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Imagine there's no diagnosis, it's easy if you try

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Abstract

The recent discussions over the reliability, validity, utility, humanity and epistemology of psychiatric diagnosis have had wider implications than might at first sight be apparent. Diagnosis is, for many people, both the entry-point to services and the starting-point for public debate. Challenges to the scientific and professional basis for diagnosis, therefore, can have profound implications. Such is the dominance of traditional diagnostic thinking about mental health care that it is often wrongly assumed that there is little alternative – or that any possible alternatives would require lengthy and expensive periods of development. In fact, there is no present impediment to the development of new ways of thinking and delivering services, and especially no impediment to practical and scientifically valid alternatives to diagnosis.

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Introduction

Problems with diagnosis

There have been long-standing concerns with diagnostic systems in psychiatry, which have always been criticised for their poor reliability, validity, utility, epistemology and humanity. These criticisms have been outlined elsewhere (British Medical Journal, 2013; Division of Clinical Psychology, 2013; Kinderman, Read, Moncrieff, & Bentall, 2012; Lancet, 2012) and in other papers in this special issue. Although it is possible for diagnoses to be reliable, the

Careful clinical protocols necessary to achieve this are rarely adopted in clinical settings. In addition, of course, it is entirely possible to make reliable diagnoses of entirely invalid diagnoses - the mere fact that there is agreement between diagnosticians is no guarantee that the diagnoses about which they agree actually correspond to meaningful clusters of symptoms, with distinct pathophysiology and aetiology, which predict the effectiveness of particular treatments. We have seen many potentially reliable but nevertheless invalid 'diagnoses' in the past. Although human sexuality is a wonderfully multi-faceted concept, and therefore there is little reliability in social constructs of sexuality, something of the nature of the invalidity of supposed diagnoses can be seen in the way that non-conventional expressions of sexuality have moved from being sins to being illnesses before being accepted (I hope) as merely part of what makes us all human.

Many people educated in the history of mental health know that a 19th century American doctor called Samuel Cartwright seriously suggested that slaves who attempted to escape from their captors were suffering from the mental illness of 'drapetomania' (Caplan, McCartney, & Sisti, 2004; Cartwright, 1851) although it's very important to acknowledge that the establishment of the time did not accept his proposals. The same cannot be said about the establishment stance towards sexuality. Whereas we now (and I certainly) regard the various complex variants of sexuality something to celebrate, including finding members of your own gender sexually attractive, it was not until 1973 that the American Psychiatric Association declassified homosexuality as a mental disorder. Something of the influence of the American system can be seen in the fact that the World Health Organization followed in declassifying homosexuality as a 'disorder' in 1990. It has taken some time for sexual preferences to disappear from the diagnostic manuals. Currently a vestige of this approach can be seen in the fact that persistent and marked distress about your own sexual orientation remains a focus for some diagnosis. It's worth being clear, here. Distress, of course, is important. But it is significant (I believe) that diagnosticians choose when to draw attention to such issues as sexuality in the criteria for diagnosis. While it seems important to note if distress is associated with sexuality, we do not see such diagnoses as 'parental rejection distress syndrome', 'heterosexual inadequacy syndrome' or 'post redundancy impoverishment stress disorder'. These labels do not reflect real entities, revealed by systematic observation, but rather mirror contemporaneous social values.

These discussions are important. Returning briefly (for illustrative purposes) to so-called disorders of sexuality, we know that a range of 'therapies' - from aversion therapy to more modern approaches based on what is, in my opinion, a perverted version of CBT - have been proposed to 'treat' or 'cure' people of their homosexuality (see, for instance, Scott, 2013). How we describe psychological problems is intimately associated with how we choose to respond. And the ways we are encouraged to think about psychological problems in diagnostic manuals such as DSM-5 remain very worrying.

The poor validity of psychiatric diagnoses is reflected in their failure to predict prognosis or the likely benefit (or otherwise) of treatment options, and in their failure to map onto biological findings, which are typically highly nonspecific and cross diagnostic boundaries. Diagnoses in psychiatry have consequential epistemological problems. Once made, the diagnoses are used as pseudo-explanations for troubling behaviours - it is presumed that people are behaving as they are, or experiencing unusual perceptions, because of the illness. But, in the absence of valid underlying pathological processes, this argument is logically circular - the behaviour is explained by a label which consists of nothing more than a shorthand for that behaviour. The diagnostic approach also threatens our humane and empathic response. Since diagnoses subtly or unsubtly convey the idea that mental health problems can be understood as illnesses or diseases, as pathologies of the body, we are in danger of ignoring any psychological meaning in people's 'disordered' responses and experiences. This tends to limit the extent to which people understand how they might use their own resources to address their difficulties.

As other papers in this special edition detail, the recent publication of DSM-5 threatens to exacerbate these problems. Many fear that DSM-5, if used in clinical practice, would lead to a lowering of a swathe of diagnostic thresholds, and inflate the assumed prevalence of mental health problems in the general population. Many have commented on the fears that this may not be unrelated to the commercial interests of pharmaceutical companies, and that this is a potential threat to the general public and especially vulnerable populations such as children and older people (Lancet, 2012).

An alternative

As has been argued elsewhere (Kinderman et al., 2012), we need a wholesale revision of the way we think about psychological distress. That revision should be far-reaching and comprehensive, and include service delivery and ethos as well as assessment issues. But this paper is specifically concerned with diagnosis and assessment. And in that area, we already have available alternative approaches to diagnosis.

Any system for identifying, describing and responding to distress should use language and processes that reflect the fact that such distress is a normal, not abnormal, part of human life; we occasionally respond to difficult circumstances by becoming distressed. Our approach to assessing and communicating about such distress must also be able to accommodate the overwhelming evidence that psychiatric symptoms lie on continua with less unusual and distressing mental states. There is no easy 'cut-off' between 'normal' experience and 'disorder'. Such language should also recognise that there is clear evidence that psychosocial factors such as poverty, unemployment and trauma are major causal factors for psychological distress (Read & Bentall, 2012).

Rather than use diagnostic labels for putative 'disorders', therefore, we should instead simply list a person's problems. A simple list of problems, defined with appropriate scientific rigour, would be more than sufficient as a basis for individual care planning, for communicating between professionals, as the basis for research and for the design and planning of services. It would be inappropriate to try to generate a comprehensive list here. If such a list were in fact necessary (we don't, for example, feel the need to have a list of all the reasons why a person gets into debt), it should be developed with a degree of professional and international consensus. But it is relatively easy to see how it might work. While the diagnosis of 'schizophrenia' is confusing and unhelpful, we understand what it means when someone has low mood, has auditory hallucinations, or intrusive anxious thoughts or performs compulsive behaviours.

We can identify and define such specific phenomena with proper scientific rigour. The scientific method - "a method or procedure that has characterized natural science since the 17th century, consisting in systematic observation, measurement, and experiment, and the formulation, testing, and modification of hypotheses" (The Oxford English Dictionary, 2013) – is well-established and commands widespread support. Applied scientists such as clinical psychologists use operational definitions of relevant concepts. We develop hypotheses. We collect data. We don't need to meet the challenge of a new technological alternative to diagnosis and the "disease model". We've had it since the 17th century. So what would it look like in practice if we adopted this approach?

The client's experience

Many people say that they find a name or a diagnostic label helpful. However there are good reasons to believe that this perceived helpfulness results from the experience that, when given a diagnosis, the client knows that their problems are recognised (in both senses of the word), understood, validated, explained (and explicable) and they have some sense that help is forthcoming. This has two consequences. First, unfortunately, clients often find that the diagnostic approach fail to deliver. Since, as I have argued, diagnoses are often unreliable, invalid and separate inappropriately the person from their experiences, the benefits for the client are often marginal at best. Secondly, there is absolutely no reason why these benefits cannot follow from a different approach. A clear description of a person's real problems in ordinary language would clearly meet all these criteria.

In practice, then, clients would no longer find the experience of helpfulness dependent on the acceptance of Latinised or otherwise obscure medical terms that signal the official acceptance of the reality of their problems, but also distance both them and us from the reality of their experiences. We would all start to use common-sense language to communicate a shared understanding.

Psychosocial formulations

As we have argued elsewhere (Kinderman et al., 2012) clinicians are likely to be more effective if they respond to an individual's particular difficulties rather than their diagnostic label. Clinical psychologists and psychiatrists do not, in practice, base their plans for care merely on lists of problems or, indeed, diagnoses. In order to understand and explain people's experiences, and to plan care, we develop 'formulations' (Division of Clinical Psychology, 2011).

For clinical psychologists, it is via these formulations that we can incorporate social causal factors such as poverty, unemployment and trauma and the psychological processes that mediate our responses to those events in order to understand the problems with which people present to services. These formulations, for all professionals, are central elements of clinical practice. But such formulations are just as easily developed to address problems as they are to address diagnostic entities. In fact, because such diagnostic entities lack validity, it is much easier and more appropriate to develop formulations around specific operationally defined problems. Moreover, since the diagnostic approach tends towards a simplistic 'diagnose and treat' mentality, and mitigates against finding meaning in a person's experiences, there is a danger that such issues are under-emphasised in services dominated by a diagnostic approach.

Communication between professionals

Many mental health professionals argue that a key function of diagnoses, a key reason for their use, is to facilitate communication between professionals. This is vital, of course, and the diagnostic system is widely used and well understood. We are all familiar with the experience of receiving letters discussing clients' problems with reference to diagnoses. The presumption is that these diagnostic labels help us to communicate with each other, and are helpful in making treatment decisions. But in reality, this presumed communicative benefit is rather elusive. Diagnoses are invalid in many respects, including because it is possible for two people with the same diagnosis to have entirely different experiences or problems. Equally, diagnosis seems to be only very loosely associated with prognosis or treatment decisions (Moncrieff, 2008). In short, diagnoses are unhelpful for the purpose of communication. In the immediate aftermath of the publication of DSM-5, and of the criticisms of that document, one senior and influential contributor to an on-line blog (hosted by a well known and respected institution) tried to defuse this row by saying that; "clinicians need to communicate to each other, and even a wrong diagnosis allows them to do so". This appears rather unhelpful.

A 'problem-based' approach would serve the needs of professionals to communicate with each other very well. It is clear how precision would be served by communication based on the listing of key, operationally defined, problems. In order to facilitate such communication, it would be helpful if professionals, internationally, were to agree on the operational definitions of these problems. There is no reason to suppose that this would be an extensive or unmanageable list. In two as yet unpublished research studies by doctoral students (Gemma Parker and Kate Allsopp), we analysed the specific problems or symptoms that were listed in DSM-IV (American Psychiatric Association, 1994) and ICD-10 (World Health Organization, 1992) respectively. Rather unexpectedly, only some 65 different specific symptoms were represented in the much larger number of diagnostic categories in DSM-IV, and only some 57 common presenting problems underpinned ICD-10. This is a fascinating observation. It means that the very large number of different diagnoses can be explained in part by the huge variety of ways in which these problems can be combined. And that gives considerable (and welcome) flexibility to clinicians and researchers. If we imagine a scenario where a clinician writes to a colleague listing their client's three major problems, using an agreed taxonomy of problems, there are over 175 thousand different possible three-problem combinations. Simple systems, if used elegantly, are more than capable of conveying huge complexity.

This way of using a list of well-defined problems highlights the important differences between a problem-based and a diagnostic system. In the well-publicised launch of DSM-5, and the subsequent criticism, it would have been easy to misunderstand these differences. Indeed, the casual addition of 'disorder' to a definition of a problem by diagnosticians is partly to blame for this confusion. Thus, for example, when a person is traumatised by war, it makes sense to think about 'post-traumatic stress'. That definition itself has major problems, not least of which is the definition of 'stress'. But it is significant to consider the differences between a problem-list approach and a diagnostic approach. It is very different to talk about 'post traumatic stress' and a diagnosis of post traumatic stress 'disorder' or PTSD. When we recommend replacing diagnoses with simple problem-lists, it is common for colleagues strongly wedded to the diagnostic tradition to suggest that they are essentially the same thing – both that a set of diagnoses essentially consists of a list of problems, and that a list of specific problems is functionally equivalent to a list of diagnoses. But there are many essential differences, and the case of PTSD illustrates them. Diagnoses are generated by combining symptoms with "if-then" rules. A problem-list approach explicitly keeps these problems individuated. It is only a very small number of diagnoses that have essentially only one symptom.

So, in practice, diagnoses obfuscate the possible relationships – and on-relationships – between problems. This means that, whereas diagnoses inappropriately cluster problems that may, or may not, be linked, an individual problem-based approach permits flexibility and clarity.

But there are other differences too. There is a fundamental philosophical difference between the epistemologically neutral identification of a problem and the identification of a ‘symptom’; with the clear implication in the latter case that the symptom is the result of an illness, and probably a biological illness at that. