

Case Report

Planting a misdiagnosis of Alzheimer's disease in a person's mind

Merckelbach H, Jelicic M, Jonker C. Planting a misdiagnosis of Alzheimer's disease in a person's mind.

Objective: There is an extensive corpus of knowledge about how misinformation may distort autobiographical memories. A diagnostic error can be conceptualised as a form of misinformation.

Methods: The authors discuss the case of a 58-year-old woman who was given a misdiagnosis of Alzheimer's disease.

Results: The patient was deeply convinced that the diagnosis was correct, even when she was confronted with contradictory evidence.

Conclusion: A diagnosis is not a neutral piece of information. It profoundly affects the lives of patients. The consequences of a misdiagnosis may be similar to persistent false memories.

Harald Merckelbach¹, Marko Jelicic¹, Cees Jonker²

¹Faculty of Psychology and Neurosciences, Maastricht University, Maastricht, The Netherlands; and ²Department of Psychiatry/Alzheimer Centre, VU University Medical Center, Amsterdam, The Netherlands

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Dr Harald Merckelbach, Faculty of Psychology and Neuroscience, Maastricht University, PO Box 616, 6200 MD, Maastricht, The Netherlands.
Tel: 043 3881945;
Fax: 043-3884196;
E-mail: H.Merckelbach@maastrichtuniversity.nl

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Numerous studies have documented that misinformation may contaminate people's memory. In the classic experiments of Beth Loftus, research participants watched a video of, for example, a red car going past a stop sign and were then asked misleading questions like 'did another car pass the red car when it stopped at the yield sign?' When participants later tried to remember the details of the video, a majority of them would insist that they saw a yield sign. Misinformation does not only distort crucial memory details it may also create what has been termed 'rich false memories'. Thus, confronting individuals repeatedly with false information about a fictitious event (e.g. being lost in a shopping mall as a child) leads many of them to develop detailed recollections of this event (1). These false memories tend to be robust. That is, many participants will stick to their false memory even when they are confronted with contradictory evidence. This is illustrated by patients who develop false memories of fictitious childhood traumas as a result of suggestive psychotherapy. Some authors have noted that retracting such memories takes longer than developing them (2).

Misinformation may also affect how patients perceive symptoms. Like memories, symptoms are often ambiguous. This ambiguity makes symptom

perception susceptible to misinformation. A case in point is breathlessness in asthma patients and its imperfect correlation with airway obstruction. When asthma patients are given false feedback about respiratory sounds, many of them will manifest breathlessness irrespective of pulmonary functioning (3). Non-organic memory complaints of elderly patients are also ambiguous symptoms (4). Clinicians' attempts to interpret such symptoms in the absence of a thorough neuropsychological assessment of the patient are fraught with risks. A recent German study, for example, found that neuropsychological follow-up assessments confirmed a clinical suspicion of Alzheimer dementia in only 38% of 47 consecutive referrals (5). The authors of this study rightly pointed out that a false-positive diagnosis of Alzheimer dementia may have far reaching consequences as the diagnosis *per se* may set into motion all kinds of negative reactions. Here, we describe the case of a woman who was provided with misinformation about her memory difficulties and came to believe that she suffered from Alzheimer's disease.

In early 2000, a 58-year-old woman consulted a neurologist in a general hospital because of her memory difficulties. She was a shop owner and had recently noticed that for the first time in her life,

she needed a calendar to help her remember her appointments. Ten years earlier, her mother had been diagnosed with Alzheimer's disease and the patient was afraid that she began to develop the first signs of this condition. Except for rheumatic complaints and lumbago, her medical history was unremarkable. The neurologist's investigation included a brain single photon emission computed tomography (SPECT), which was reported to show frontal hypoperfusion. The neurologist interpreted this as an indication of mild-to-moderate Alzheimer's disease. In the patient files, he estimated her mini-mental state examination (MMSE) score to be 22, although he never carried out a formal MMSE (6). The neurologist prescribed the patient 2 × 6 mg/day rivastigmine. In the months that followed, the patient was permanently in a state of confusion and felt devastated by the diagnosis, up to the point that she considered suicide. The neurologist included her in a research trial and in that context blood samples were taken from her. According to the patient, being a research subject made the diagnosis and the medical routines (e.g. blood sampling) even more outstanding.

