Self-Diagnosis in Psychiatry and the Distribution of Social Resources

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Abstract

I suggest that the diagnosis that an individual self-diagnoses with can be influenced by levels of public awareness. Accurate diagnosis requires consideration of multiple diagnoses. Sometimes, different diagnoses can overlap with one another and can only be differentiated in subtle and nuanced ways, but particular diagnoses vary considerably in levels of public awareness. As such, an individual may meet the diagnostic criteria for one diagnosis but self-diagnoses with a different diagnosis because it is better known. I then outline a potential negative consequence of this. Psychiatric diagnoses can grant access to what I call social resources, namely, political advocacy, campaigning for support, participating in scientific research, building diagnostic cultures, and opportunity for social interactions with people who have the same diagnosis. The strength of the social resources for a particular diagnosis can be made stronger when more people have that diagnosis. As such, inaccurate self-diagnosis can result in the social resources for one diagnosis being strengthened whilst not being strengthened in relation to another diagnosis in comparison to accurate diagnosis. This shows how inaccurate self-diagnosis can alter the distribution of social resources. We need to consider whether this is unfair to people who are diagnosed with less well-known conditions.

1. Introduction

Self-diagnosing psychiatric diagnoses, whereby an individual diagnoses themselves rather than seeks out a medical professional, is a controversial topic. Advocates of self-diagnosis argue that it helps people who cannot access the diagnostic process and that it also helps people who will be misdiagnosed by medical professionals. Critics of self-diagnosis argue that only medical professionals have sufficient expertise to make reliable diagnoses. One important question to consider is the consequences of inaccurate self-diagnosis. What, if any, negative consequences follow from someone self-diagnosing with a condition that they do not actually have? Official diagnoses can play a role in eligibility for medical resources like treatment and support, but self-diagnosis does not typically grant eligibility to these. As such, there is little opportunity for people who self-diagnose to (fairly or unfairly) get access to those limited resources.

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In this paper, I will argue that self-diagnosing individuals have access to an alternative type of resource which I name social resources. Also, I argue that inaccurate self-diagnosis can alter the strength of these social resources for different diagnoses.

Social resources are means of improving engagement with society and getting fair treatment from society. I outline five different social resources relating to psychiatric diagnoses. These are political advocacy, campaigning for support, participating in scientific research, building diagnostic cultures, and opportunity for social interactions with people who have the same diagnosis. People with the same diagnosis can group together to campaign for social changes, for better support, and for better scientific research. They can also form diagnostic cultures whereby they promote their condition as a unique and valuable way to live. Finally, they can meet other people with the same diagnosis, providing a source of social interactions with people who might share similar characteristics.

I argue that the strength of these social resources is influenced significantly by the number of people who have the diagnosis. The more people with that diagnosis means more people to campaign and form cultural movements in relation to the diagnosis, and more people with that diagnosis who can meet one another. The number of people with a diagnosis can have important consequences through strengthening or weakening these social resources. As such, inaccurate self-diagnosis can alter the strength of those resources.

I consider whether self-diagnosing individuals can reliably establish which diagnosis they fit. I provide a detailed example of how different diagnoses can appear superficially different but are only distinguished in subtle and nuanced ways. I then review existing literature on self-diagnosis to establish whether self-diagnosing individuals investigate a range of diagnoses and are aware of how different diagnoses can be distinguished in subtle and nuanced ways. The existing empirical literature gives little reason to believe that they do, but I recognize this might only reflect limitations with that empirical literature. I then outline an additional problem, namely that there is much higher public awareness of some diagnoses compared to others and suggest this can alter the process of self-diagnosis in a manner that increases inaccurate self-diagnosis.

Given that there are hundreds of psychiatric diagnoses it is difficult to make generalizations. The accuracy of self-diagnosis and any negative consequences of self-diagnosis may vary significantly between different diagnoses. I will support my argument with empirical evidence but detailed investigation in relation to specific diagnoses is needed to understand exactly where this issue is applicable.

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2. Self-Diagnosis in Psychiatry

There are many barriers to receiving an official diagnosis. Firstly, there are few professionals available to providing an official diagnosis which has led to long waiting times (McDonald, 2020, p. 15; Lewis, 2016; Lewis, 2017, p. 578; Sarrett, 2016, p. 31). Secondly, in some countries there can be significant financial costs to being assessed by an official diagnostician (McDonald, 2020, p. 15; Lewis, 2016; Lewis, 2017, p. 578; Sarrett, 2016, p. 31). Thirdly, some individuals find navigating the healthcare system difficult (Lewis, 2016). Fourthly, some individuals believe they will struggle to describe their symptoms to professionals (Lewis, 2016). Fifthly, there are concerns, typically based on past experience, that medical professionals or institutions may harm the individual seeking the diagnosis (Lewis, 2016; Lewis, 2017, p. 578). Sixth, putting a psychiatric diagnosis on a medical record could harm future prospects, such as employment prospects (Lewis, 2016; Lewis, 2017, p. 578; Sarrett, 2016, p. 31). Seventh, given that there are typically so few services available, it is not always clear if there is much benefit in receiving an official diagnosis (Lewis, 2016; Lewis, 2017, p. 578). Finally, there is concern that the specialist will falsely claim that the individual does not meet the diagnostic criteria (Lewis, 2016; Lewis, 2017, p. 578).

