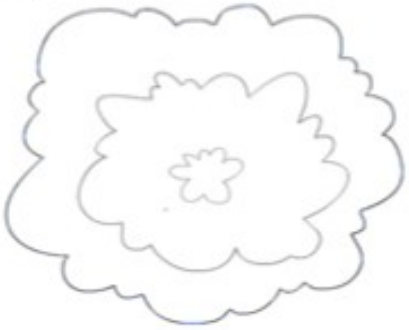
Let's say that a person has a non-physical mind which is normally connected to biological filters in the brain. One filter passes sensory data from the brain to the mind, and another sends out motor commands and other brain state specifications from the mind to the brain. Let's also assume that when something happens to shut down the sensory filter, the mind switches by default to a non-physical filter that receives data from a different source. This source is an information field such as the place from where archetypal dream imagery comes. The narcoleptic person might see this information as hypnagogic imagery. In the NDE, the mind receives information focused more on particular archetypal imagery such as the 'white light at the end of the tunnel', and the images of family and acquaintances who have passed on. Figure 1 shows a diagram of this model of the mind and its connections.

Information field (e.g., archetypal images, long-term memories, personality constructs)

Memories and Archetypal images

Control signals and data objects

Mind filters

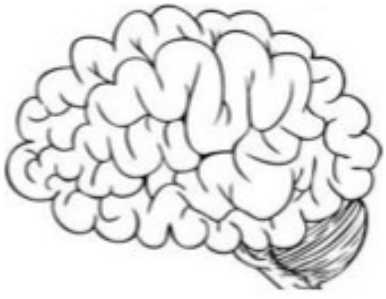


Mind (e.g., short-term memory, attention, creative processes)

Brain states

Sensory encodings

Biological filters



Brain (e.g., sensory processing, motor output, automatic sensory-motor activity)

Figure 1. A model of the mind-brain system.

In this model, the Brain is the Mind's interface with the physical world. It's computational resources are dedicated in part to creating higher-level encodings of the information gathered by the senses. These are passed on to the Mind where they are used in creative cognitive activity such as problem solving. The results of such activity would include executive decisions about where attention should be directed by the Brain. The decisions are implemented by sending to the Brain, via the 'brain states' filter, the successive states that the Brain is to adopt. Further, the Mind has access to the non-physical Information Field, and information is sent there by the Mind to be stored in a long-term memory (LTM). The Mind can also send control signals there along with its current state to initiate retrieval of existing memories from the LTM, or to receive archetypal images possibly from something like the collective unconscious.

The narcoleptic person experiencing Excessive Daytime Sleepiness (EDS) loses awareness of the physical surroundings at inappropriate times. This implies that the 'sensory encodings' filter may not be functioning as it should, and that it can become effectively disconnected from the Mind. If the 'brain state' filter is still functional, the Mind would be able to send information to activate the motor system albeit without sensory feedback. On the other hand, when the 'brain state' filter is blocked but not the 'sensory encodings' filter, a loss of motor control (cataplexy) may result as well as so-called sleep paralysis while the person is still awake. When both filters are blocked, the Mind cannot communicate with the Brain at all. This is the case during the NDE when the Brain has lost all life support. Any motor activity experienced then would have to occur in the non-physical domain of the Mind, and this is what appears to happen.

Besides encoding sensory data for the Mind, the Brain also does processing for local use. It is capable of autonomously performing habitual behaviours that don't need supervisory control. During sleep, some narcoleptics are able to perform well-learned motor tasks such as writing, typing, and even driving. It appears that automated sensory-motor behaviours can proceed without any 'sensory encodings' being sent to the Mind. Feedback for such automated tasks seems to be generated locally in the Brain. This means that only automated motor activity should occur during a narcoleptic sleep attack.

But the model predicts that a non-habitual form of automatic writing could also occur, perhaps especially when the sensory input to the Mind is blocked. People in altered states of consciousness have been known to write down material from a source that appears to be transpersonal. According to the model, the transpersonal source would be some part of the Information Field accessed by the Mind. In turn, the Mind would send the appropriate sequence of states to the Brain's motor system to generate writing.

Clearly, there are times when something interferes with the 'sensory encodings' filter that enables conscious awareness of the physical environment. This is considered normal if it happens during the night when we want to sleep. At other less appropriate times, however, it is experienced as abnormal and we may call it narcolepsy. The model suggests a possible strategy to delay or prevent a cataplectic attack and the ensuing loss of wakefulness.