It happened that her husband was diagnosed with prostate cancer. Because the patient worried that medication side-effects might interfere with her abilities to care for her husband, she contacted a telephone helpline of an Alzheimer resource centre. The expert of the centre advised her to seek a second opinion. In the summer of 2000, she then consulted the neurologist of a university clinic (C. J.). He conducted a full anamnesis as well as a neurological examination. He also ordered a second brain SPECT and a standardised neuropsychological assessment battery that involved testing of memory, perception, attention, language, executive functions, as well as the MMSE and the cognitive screening test (CST) (7). All were unremarkable and her MMSE and CST scores were in the normal (i.e. non-pathological) range. The neurologist concluded that the frontal hypoperfusion that had been found on the first SPECT probably was an aspecific reflection of a mild depression. Indeed, when the patient first began to worry about her forgetfulness, she went through a stressful period. She had a conflict with a close family member, her commercial activities were hectic and she was tired.

The university hospital neurologist went to great lengths to explain this pattern to her. Nevertheless, it proved to be difficult to convince the patient that she did not suffer from Alzheimer's disease. It was only after two lengthy sessions in which the test results were shown and explained in detail to her that the patient began to doubt that she suffered from the condition. Even long after these sessions, she had episodes during which she was deeply concerned that

she had Alzheimer's disease although it was obvious that she was functioning normally.

We (H. M. and M. J.) recently interviewed the patient. She related that she often had intrusive thoughts about the misdiagnosis. She also had a tendency to catastrophise about minor memory lapses. Furthermore, she had developed an intense suspicion and fear of hospitals, medical interventions and especially blood sampling. She exhibited the signs of a blood-injury-illness phobia. In 2009 and 2010, two official investigative committees documented that the neurologist of the general hospital had misdiagnosed a number of patients with Alzheimer's disease. The neurologist was forced to resign and all in all 26 malpractice suits were filed against him and the general hospital. The patient described here was not involved in litigation. In her case, revoking the misdiagnosis of Alzheimer's disease took place years before the patient became aware of the fact that other patients had filed malpractice suits against the general hospital neurologist.

Discussion

Earlier reports showed that a number of factors may contribute to the misdiagnosis of Alzheimer's disease, including overreliance on brain imaging techniques, failure to rule out depressive symptoms as a confounder and absence of neuropsychological assessment (8). Obviously, these factors also played a role in the misdiagnosis described here.

Meanwhile, earlier reports have been less concerned with why patients accept a misdiagnosis of Alzheimer's disease in the first place. Our case suggests that there are some interesting parallels with false memory phenomena. First, the extant literature on false memories shows that misinformation is most potent when it is provided by trusted persons. In the case described here, the neurologist presented himself to the patient as a friend of the Dutch royal family and in this way impressed her. Second, misinformation impacts memory most when it is repeated and when it is connected to accurate details. In one of her studies, Loftus interviewed adults about childhood events. Participants were interviewed two times about the events: some events actually happened and had been supplied by family members, but one event – being lost in a shopping mall – was false. In follow-up interviews, many participants recalled the false event in great detail (1). Likewise, in the current case, the patient was repeatedly told by the neurologist that she suffered from Alzheimer's disease. Because this information was embedded in discussions about her mother (who had been diagnosed with the disease),

the SPECT results and a research trial on Alzheimer's disease, the patient became fully convinced that the diagnosis must be correct. Third, in Loftus' study, some research participants insisted that the false event had happened to them even after debriefing (1,2). Similarly, the disease conviction of the patient described above proved to be difficult to correct. Fourth, research shows that misinformation only contaminates memory when the misinformation is plausible to begin with. In the case described here, the patient did have memory complaints and there was a positive family history for Alzheimer's disease. The ambiguity of her memory complaints created the opportunity for misinformation to be effective (3,4,9).

Admittedly, our case provides only an anecdotal illustration of the similarities between the effects of misdiagnosis and false memories. Clearly, these similarities deserve systematic study and this is particularly true for the misdiagnosis of Alzheimer's disease: there are reasons to suspect that such misdiagnosis are more common than one would expect (5,8). Conferring a diagnostic label is far from a neutral act (10). Many diagnostic labels have strong stereotypical connotations and sometimes, these will automatically shape the experiences and behaviour of patients, a phenomenon called 'diagnoses threat' (11). Studies on how misinformation can create diagnosis threat may help us understand the huge impact that wrong diagnosis may have (9).

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