Biography

Sam Fellowes is an autistic philosopher of psychiatry based at Lancaster University. He is interested in the philosophical status of psychiatric diagnoses, experts-by-experience in psychiatric research and self-diagnosis. He has recently published 'The importance of involving experts-by-experience with different psychiatric diagnoses when revising diagnostic criteria' and 'Self-diagnosis in psychiatry and the distribution of social resources'.

Scientific expertise, service users and democratising psychiatric research

Friesen outlines six different reasons for democratising scientific research. Three of them are epistemic and three are ethical. In this commentary I consider how service users might relate to values if significant levels of scientific knowledge are required to understand those values. I specifically consider the traditional theoretical virtues discussed by philosophers of science (Psillos, 1999; Solomon, 2001) whereby we might judge scientific concepts based upon their simplicity, consistency or coverage. This raises questions of how democratic approaches should function when expertise is important.

There is a general problem of how democratic institutes should function when members lack understanding. For example, most voters in current European democracies have limited understanding of economics. They may understand some broad principles but would not understand how to actually manage an economy on a daily basis. A simple solution to this is that political parties outline a broad framework and then are given consent to run the economy once elected. Our elected representatives or members of an unelected bureaucracy actually then make the 'on the ground' decisions about how to run the economy given the broad framework which the political party was voted in on. This hopefully then means that, with varying degrees of success, people who have some understanding of economies are playing a key role. We can certainly ask important questions about this system, such as what level of economic understanding do citizens have and what level they need, who should constitute the unelected bureaucracy and whether the bureaucracy could actually be elected. My simple point is that this is one approach to limiting the decision making of people who may lack economic expertise. In relation to democratising psychiatric research, I consider whether Friesen's approach might mean service users require a level of expertise that they typically lack.

Friesen outlines how there is a very high level of value decision involved in psychiatry given the gap between data and theories. Friesen thinks service users should be included in decisions over what values to employ. I now provide an example of where making good value decisions might require significant levels of scientific knowledge. I consider a specific type of value applied to a specific area. There has been recent discussion of service users being involved in decision making over modifying psychiatric diagnoses, whereby they might play a role in deciding what psychiatric diagnoses there are and what their diagnostic criteria should be (Beuter, 2019; Fellowes, 2023; Tekin, 2022). I consider how we can assess psychiatric diagnoses using theoretical virtues. It should be emphasised that this problem may or may not have applicability to other areas of service user involvement, that theoretical virtues are not the only values which are important for assessing psychiatric diagnoses and that scientists might themselves make bad decisions in relation to theoretical virtues. I now outline five theoretical virtues.

Firstly, simplicity. There are lots of different ways to understand simplicity but here I consider how simple a system of psychiatric diagnoses (i.e. the DSM) is. We can ask if the system of psychiatric diagnoses is too simple because it contains too few diagnoses or too complicated because it contains too many diagnoses. Simplicity and complexity might also depend on the degree different diagnoses have overlapping symptoms. We can judge a particular psychiatric diagnosis on the degree it adds to simplicity or complexity. Establishing the strength of this theoretical virtue requires knowledge of many different psychiatric diagnoses.

Secondly, coverage. This relates to the degree that all the phenomena which we desire covered are being covered. We can ask whether a system of psychiatric diagnoses is or is not covering all the symptoms that we think need covering by psychiatry. We can judge particular diagnoses on how they contribute to coverage. Assessing this requires knowledge of a vast range of symptoms.

Thirdly, embedded within a theoretical network. Scientific concepts can be connected to other scientific concepts. A diagnosis can be judged on the degree it connects to other well established areas of science, whereby the diagnosis might have been formulated based upon being compatible with or entailed by other well established scientific concepts. This requires significant knowledge of other sciences, such as biology, neuroscience, psychology and sociology.

Fourthly, identified causal mechanisms. We can ask if the causes of the psychiatric diagnosis or aspects of the diagnosis have been established. Also, we can ask if we have a mechanistic understanding of how the causes produce the diagnosis or produce aspects of the diagnosis. This requires significant knowledge of causes in psychiatry and other sciences.

Fifthly, accuracy. We can ask how accurately the scientific concept is at describing the phenomena it aims to cover. For example, diagnoses typically cover a collection of symptoms. We can judge a particular diagnosis on the degree of frequency that the symptoms it aims to cover occur together. This requires knowledge of the statistical frequency of how symptoms cluster.

Theoretical virtues can be used to judge the adequacy of psychiatric diagnoses (though they are not the only relevant criteria). We might look more favourably upon diagnoses which exhibit higher levels of theoretical virtues in those theoretical virtues we judge as being more important. Ideally, autistic people would rate the levels of theoretical virtues exhibited by DSM notions of autism and alternatives to DSM autism, such as modifications to the diagnostic criteria or diagnoses that would completely replace autism. The autistic person can then make a value judgment over which approach is best given the level of theoretical virtues exhibited and the importance placed upon each theoretical virtue. This does not just require a value judgment, it also requires a level of scientific understanding to recognise the degree that the theoretical virtue is present. Much has been written about how lived experience can be a source of scientific knowledge but all five of the theoretical virtues listed above require understanding that goes far beyond lived experience, such as knowledge of how symptoms cluster in many different people, knowledge of many different psychiatric diagnoses and knowledge of areas of science other than psychiatric diagnoses. As an autistic individual, I am aware that there is a massive gap between my own lived experience of being autistic and the knowledge required to answer these questions.

Additionally, I feel that some of the existing debate about modifying autism by autistic people does not help the autistic community to fairly assess these theoretical

virtues. For example, my preference is for sub-typing autism (Fellowes, 2021). I might be making a bad judgment here but I feel the debate is worth having. However, my perception is that discussions of sub-typing rarely go far because it keeps coming back to autistic individuals expressing objections to notions of high vs low functioning. I feel that high and low functioning autism are bad subtypes but there is a near infinite number of ways we could subtype autism which are not based upon functioning level, such as based upon specific symptoms, causes, or combination of symptoms and causes. I would love to see autistic people discuss the merits of a range of subtypes but, at least in relation to the debates I see occurring, among autistic people the debate generally keeps coming back to the problems with high and low functioning autism (with the possible exception of discussions of pathological demand avoidance as a possible subtype of autism). I think that a significant range of alternatives need be considered to adequately assess theoretical virtues. Friesen does mention that service users can be a fruitful source of alternative scientific notions. This is true but at the same time we need to apply to them the same standards we need apply to non-service user scientists when it comes to assessing how adequately they conceptualise alternatives. We need establish what factors are driving their conceptualisations and how these might be limiting factors (Solomon, 2021).

I believe the issues of whether scientific knowledge is required to assess theoretical virtues and whether alternative scientific conceptions are given fair consideration raise important questions about how we want to practically implement democracy in psychiatric research. I think the traditional approach to revising the DSM whereby there are literally hundreds of scientific professionals involved, has one benefit of ensuring that those making the decisions have at least some level of scientific expertise in some of these areas. The key question is what role any service users who lack that expertise should play in that process or other areas of psychiatric research.

References

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