Doubts about dementia diagnoses

Inclusion of individuals who have lived experience of a relevant medical or mental health disorder in research, policy, and service design undoubtedly enriches quality and focus. However, there are disease areas where it might be anticipated that substantial challenges could undermine the ability of patient populations to contribute a meaningful voice. Within my own field, experts by experience, sometimes called dementia advocates or ambassadors, have emerged as champions and representatives for people with dementia. The backgrounds that typically qualify a person for these roles are varied. They might be professionals from a relevant care area, those having experience of caring for a family member or friend with dementia, or people who have themselves received a diagnosis of dementia. Of course, the direct personal experience of living with dementia, combined with self-identification as a capable individual who refuses to submit to what many would see as a hopeless diagnosis, gives enormous personal significance and influence to members of the last of these groups.

I have listened to conference presentations, read blog postings and tweets, and sat in meetings with people who have qualified for this role because they have been given a diagnosis of dementia. But here my difficulties begin. In almost all of these situations, I have felt a sense of doubt about the security of their diagnoses. Put bluntly, they are not a bit like the people with dementia that I have diagnosed and treated. They are often relatively young, many having received their diagnosis in their 40s or 50s, they might have been diagnosed with a more unusual dementia such as dementia with Lewy bodies or frontotemporal dementia (where diagnosis can be difficult), and there appears to be some inconsistency between their subjective symptoms and objective performance.

Perhaps most tellingly, review of their performance at meetings, and of the content of their written output, indicates to me no evidence for progression of underlying deficit, sometimes for many years.

Does this really matter and why should it trouble me? First, everyone deserves a correct diagnosis, particularly when it is as life-changing as the diagnosis of dementia. Although none of these individuals has been my patient, observing their performance at meetings or through their writing has led me to develop serious doubt about the diagnoses that they carry. If they do not have dementia, then other treatable difficulties might underpin their symptoms and it is difficult for a doctor to ignore this. Second, because the usual lived experience and course of dementia is so different from that seen in these individuals, people with dementia and their families might gain the demoralising impression that somehow they are failing to live up to the expectations set by their example. Third and perhaps most simply, dementia deserves to be honestly represented in these roles by people who truly do have dementia or have experience of caring for someone with the condition.

The questioning of diagnosis in this situation is taboo. When I shared my doubts about an individual who had participated in national-level discussions over several years without signs of deterioration, colleagues would agree but there was no mechanism to challenge this. The online blogs of these people often contain accounts of how they have fallen out with friends or family members who have upset them by questioning their diagnosis. We are told that questioning is deeply offensive to the individual, the doctors who have given them their dementia diagnoses, and the wider population of people with dementia, since this implies the discriminatory assumption that a person with dementia could not function as these people are seen to do. Questioners are sometimes referred to as “dementia deniers”, as if they represented some kind of organised malign group. But such dogmatism and the accompanying hostility misses the point that without neuropathological confirmation, diagnosis in life can never be more than probable and, if made at the mildest stage, should always be open to review as more evidence inevitably emerges with time and with the characteristic progression of dementia.

I have no reason to doubt that these people sincerely believe that they have dementia and I hope in turn that they will not see this piece as an attack upon them. But, mistakes can be made around dementia diagnosis, and functional cognitive disorders are a heterogeneous group that can sometimes be difficult to distinguish from early dementia. Self-monitoring of psychological symptoms, such as subjective memory difficulty, is vulnerable to misinformation and consequent iatrogenic amplification and it is easy to see how powerful the effect of a dementia diagnosis could
be.5 Any review and potential reversal of diagnosis is likely to be difficult to manage without sophisticated psychological support, particularly if the associated roles have become important to an individual. Appropriate mechanisms for clinicians to raise their concerns would both protect individuals from the effects of misdiagnosis and maximise the true value of the expert by experience.

Robert Howard
Division of Psychiatry, University College London, London W1T 7NF, UK
robert.howard@ucl.ac.uk

I declare no competing interests.

1 Shunichiro S, Catindig JA, Block NR, Miller BL, Rankin KP. When a little knowledge can be dangerous: false-positive diagnosis of behavioural variant frontotemporal dementia among community clinicians. Dement Geriatr Cogn Disord 2016; 41:95-108.