

## Editorial

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**The purpose of diagnosis**

Diagnosis is essential to the rational practice of medicine. A diagnosis focuses attention on salient problems. It facilitates predictions (prognosis). It can reassure as well as make plain threats. It can serve as a stimulus to gaining and spreading knowledge. As a social act it confers a special status upon those so diagnosed. It can unlock resources to the individual and toward groups, sanction behaviors, excuse the diagnosed from responsibilities and endorse the flow of material and in-kind support (Grue, 2024).

These effects of diagnosis apply whether it is of a physical or mental condition. The latter seldom if ever justify the designation of diseases defined by demonstrable pathology. According to Kendler, Zachar, and Craver (2011), psychiatric diagnoses do not as a rule, rely on 'objective' biomarkers, nor are they entirely 'socially constructed' or labels of convenience but are instead 'fuzzy' constructs, with embedded causal structures (some symptoms/behaviors cause other symptoms/behaviors). One useful definition is that psychiatric disorders are harmful dysfunctions (Wakefield, 2007) combining the naturalistic component of dysfunction as a failure of biologically supported functioning (including psychological functioning) and a value, i.e. harm.

Within psychiatry, the limits of diagnosis and weakness of the practice are widely acknowledged by all but the most unthinking practitioners, but typically it is claimed that on balance, a diagnosis benefits the recipients or is at least made in their interests and justifiably belongs within core values of medicine (e.g. Craddock & Mynors-Wallis, 2014).

Critics continue to raise concerns around the misuse of diagnosis in psychiatry. These have two main themes: one is overmedicalization (after Illich), that is diagnostic 'creep' in which normal reactions and variations (e.g. grief, naughtiness) attract a pathologizing label. The other has persisted since the so-called antipsychiatry movement of the 1960's, wherein diagnosis is seen as a mechanism of social control and an exercise in bad faith (after Foucault), designed to serve the interests of the profession and other powerful groups in society (Moncrieff, 2010).

Into this contested arena comes *self-diagnosis*. The phenomenon arises out of grass roots movements where lived experience is accorded special value in contrast to the institutionally endowed power of psychiatry, and where diagnosis (of mental disorder) is in itself challenged. One such strand is the neurodiversity movement which reframes several diagnostic categories as (mere) variations of normality. Neurodiversity has achieved most traction in relation to autism although other psychiatric and neuropsychiatric conditions are also amenable to the neurodiversity framework for example attention-deficit hyperactivity disorder (ADHD) and bipolar disorder within psychiatry, Tourette's in neuropsychiatry, and dyslexia and dyspraxia within educational and developmental neuropsychology.

Academic psychologist and autism expert Baron-Cohen (2017) states the strongest version of their case as follows:

*The notion of neurodiversity is highly compatible with the civil rights plea for minorities to be accepted with respect and dignity, and not be pathologised. Left-handers are an example of neurodiversity in a majority right-handed world...*

He goes on to argue that neurodiversity is *incompatible* with 'disorder' (since the latter implies the need for treatment, 'normalization' or even eradication) while the term disability with its well-articulated social model (it is society's response to diversity or lack of it which renders the individual disabled), *is* compatible.

**We're all on the spectrum**

The benefits and potential costs of the continuum concept as applied to mental phenomena have been considered in detail (David, 2013). One benefit according to its advocates is that it side-steps the need for diagnosis as a more or less arbitrary drawing of a line between abnormal and normal. As part of an alternative, neurodiversity attracts attention to how 'differences' may be advantageous or even seen as strengths – such as the ability to focus, and attention to detail in autism, or creativity (particularly linked to bipolar disorder). But it is acknowledged

within the neurodiverse community that this is highly context specific and even those self-diagnosed can, paradoxically, feel 'othered' (Lewis, 2016). The main benefit of having a diagnosis – either ascribed or chosen for one's self – which is well described by personal testimonies in qualitative research (Russell et al., 2019) as well as surveys – is the feeling of being understood; that elements of one's personal experience can be explained and that this explanation is generalizable such that one feels connected to others with the same diagnosis. Indeed this may even take on the salience of an illness identity, but unlike the identity which, in chronic psychiatric illness sometimes emerges from an imposed diagnosis, and tends to be self-limiting and stigmatized (Yanos, DeLuca, Roe, & Lysaker, 2020), the identity from self-diagnosis is a source of pride and strength.

To illustrate, here is a fictional account of the sort one hears frequently in lay press and media. Take a middle-aged man who talks of his strong narrow interests as a child, and feeling he was different from children his age growing up. When older he manages to channel these interests into an occupation and gains admirers for his ability to articulate them with passion but runs into conflict for being uncompromising and 'obsessive'. He then embraces a diagnosis of autism – into which his life-story fits neatly. It 'explains' his interests, attitudes, and difficulties. He needn't feel at odds with the world in the same way. The world needs to accommodate him and 'his autism', but he is not seeking 'a cure' even if one was available. It is easy to appreciate the feeling of being (finally) understood and of not being alone. However, it is not obvious how lasting such feelings are and there is little research on this matter. One could imagine that the same biography – in the absence of more detail – could be explained just as credibly, with compassion and understanding, using the language of personality traits ('that's just the kind of person you are') and this not having nearly the same revelatory impact.