The reliability of self-diagnosis has been debated by diagnosed individuals (the views expressed in this and the next paragraph are from interviews that Sarrett conducted with officially diagnosed autistic individuals). The main reason why self-diagnosis is considered reliable is that someone with the condition knows the condition in a way that someone without the condition does not (Sarrett, 2016, p. 30). This means the self-diagnosing individual has a level of epistemic authority which the official diagnostician lacks. Therefore, someone with the condition is in a better position to judge that they have the condition compared to an outside observer, including medical professionals. A related issue is that the self-diagnosing individual has access to information which is not accessible within a clinical setting. As one autistic individual writes, 'lived experience is more important and complex than clinical assessment' (unnamed autistic individual quoted in Sarrett, 2016, p. 31).

The main reason why self-diagnosis is considered unreliable is that accurate diagnosis is believed to require trained professionals (Sarrett, 2016, p. 27). There is also a concern over self-bias in self-diagnosis. An individual who thinks they have a condition might subconsciously start looking for traits which are not present. This could

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lead an individual to self-diagnose when they do not meet the diagnostic criteria (Sarrett, 2016, p. 28). An individual might wish to receive a diagnosis because of possible state benefits (Sarrett, 2016, p. 29) or because they think they will feel special (Sarrett, 2016, p. 29). Another potential concern stems from the belief that an individual needs to have a certain level of disability to have a psychiatric diagnosis. This could mean that anyone with that level of disability would have been spotted by medical professionals (Sarrett, 2016, p. 28).

It is important to demarcate between two different approaches to self-diagnosis. Firstly, self-diagnosis can relate to official diagnostic criteria found in the DSM or ICD. A self-diagnosing individual might be better able to establish whether they meet the official diagnostic criteria than a professional diagnostician is able to. For example, the DSM criteria for autism include an intensely focused interest on specific topics. Stereotypical examples of this would be an intensely focused interest on transport or computers. However, some argue that these stereotypical examples are much closer to how some white Western male autistic individuals exhibit intense interests. In contrast, some autistic girls might instead focus more on ponies or boy bands (Moseley, Hitchiner, and Kirby, 2018, p. 2). Consequently, a diagnostician might look for stereotypical notions of autism and consequently miss the way in which an autistic female presents as autistic. In contrast, an autistic female who self-diagnoses might not be influenced by inaccurate stereotypes of autism and thus accurately judge that they are autistic. On this approach the DSM or ICD is taken as providing the standard and the relevant question is whether the diagnostician or the self-diagnosing individual is more likely to accurately assess whether the individual meets the DSM or ICD diagnostic criteria.

Secondly, self-diagnosis can relate to rejecting official diagnostic criteria. For example, the self-diagnosing individual recognises that they do not meet the official diagnostic criteria in the DSM or ICD, but they still consider themselves to have the condition. They consider the official diagnostic criteria to be in some way flawed. The self-diagnosing individual believes they have superior knowledge of at least one psychiatric condition in at least one manner when compared to the DSM and ICD. There is at least one way in which the psychiatric condition can manifest itself which official diagnostic criteria fail to capture but which the self-diagnosing individual has accurately captured. The dispute between the self-diagnosing individual and a potential diagnostician is not about

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whether the individual meets the official diagnostic criteria but what the correct diagnostic criteria should be.

My argument is applicable to both approaches but will only give examples in relation to the first approach. Presumably, those who reject the DSM still posit that there exist multiple diagnoses and self-diagnosing individuals still need to work out which of those diagnoses they fit. They just reject the notion that the way to diagnose and demarcate between different diagnoses is through consulting the DSM. I focus upon the first approach because I can draw upon detailed empirical examples. To provide examples of how my argument applies to the second approach I would need detailed information of the way in which self-diagnosing individuals alter the diagnostic criteria of multiple diagnoses. To my knowledge, no publication outlines this.

3. The Problem of Alternative Diagnoses

I now consider how self-diagnosing individuals need to consider a range of diagnoses for self-diagnosis to be accurate. Almost all currently employed psychiatric diagnoses cover overlapping symptoms (Kendell & Jablensky, 2003, p. 6; Zachar, 2014, p. 113). Some symptoms on the diagnostic criteria for a particular diagnosis will be present on the diagnostic criteria for a different diagnosis. Diagnoses with symptoms that are exclusive to that diagnosis are extremely rare. I now provide a specific empirical example of how this could occur. I show the similarity and nuanced differences between the diagnoses of autism, schizoid personality disorder, and schizotypal personality disorder.