3. A proposed coping strategy

According to CO's experience, the onset of sleepiness continues even when she is surrounded with familiar noises. On the other hand, it appears to be slowed or halted by mental stimulation. A short story from Narcolepsy UK could lead to a similar conclusion. That is, “one narcoleptic patient attended a symposium on sleep disorders held out of town. Although he normally naps frequently and has little energy or enthusiasm during the day at home, he was able to remain wide awake and alert almost all day at the symposium”. Perhaps the stimulation needs to be novel in order to be effective.

In terms of the model of Figure 1, this notion suggests that the malfunctioning 'sensory encodings' filter blocks familiar inputs more readily than novel inputs. From CO's description, a novel stimulus may be defined as one that triggers a new train of thought. Perhaps an episode could be delayed by continuously performing some kind of creative or problem solving task.

The task could involve solving a puzzle of some kind such as a crossword, a word cryptogram, or a word jumble. Or it could be a spatial problem where one has to decide which pattern does not belong in a group of patterns. Or it could be a problem where mental rotation is required to match two objects.

Such puzzles require organizing new sensory inputs in relation to existing representations in the Mind. A sufficient degree of creative effort involving data transfers through the 'sensory encodings' filter may help to keep it open. Difficulty levels should be such that the puzzles are solvable, since getting stuck would likely halt the creative activity.

A case study was carried out by CO to determine if the strategy would be effective. The creative activities tested were (1) solving the Rubik cube, (2) drawing a picture, and (3) playing solitaire on the computer. For comparison, a non-creative control activity was included. This task was simply to write a sequence of alternating ones and zeros on paper, and was predicted to be completely ineffective. For each task, a log was kept to monitor its effect.

3.1 Results

An indication to CO that a sleep attack is on the way is a change in the temperature of body extremities. About 30-40 minutes beforehand, the hands and feet start to feel cold and serve as a warning. In general, the Rubik cube task, drawing, and solitaire were all effective at stopping the onset of cataplexy. Sleep occurred only twice in three weeks during the experimental treatments. Prior to this period, sleep occurred between three to eight times per week. Obviously, the creative activity resulted in a major improvement.

The Rubik cube task did not always stop the sleep attack, probably because it was too difficult to complete and creative activity halted as a result. Typically, only two sides of the cube were completed. However, the drawing task was completely effective. As expected, the mundane control task of writing zeros and ones was completely ineffective. The thought of putting pen to paper was enough to cause sleep onset.

An interesting side effect was the difficulty in stopping the creative task. Drawing and solitaire became an obsession. Solitaire was easily stopped when the game on the computer was finally won, but drawing could continue all day. So although drawing pictures gave the best results, it was also the hardest task to stop doing. CO estimates that after 30-40 minutes of stimulation with these tasks, the need to sleep passed completely. Therefore, a time limit of one hour is now imposed, and this helps to break away from the obsessive drawing activity.

3.2 Discussion

This case study demonstrates that the kind of activity in the mind determines whether a person suffering from narcolepsy is able to resist falling asleep. According to the model of Figure 1, creative activity operating on incoming sensory information keeps the 'sensory encodings' filter from the brain to the mind active, thus keeping the mind connected to the physical world. The filter stays open as long as it is being used, but may shut down when it is no longer needed.

The strategy has so far been tested by only one person, and for her it worked very well. Further tests are needed to determine if the successful result will generalize to others wishing to control their bouts of EDS. Since the suggested tasks are common forms of entertainment, the self-treatment can do no harm.

If these tasks are not to an individual's liking, another more acceptable task should work just as well as long as it continually uses sensory information. An employer might even be able to assign work of such a nature to a person having difficulty staying awake. However, as when the Rubik's cube task became too difficult, effectiveness may wane with interest in the task.

4. Conclusions

A strategy for the self-treatment of narcolepsy was developed based on the psychological theory of F.W.H. Myers. The treatment consists of performing a creative or problem-solving task while the urge to fall asleep is present. The task should be one where the mind creatively solves a problem that uses sensory information. A single case study found that sleep was put off and that the urge to sleep faded after performing the task for less than an hour. The frequency of excessive daytime sleepiness was reduced from a range of 3-8 times per week to

2 times in three weeks. Effective tasks were drawing a picture or playing solitaire on a computer. Solving Rubik's cube was also effective as long as the puzzle was not found to be insoluble.