### Problems with self-diagnosis

A problem with self-diagnosis is identity politics. Ginny Russell, a social scientist who has written extensively on these matters with notable even-handedness (2020) says there is:

*... friction within identity politics over definitions of who is included as 'in' a particular group. First, the [neurodiversity] movement has been accused of being unrepresentative of all people who are 'neurodivergent,' and specifically unrepresentative of more impaired people on the autism spectrum (a criticism made by some clinicians, autistic people, and parents).*

Perhaps the most serious consequence of taking the prerogative of diagnosis out of the hands of psychiatrists is that it almost inevitably shifts the focus toward the milder end of the spectrum. Clinicians are motivated to relieve suffering and see treatment or even cure as a noble goal and will naturally see this as most urgent for those most severely affected when applying a disorder model, or at the severe end of the spectrum if using a continuum. This in turn has several consequences. The appeal for the condition to be taken seriously from both a biomedical and social perspective is 'diluted' when set against other manifestly life limiting conditions. Conversely, people who are less articulate or non-verbal are, in the arena of self-diagnosis, marginalized and denied a voice – an example of testimonial injustice (Kious, Lewis, & Kim, 2023). This is ironic since some accuse psychiatry of being inherently unjust in this sense precisely because it denies or at best downplays the voices of its supposed beneficiaries.

In addition to the *de facto* exclusion of people with severe conditions, there is the exclusion of others who find themselves in the 'out' group. For example, academic classificatory systems might place the psychoses especially schizophrenia, within a neurodevelopmental rubric but self-diagnosis of schizophrenia does not seem to be an option and the neurodiversity movement does not include people with these conditions. Perhaps this is because there is little social advantage in adopting this diagnosis which carries no added benefits. However, given the capricious nature of stigma we consider that the social advantages currently accorded to an autism diagnosis may be transient should negative associations gain traction in the media – such as autism as a means of avoiding responsibility for otherwise unacceptable behavior, or if autism becomes linked in the public imagination to prominent cases of undesirable behaviors such as stalking or online offending (see Shields & Beversdorf, 2021).

Fellowes (2023) sets out how an 'official' diagnosis enables access to what he calls social resources, and these go beyond concrete financial support and benefits but encompass a long list including advocacy, participation in research and social interactions with people who share the same condition. The strength or social resources for a particular diagnosis can be increased when more people have that diagnosis. However, they may be taken up with those with lower levels of need which correspondingly disadvantages the most severely affected.

Fellowes also points out that misdiagnosis is bound to occur in the self-diagnosed. Of course professionals mis-diagnose and re-diagnose all the time but not through any ideological allegiance to one diagnosis over another. Psychiatric diagnosis requires training; difficult cases should be discussed with other experts with the aim of reaching a consensus. A good clinician is always open to the possibility that they have got it wrong. Take a common tricky case. A person notices that their life story is marked by notable highs and lows. They are drawn to alcohol and other drugs in an attempt as they see it, to 'self-medicate'. They embrace the diagnosis of 'bipolar'. A skilled clinician may seek to disentangle the effects of substances and mood shifts and reach the conclusion that it is the cycle of excessive use and withdrawal of substances that produces the wide fluctuations in affect and subsequent social dysfunction and that controlling such use should be the prime target of any intervention including lifestyle modification. This may make all the difference and obviate the search for an effective 'mood stabilizer'. The implications of getting the diagnosis right may be profound.

Experience from a specialist clinic showed that only around a half of referrals of people with a high-index of suspicion that they have autism spectrum disorder met operational diagnostic criteria. The important point is that the remainder often had alternative and treatable conditions such as OCD, social phobia and depression (Russell et al., 2016).

Another common error in self-diagnosis is of dementia *v.* functional cognitive disorder (McWhirter, Ritchie, Stone, & Carson, 2020). It is easy to see why a person's lapses of memory and attention may strike them as signs of dementia – especially in an age of increased recognition of the disorder. However, part of the functional cognitive disorder syndrome is a cycle of thinking which gives undue weight to instances that apparently confirm the individual's diagnostic suspicions which in turn increases vigilance to further instances and so on. The passage of time then takes on an important role in diagnostic validation. Either relentless worsening of presenting symptoms or accretion of others declare themselves confirming a neurodegenerative diagnosis, or

fail to do so, refuting it. This challenging clinical problem has taken on a new dimension with a small group of advocates using non-progression as evidence, not of a functional disorder, but against the pessimism of professional diagnosticians' concept of neurodegenerative disease. The problem of the 'living well with dementia' notion is not the desirable promotion of adaptive coping styles (Wolverson, Clarke, & Moniz-Cook, 2016) but the offer of an attractive alternative and even a net benefit to personal growth, precluded by the official diagnosis. This traps those so misdiagnosed in an alternate reality, gives false hope to sufferers and families of people with dementia and confuses those tasked with providing care and other resources. Some commentators from social science see this, worryingly, in less black and white terms but more the results of 'dissonant dementia' where notions of normal ageing clash ideologically rather than empirically with pathological entities in a manner analogous to the neurodiversity-disorder conflict (Fletcher & Maddock, 2021).