I first compare autism with schizotypal personality disorder and then consider schizoid personality disorder. The diagnostic criteria of both autism and schizotypal personality disorder include social differences. Both autistic individuals and schizoid personality disorder individuals relate to others in ways which are atypical. They are both considered to struggle in most social situations. Also, both can exhibit restricted and repetitive activities. In these regards, there are significant overlaps between them. They are mainly demarcated by what are known as the positive symptoms of schizophrenia. Schizotypal personality disorder is considered to be on the schizophrenia spectrum. It has some of the positive symptoms of schizophrenia, i.e., the symptoms of schizophrenia which are additional characteristics compared to what typical people exhibit, such as ideas of reference (incorrectly thinking events have significance for

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themselves), magical thinking, interest in superstition and paranormal phenomena, and paranoid beliefs (as opposed to negative symptoms where characteristics which are usually present in a typical person is absent in the schizophrenic individual) (APA, 2013, p. 656). However, schizotypal personality disorder lacks the hallucinations which are typically present in individuals with schizophrenia.

There are, however, significant complexities in how autism and schizotypal personality disorder overlap and how they are distinct. Firstly, they both have social communication differences. However, there appears to be differences in how and why social behaviour and communication manifest. For example,

> SPD [schizotypal personality disorder] criteria include odd speech that is vague, circumstantial, and metaphorical whereas AD [autism] criteria focus on problematic non-vocal communicative behaviors. While both AD and SPD appear to have communication deficits, the modifiers for SPD odd speech (vague, circumstantial, metaphorical, overelaborate) suggest a highly developed, though disordered, expressive vocal repertoire while the AD criteria suggest a disordered repertoire related to understanding body language. (Hurst *et al*., 2007, p. 1712)

Also, 'there is an overlap between Asperger [stereotypically considered higher functioning autism] and Schizotypal traits in the expected areas; i.e., social overlaps with interpersonal and communication overlaps with disorganized [but there was less strong overlaps in other areas]' (Hurst *et al*., 2007, p. 1718).

Secondly, they both have restricted and repetitive behavioural differences. However, there seem to be differences between these because 'repetitive-restricted behaviors domain includes verbal behavior in SPD (e.g., stereotyped thinking and speech), whereas AD criteria include stereotypic, repetitive, inflexible, and persistent patterns of behavior without reference to speech or thinking' (Hurst *et al*., 2007, p. 1713).

Thirdly, autism and schizotypal personality disorder are demarcated by some of the positive symptoms of schizophrenia. However, '[c]riteria unique to schizotypal PD are those related to psychotic-like experiences and magic thinking, which may well be present in people with PDD/ASD [autism], although not among the core features' (Lugnegård, Hallerbäck, and Gillberg, 2012, p. 337; see also Ford & Crewther, 2014, p. 2).

Whilst they do not appear to be identical, there can be great difficulty in demarcating between autism from schizotypal personality

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disorder. Two quotes highlight the difficulties of demarcating between them.

> There may be great difficulty differentiating children with schizotypal personality disorder from the heterogeneous group of solitary, odd children whose behaviour is characterized by marked social isolation, eccentricity, or peculiarities of language and whose diagnoses would probably include milder forms of autism spectrum disorders. [DSM-5] (APA, 2013, p. 658)

> […] it may be that at some point in the developmental course of the two disorders [autism and schizotypal], they may appear almost identical, and in fact, individuals on the two spectra who become ''stuck'' within this behaviorally similar period may never be able to be differentiated based upon behavioral tests, alone. (Hurst *et al.*, 2007, p. 1719)

I now consider schizoid personality disorder. Schizoid personality disorder is, like schizotypal personality disorder, also considered to be on the schizophrenia spectrum. Schizoid personality disorder differs from schizotypal personality disorder by lacking the positive symptoms of schizophrenia. Thus, both autism and schizoid personality disorder are demarcated in the DSM from schizotypal personality disorder by a lack of magical thinking and odd beliefs (APA, 2013, p. 655) though, as mentioned above, these can be present in autism. Autism and schizoid personality disorder are demarcated by autism having more pronounced social communication difference and more pronounced stereotyped behaviour (APA, 2013, p. 655).

Firstly, autism and schizoid personality disorder both share social communication differences. However, it appears that both differ in how social differences present themselves and what causes them. Autistic individuals often want to socialise but seem to lack an intuitive social sense which is typically employed in social situations. Also, they struggle to read unconscious body language. As such they often struggle in social situations even though many often want to engage in socialising. In contrast, schizoid personality disorder individuals are often taken as having social skills in principle but often choose not to engage in socialising. This can involve a simple lack of desire to socialise but can also relate to not receiving much experientially from socialising, much like how individuals with schizoid personality disorder can often feel little from bodily contact and sexual activity. However, these demarcations between each diagnosis are not clear-cut. It is also well known that some autistic individuals are content with not socialising in principle, as opposed to choosing not to

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socialise because they find it difficult. Also, autistic individuals sometimes have both hyper (excessive) and hypo (weak) sensitivity which can lead to socialising being unfulfilling independent of problems caused by innate lack of typical social intuition. Additionally, autistic people often have quite specific interests and are often bored by typical conversations, especially by small talk. This again seems to occur independently of any innate lack of typical social intuition. Finally, whilst schizoid personality disorder individuals may not desire to socialise, their lack of experience at socialising may lead to reduced social skills when they actually attempt to socialise.

Secondly, the repetitive and restricted behaviour in autism is typically quite pervasive, whereas it is typically more delineated in schizoid personality disorder. Autistic repetitive and restricted behaviour covers phenomena like disliking unexpected changes, desire for routines and narrowly circumscribed but intense interests. In contrast, individuals with schizoid personality disorder will typically prefer solitary hobbies which may result in them engaging in more uniform behaviour compared to engaging in non-solitary hobbies which may involve more dynamically changing situations. Also, there can be elements of repetitive and restricted behaviour in relation to thought and speech. For example, 'the stereotyped thinking and speech, a clinical feature observed in patients with schizoid personality disorder, may be taken as "rigid"' (Sugihara, Tsuchiya, and Takei, 2008, p. 1998). However, the demarcation is not clear-cut. Many autistic individuals will also prefer solitary rather than social activities. Also, repetitive thoughts are also common in autistic individuals (same thought reoccurring), but rigid thoughts do not appear to be higher than non-autistic controls (number of different topics of thought) (Cooper *et al.*, 2022, p. 856). Both autism and schizoid personality disorder seem to have repetitive and restrictive aspects but there are both similarities and differences in form.

These similarities mean that it can be difficult to demarcate between autism and schizoid personality disorder in a diagnostic context. These two quotes highlight this:

> There may be great difficulty differentiating individuals with schizoid personality disorder from those with milder forms of autism spectrum disorder. [DSM-5] (APA, 2013, p. 655)

> Children with Asperger's were indistinguishable from "loner" (parent rated schizoid personality traits) children on a schizoid scale (49) suggesting potential misclassification of schizoid PD as Asperger's disorder due to comorbid schizoid trait in "loner" and Asperger's Children. (Ford & Crewther, 2014, p. 3)

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4. Self-Diagnosing Individuals and Multiple Diagnoses

I have given a detailed example of how autism is demarcated from two other diagnoses in nuanced and subtle ways. I now relate this general issue to self-diagnosis. Do self-diagnosing individuals consider a range of diagnoses when self-diagnosing? Are they aware that some diagnoses are differentiated from each another only in subtle and nuanced ways? Are there any factors that might increase or decrease this awareness? Are they able to apply these subtle and nuanced distinctions to themselves when self-diagnosing? Unfortunately, there is extremely limited empirical data on these questions, but I shall draw upon what is available in the academic literature.

Firstly, a few papers have empirically investigated individuals who self-diagnose as autistic, but none mention those self-diagnosing individuals investigating a range of diagnoses. In relation to individuals who self-diagnose as autistic, 'the more they learned about ASD, the more confident they became in their self-diagnosis' (Lewis, 2017, p. 577) and 'the more they learned about ASD, the less they could doubt their own belief that they had ASD' (Lewis, 2017, p. 577). Similarly, '[m]ost self-diagnosed autistic adults find that, after learning about and researching autism, they have the self-awareness to state confidence in having autism' (Sarrett, 2016, p. 30). These three quotes relate to learning the diagnostic criteria of autism, rather than gaining in confidence when they learned the diagnostic criteria of autism *and also other diagnoses*. Indeed, neither Sarrett (2016) or Lewis (2016, 2017), who both interviewed individuals self-diagnosing as autistic, ever mention a self-diagnosing individual considering any diagnosis other than autism. The notion that an individual has or has not consulted all the relevant diagnoses that they need for accurate self-diagnosis is simply not mentioned in either paper, either by the interviewed participants or the authors of the paper. If the vast majority of individuals who self-diagnose as autistic not only investigate multiple diagnoses but also do so in a manner that appreciates the subtle and nuanced distinctions that I grasped through reading multiple scientific studies, then it is surprising that none of the four empirical papers on self-diagnosis of autism contain even a single sentence mentioning this.

Secondly, portrayals of psychiatric diagnoses have been studied on social media. A recent study looked at the hundred most popular videos on ADHD on TikTok (some exclusion criteria were applied). These videos had a combined total of 283,459,400 views. The study considered 52 of those 100 videos as misleading, with the other 48 videos classified as either useful or personal experience.

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Crucially, for my purposes of considering how self-diagnosing individuals relate to multiple diagnoses, '[o]f the 52 misleading videos, 37 videos (71%) misattributed transdiagnostic psychiatric symptoms as being specific only to ADHD, including anxiety, depression, anger, relationship conflicts, dissociation, and mood swings' (Yeung, Ng, and Abi-Jaoude, 2022, p. 91). If this claim is true, then it raises the concern that people who view this content might mistakenly take various behaviours to be instances of ADHD rather than as potentially indicative of a range of conditions. However, even assuming this paper accurately assesses those videos, it only indirectly and tentatively provides evidence about self-diagnosis. We lack information about how many people who self-diagnose with ADHD view such content and how many of those people then believe such content to be reliable. We also lack information about how much reliable information on ADHD they come across and how they weigh inaccurate social media portrayals against accurate information about ADHD. I can only suggest that anyone significantly influenced by such social media posts might have reduced ability to recognise that multiple diagnoses may refer to broadly similar symptoms but are actually demarcated by nuanced and subtle differences.