Similarly, those predisposed to stigmatize people with mental health conditions will point to what some take to be the self-diagnosed's special pleading (to be given dispensation without the official sanction of a proper diagnosis and without overt disability), leading to trivialization (Clements, 2019). Saying someone is 'on the spectrum' has taken on this implication such that neurodiversity adherents, despite their philosophical embrace of the spectrum concept, prefer to self-identify as 'autistic' pure and simple.

Baron-Cohen (2017) tried to argue in relation to autism that, say, profound intellectual disability is not inherent to the construct and can be the target of support or interventions without compromising the neurodiversity idea. The syndromic nature of autism includes the frequent association with other disabilities and manifest disadvantages including those affecting intellect, as well as those clearly pathological such as epilepsy, self-mutilation, incontinence, and so on, even though these are neither necessary nor sufficient for a diagnosis. Indeed, Baron-Cohen moved away from this position (see Baron-Cohen, 2019) in the light of the frequency with which autistic traits and their penumbra engender distress and problems of living, in certain contexts, giving rise to a more nuanced view that difference/diversity, disability and even disease can all co-exist with the autism spectrum phenotype.

### Why neuropsychiatry?

Several commentators have noted the explosion in usage and application of the 'neuro' prefix to seemingly unlimited areas of discourse (Muzur & Rinčić, 2013). As well as being inherent to neurodiversity, it seems to have caught on by adding an authoritative gloss by virtue of its scientific, modern, technological associations, to disciplines within social science and education as well as being misused by advertisers and other commercial interests. One unfortunate implication of the neuro prefix in self-diagnosis is an oversimplification of research findings: that a said groups' brains (or genes) are demonstrably different, and this underpins claims on rights and resources (Russell & Wilkinson, 2023). Searching for brain correlates or biomarkers is an active area of research across many psychiatric diagnoses but current unanswered questions revolve around the nature of any brain (or genetic) differences, how reliably are these detected and how they relate to the phenotype in question. As yet there are no reliable brain biomarkers for any of the conditions we have so far considered.

The other consequence of neurophilia – unintended or not – is the second point made by Russell (2020) around agency:

*The problem is a 'born this way' narrative deemphasizes personal responsibility, which can be tremendously helpful, but can sometimes be used as an excuse to avoid culpability.*

Indeed one of the potentially troubling (mis)uses of the neuro-prefix relates to the law (Gkotsi, Gasser, & Moulin, 2019) and the courtroom where neurological evidence is deployed to bolster other conventional evidence in a way that goes beyond the data – principally by seeking to draw inferences on an individual case – usually around responsibility – from data mostly based on averages across groups and hence probabilistic. It is therefore essential, not only in forensic settings but other formal circumstances such as qualification for state benefits, that diagnostic labels retain some element of objectivity, in the sense of being externally applied (hopefully on the basis of evidence and earned authority) rather than self-designated. More broadly, it has been suggested that neurodata when applied indiscriminately – especially neuroimaging – are unjustifiably 'seductively alluring' (see Michael, Newman, Vuorre, Cumming, and Garry (2013) for a review).

But even outside the courtroom, an adversarial atmosphere can pervade many areas where diagnosis is contested leading to self-diagnosis. For some, the primary attribute of the condition encapsulated in the neurological-sounding diagnostic labels myalgic encephalomyelitis/encephalopathy or 'ME', a diagnosis preferred by some self-help and advocacy groups, is its lack of any psychosocial underpinnings. This conflicts with the more neutral 'chronic fatigue syndrome', favored by most practitioners, and compatible with a boarder biopsychosocial model and effective treatment approaches (White et al., 2023).

Interestingly arguments over whether one has/suffers from/is a person with (autism, schizophrenia, dementia) *v.* one is autistic, schizophrenic, demented, have resurfaced in the context of self-diagnosis. While the form of words, *a person with...* has become the favored if not required usage by professionals and patients alike, a strand of discourse bolstering the 'is' against 'has', has found a new voice. The former, it is argued is more authentic and denotes a deeper appreciation of the nature of the condition in question (Sass, 2007).

### Conclusions

Like any significant intervention, diagnosis can have harms as well as benefits. Self-diagnosis is no different. We argue that the problems of self-diagnosis are that:

It is not a sufficient basis for accessing the benefits which medical diagnosis allows; it may lead to misdiagnosis and misdirect the person from care that could help them; and also, it may alter the social meaning and standing of a diagnosis, disadvantaging those most affected and who need it the most.

The benefits of self-diagnosis include a variety of social resources: admittance to the peer support of a community, a positive illness identity and perhaps access to a narrative reframing of personal struggle and disappointments in life, enjoining sympathy and even admiration.

Finally, we might speculate as to why self-diagnosis has become so common. One element may be the growth of peer-to-peer communication via social media, fuelling the notion of lay expertise, the mistrust of power imbalances associated with professional hierarchies, and perhaps also impatience and desperation with long NHS waiting lists for assessment and/or the prohibitive expense for many, of privately sought diagnoses.

**Competing interest.** None.

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