Another recent study interviews people who view mental health content on TikTok. The article discussed multiple diagnoses, including ADHD, bipolar, and PTSD. Some interviewed individuals were concerned that 'many content creators chase social prestige and vitality, or clout' (Milton *et al.*, 2023, p. 2) through content which described their experience of mental health. This raised the concern that some content creators had self-diagnosed with the conscious or unconscious motive of creating content rather than because they genuinely believed they exhibited the condition. At the same time, the interviewed individuals were concerned about their ability to adequately judge who was faking and who was genuine, showing that at least some individuals who consume mental health content on TikTok are critically reflecting upon the content they see. Another recent paper, which did not interview any social media users, expressed these concerns in a much stronger fashion. It claims that in social media spaces

> [mental health] identities or personas can be claimed at will […] social and emotional resonances may amplify and reinforce identification with the persona and may even predict later behaviors in line with it [and] may increase the likelihood that the "self-diagnosed" identity is reified and incorporated into one's self-concept. (Haltigan, Pringsheim, and Rajkumar, 2023, p. 5)

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My mental health social media experience mainly consists of running an academic account on Twitter, so I am not in a position to judge the accuracy of this claim. Also, even if this is true then there is still the issue of the degree in which such content influences viewers who self-diagnose. I can only suggest that if some individuals who self-diagnose are influenced by social media content produced by individuals who falsely present themselves as having a particular condition, then this could reduce recognition that different diagnoses can appear to cover the same symptoms but that each diagnosis actually has nuanced and subtle differences.

None of the evidence I have offered is conclusive, but I also believe this evidence cannot simply be dismissed. I think it gives us good reason to seek more empirical data on these and related issues, rather than that it shows that we have sufficient empirical data from which we can draw strong conclusions. Also, some of this evidence might be partly true, but this does not then indicate the degree of partial truth. Imagine if the majority of self-diagnosing individuals avoided the above problems, but not all did. This is compatible with, say, 5%, 15%, or 30% of self-diagnosing individuals being significantly influenced by problematic information. Rather than making any firm judgments, I will outline a further factor that could make self-diagnosing individuals less likely to consider multiple diagnoses.

5. Public Awareness of Different Diagnoses Differs Significantly

A significant factor likely influencing which diagnoses someone considers when self-diagnosing is the level of public awareness of different diagnoses. Psychiatric diagnoses differ significantly in how greatly they enter public consciousness. They mainly enter public consciousness through various forms of media. They vary in how often they are mentioned in news articles, how greatly they feature in films or TV programmes, or how often they are mentioned on social media. This can be influenced by many different factors. Diagnoses vary in the degree that symptoms of the condition are observable or prominent, the degree a diagnosis has positive or negative associations, the degree of advocacy relating to the diagnosis, and the degree the relevant condition is present in the population. I shall highlight this by drawing again upon my examples of autism and both schizoid and schizotypal personality disorder.

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Autism is typically considered less disabling. The neurodiversity movement has highlighted positive elements of autism. There are many publications where diagnosed autistic individuals claim that autism is either not a bad thing or is a good thing (for example, Kapp, 2020; Walker, 2021). Schizoid and schizotypal personality disorder have more negative associations due to their associations with schizophrenia and the notion of a disordered personality. I cannot locate a single paper relating schizoid or schizotypal personality disorder to neurodiversity. Many people would prefer to think of themselves as having a neurological difference or being neurodivergent rather than being disordered or diseased (which conditions should be considered divergences rather than disordered, and whether this distinction is sustainable, is not an issue I comment upon here).

The level of advocacy is much higher for autism compared to schizoid and schizotypal personality disorder. A glance at social media reveals this. For example, the number of tweets when putting #autism into the search box on Twitter is typically over a hundred times higher over the same time period compared to putting #schizoid, #schizoidpersonalitydisorder, or #schizoidpd into that search box. The same is true in relation to #schizotypal, #schizotypalpersonalitydisorder or #schizotypalpd.

There have been multiple television programmes relating to autism. Putting the phrase 'best tv programmes about autism' (not in quotation marks) into a search engine produces multiple websites listing the latest must-see programmes or films about autism. The same is not true when doing this in relation to either schizoid or schizotypal personality disorder.

Putting the words 'autism advocacy' (not in quotation marks) into Google Scholar produces many papers either discussing autism advocacy or papers engaging in autism advocacy. A similar result occurs when putting in the phrase 'autistic campaign' or the phrase 'autistic culture'. It is easy to find multiple relevant websites relating to campaigning for social change in relation to autism and in relation to producing an autistic culture. Finding similar papers or websites for either schizoid or schizotypal personality disorder is much harder.

Most symptoms of autism are more prominent compared to schizoid or schizotypal personality disorder. Autism typically (though not always) involves individuals who seek social contact whereas the latter two involves individuals who often avoid social contact. Additionally, much of the repetitive and restrictive behaviour of autism relates to physical actions whereas some of the repetitive and restrictive behaviour of schizoid and schizotypal personality disorder relates to speech or thought processes.

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It is unclear how common autism is compared to schizoid or schizotypal personality disorder. Autism is estimated to occur in between 1% to slightly under 2% of the population. According to the DSM-5 schizoid personality disorder is estimated to occur in 3.1% to 4.9% of the population (APA, 2013, p. 654) and schizoid personality disorder is estimated to occur in 0.6% to 4.6% of the population (APA, 2013, p. 657). A review of prevalence figures for schizoid personality disorder mentions 1.7%, 0.9%, 0.8%, 4.9%, and 0.6%, and mentions for schizotypal personality disorder 0.6%, 0.6%, 0.06%, 3.3%, and 0.6% (Samuals, 2011, p. 225). I will now consider the consequences of diagnoses varying in public awareness.

6. The Consideration of Multiple Diagnoses and Inaccurate Self-Diagnosis

I now consider how public awareness of different diagnoses may influence self-diagnosis. Firstly, an individual may only investigate some, rather than all, of the conditions that they have the symptoms of. They might not have heard of some conditions they have symptoms of. If they have heard of a condition they might not know enough about the condition, or their information about the condition is too restricted by inaccurate stereotypes to realise they should investigate the condition. They may thus not investigate a psychiatric condition even though they meet its diagnostic criteria. Also, an individual might consider multiple diagnoses, but spend significantly more effort considering some of those diagnoses and less considering others. The individual might feel, for example, after only superficial investigation of each, that they fit one diagnosis better than the other. Consequently, they only focus upon one of those diagnoses and ultimately self-diagnose with one of them when they also meet the diagnostic criteria of the other ones. Additionally, the individual may consider multiple diagnoses and realise they meet the diagnostic criteria of multiple diagnoses. However, they feel that one diagnosis fully accounts for them, so only self-diagnose with one of those diagnoses without realising they can simultaneously be diagnosed with both diagnoses.

Secondly, imagine an individual misunderstands which symptoms they exhibit. They might believe that they exhibit particular symptoms whereas actually they exhibit different symptoms. Based upon the symptoms they believe they exhibit the individual self-diagnoses with one diagnosis. However, when measured by the symptoms the individual actually exhibits, they do not meet the diagnostic criteria

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of that diagnosis but they do meet the diagnostic criteria of another diagnosis. This possibility has been highlighted when I considered the way in which some symptoms of autism only differ from some symptoms of schizoid or schizotypal personality disorder in nuanced ways. Some symptoms have significant similarities but also some nuanced differences in how they manifest themselves and in the causes for why those symptoms occur.

Thirdly, an individual might accurately assess which symptoms they have, but does not accurately understand the diagnostic criteria of the diagnoses that they do consider. They misunderstand some of the symptoms mentioned on the diagnostic criteria. They incorrectly take themselves as either exhibiting or not exhibiting a symptom of a particular condition based upon misunderstanding the text in the DSM or ICD even though they correctly understand which symptoms they themselves exhibit. For example, an individual accurately assesses that they have repetitive behaviour but fails to realise their repetitive behaviour is closer to the repetitive behaviour associated with one diagnosis than to the repetitive behaviour of another diagnosis because they misunderstand the DSM. This possibility has been highlighted when I considered how there are subtle and nuanced specific differences between some symptoms of autism and some symptoms of either schizoid or schizotypal personality disorder. It is not immediately clear how, based upon the DSM and ICD descriptions, some symptoms listed in the diagnostic criteria for autism differ from some symptoms listed in the diagnostic criteria for schizoid or schizotypal personality disorder. I have drawn on additional psychological or psychiatric literature to highlight the similarities and differences between autism and schizoid and schizotypal personality disorder. This information is not available when simply consulting the DSM and ICD.

I now consider how misdiagnosis can influence social resources that are accessible to both officially diagnosed individuals and self-diagnosed individuals.

7. Self-Diagnosis and the Distribution of Social Resources

I now outline five different social resources. These are social resources in the sense that they all involve engaging with other individuals in a manner that can directly or indirectly improve the well-being of diagnosed individuals.

Firstly, diagnosed individuals can form political advocacy movements. They can argue for increased inclusion through greater

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understanding of the diagnosis, societal acceptance, or reasonable accommodations. The lives of diagnosed individuals can be improved through changing society (Botha *et al.*, 2022; Ortega, 2013).

Secondly, diagnosed individuals can advocate for more support services and more suitable support services. They can highlight what beneficial support would consist of and then argue existing support is insufficient or even harmful. Improved services could lead to improved lives for diagnosed people (Botha *et al.*, 2022; Ortega, 2013).

Thirdly, diagnosed individuals can advocate for participatory research relating to their diagnosis. They can demand that research on their condition includes diagnosed individuals when setting research topics, designing experiments, and interpreting results. This could potentially improve scientific research and prevent harmful scientific research being done (Buter, 2019; Tekin, 2022).

Fourthly, diagnosed individuals can form part of a diagnostic culture. They can produce art, literature, and media relating to people with a particular diagnosis or relating to people with psychiatric diagnoses in general. This is a means of celebrating an alternative way of living and producing cultural products that people who feel alienated by mainstream culture can potentially relate to (Jaarsma & Welin, 2012; Runswick-Cole, 2014). Note that all these four social resources can benefit a diagnosed individual even if they choose not to be involved in them; for example, successful advocacy could improve services for all autistic people including those who do not take part in the activism.

Finally, individuals with the same diagnosis can find commonalities among one another (Abel *et al.*, 2019; Botha *et al.*, 2022). They can have shared symptoms, shared problems in daily living, and shared interests. This can lead to opportunities to socialising, an important factor given how many people with diagnosed conditions can be very isolated. Even where individuals dislike socialising, they can still engage in online interactions which allows the sharing of information and stories that can enhance self-understanding. Unlike the other four social resources, a diagnosed individual themselves needs to engage in these interactions to benefit from them.

Each of these social resources can exist in a form in which they are not tied to a particular diagnosis or are tied to a particular diagnosis. Some advocacy involves people with different diagnoses working together on a collective aim. However, significant amounts of advocacy are based around people with a particular diagnosis advocating for that diagnosis (McCoy *et al.*, 2020; Seidel, 2020). This is partly because people with a particular diagnosis are considered to have

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some level of expertise on their own diagnosis. Similarly, some productions of a culture focus on mental health or neurodiversity in general, but some also focus upon specific diagnoses as a particular way of living (Jaarsma & Welin, 2012; Runswick-Cole, 2014). Finally, there are many support groups and internet forums that focus upon a particular diagnosis rather than on psychiatric diagnoses or mental health in general (Abel *et al.*, 2019; Botha *et al.*, 2022).

I now suggest that inaccurate self-diagnosis alters the strength of social resources in relation to particular diagnoses. Each social resource can be performed in a manner that is tied to a specific diagnosis, such as autistic people advocating for autism or autistic people producing an autistic culture. When social resources are tied to particular diagnoses, then the more people who have that diagnosis strengthens the social resource in relation to that diagnosis (strictly speaking, this increase in social resources is probabilistic, so that more people with the diagnosis means more people to engage in these social resources even though not everyone with the diagnosis does engage in the social resources). Both officially diagnosed people and self-diagnosed people can alter the strength of these social resources because both have access to these social resources. The first three resources, those related to different forms of advocacy, are strengthened when more people are involved in advocacy. As such, the greater the number of people with the diagnosis means a greater number of people who may choose to get involved in advocacy. The final two, that of diagnostic cultures and finding commonalities, are also strengthened when more people have the diagnosis because more cultural products are being produced and more chance of interacting with someone with that same diagnosis.

Individuals self-diagnosing, rather than receiving an official diagnosis, can change the number of individuals who have a particular diagnosis. I have outlined how psychiatric diagnoses can overlap with one another and how different diagnoses only differ from one another in nuanced and subtle ways. I have suggested also that public awareness of diagnoses can influence how people self-diagnose when symptoms of different diagnoses overlap with one another. This then means, when measured by the DSM, that someone who self-diagnoses can misdiagnose themselves with a diagnosis of which there is greater public awareness. This then strengthens the social resources in relation to that diagnosis. Meanwhile, this person is not diagnosed with the diagnosis that they actually do fit but of which there is less public awareness. This means that the social resources for the diagnosis that they actually fit are not increased.

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Though these are not the only relevant factors, public awareness is significantly related to the strength of the social resources. Stronger social resources help generate public awareness. As such, misdiagnosis risks increasing the strength of the social resources of diagnoses which already have relatively strong social resources, while diagnoses with weaker social resources do not have their social resources made stronger.

This results in a redistribution of the strength of these social resources when compared to accurate diagnosis. People diagnosed with the condition of which there is greater public awareness have the social resources related to this condition strengthened, whereas people diagnosed with the condition of which there is less public awareness do not have their social resources strengthened. This raises important questions about the ideal distribution of social resources in relation to different diagnoses, and about who should decide the relative strength of the social resources for each condition. These important ethical questions will, I hope, be further discussed by bioethicists. I have only sought to show how inaccurate self-diagnosis can alter the strength of social resources related to different conditions, but plausibly there is something unfair about the strength of the social resources being increased for one condition rather than another because one condition is more well known. Also, it seems unfair that conditions that already have relatively strong social resources have higher probability of getting those resources strengthened further compared to diagnoses with relatively weak social resources.

8. Counterargument: Self-Diagnosis Can Be Beneficial Even When Inaccurate

I shall briefly consider whether inaccurate self-diagnosis is beneficial or harmful for the self-diagnosing individual. Psychiatric diagnoses can potentially increase self-understanding (in relation to autism (see Fellowes, 2022; Ortega, 2013). How this relates to inaccurate self-diagnosis is a neglected area of study. It could be argued that self-understanding relates to the symptoms an individual believes they exhibit rather than to the diagnosis. Therefore, two individuals who believe themselves to have the same symptoms will have the same self-understanding even if one self-diagnosed as autistic and the other self-diagnosed as schizoid personality disorder. However, it has been argued that self-understanding provided by psychiatric diagnoses relates less to the particular symptoms an individual

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considers themselves to have and more to the connotations of psychiatric diagnosis decontextualised away from particular symptom presentation (Fellowes, 2022). Two individuals with identical symptoms will gain different self-understanding if one self-diagnosed as autistic and the other self-diagnosed with schizoid personality disorder. In this situation inaccurate diagnosis might have a more detrimental effect on self-understanding. This issue merits future research. Another area of benefit or harm is how diagnoses vary in the degree of their negative connotations. As such, it could be argued on practical and ethical grounds that inaccurately self-diagnosing with a diagnosis that has positive connotations is beneficial compared to accurately diagnosing with a diagnosis that has negative connotations.

However, benefits to the individual need be weighed against any consequences for the distribution of social resources. Whether the benefits to individuals who inaccurately self-diagnose outweigh any negative consequences from changes to social resources is an ethical question which requires dedicated ethical discussion. In this article I highlight the injustice; I hope this prompts discussion by bioethicists about how best to resolve or balance conflicts between the benefit to one and the harms to another.

9. Counterargument: Official Diagnosis is Also Unreliable

One significant motive for self-diagnosis is that official diagnoses are unreliable. Both those who provide official diagnoses and metal health professionals who are met upon the path towards an official diagnosis may hold misleading views about psychiatric diagnoses. Therefore, official diagnoses result in unfair distribution of social resources.

Like with self-diagnosis, it is also difficult to make generalizations about official diagnosticians and other mental health professionals. They will vary considerably in the degree in which they hold inaccurate stereotypes in relation to any particular diagnosis. For example, one might hold deeply misleading stereotypes in relation to a small number of diagnoses but does not hold any misleading stereotypes in relation to most diagnoses, whereas another might hold misleading stereotypes in relation to almost every diagnosis, but the stereotypes are only slightly misleading in relation to each of those diagnoses. I do not know what percentage of official diagnosticians and medical professionals hold misleading stereotypes, which diagnoses are more likely to be misleadingly stereotyped, or the degree in which any

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misleading stereotypes which are held are completely false, partly false, or slightly false.

However, the key issue is that the vast majority of official diagnosticians and mental health professionals will have awareness of a significant range of diagnoses. Throughout their training and clinical work they will learn about a variety of diagnoses and meet people with a variety of conditions. Many will likely not have equal familiarity or understanding of all the hundreds of diagnoses in the DSM. Neither will they consider (with justification or not) each of those diagnoses to have equal scientific or clinical legitimacy. However, they are likely to have a baseline awareness of a significant range of diagnoses in a manner in which it might not be present in many self-diagnosing individuals.

10. Conclusion

Self-diagnosis is a topic which generates considerable controversy. There is, unfortunately, limited empirical data on self-diagnosis. Also, the process and the reliability of self-diagnosis may vary considerably across different diagnoses. In this paper, I have outlined how different diagnoses can overlap with one another. Also, I have outlined how they are differentiated in subtle and nuanced ways. I then suggested how the degree of public awareness of different diagnoses may influence self-diagnosis. When self-diagnosing, people are generally more likely to consider diagnoses which have greater levels of public awareness. Also, public awareness can influence how someone interprets themselves and interprets the DSM. There are also concerns about reliability of official diagnosticians, but any responsible official diagnostician will have working knowledge of a range of diagnoses.

I have suggested that inaccurate self-diagnosis can result in altered distribution of social resources. Social resources can be strengthened in relation to a diagnosis when more people have that diagnosis. As such, inaccurate self-diagnosis results in the social resources for one diagnosis being strengthened whilst not being strengthened in relation to another diagnosis in comparison to accurate official diagnosis. This article aims to show this to be a significant possibility and suggests that we need consider whether this is unfair to people who are diagnosed with less well-known conditions.

Some consequences follow from my argument. Firstly, I have raised important bioethical questions about what constitutes a fair distribution of social resources and who should decide on that

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distribution. These merit further investigation. Secondly, the very few existing empirical studies of individuals who self-diagnose have not outlined the degree to which self-diagnosing individuals consider multiple diagnoses. This seems an important area for future empirical studies. Thirdly, if the concerns I raise are genuine, then this gives further good reason to end the problems that lead people to self-diagnose. If there were not such long waiting lists for diagnostic assessment, if some people did not face such high financial costs getting a diagnostic assessment, and if diagnosticians did not sometimes hold inaccurate stereotypes in relation to diagnoses, then the problem I raise would largely disappear. My argument thus provides an additional reason for our society to remove these and related issues that lead people to self-diagnose.

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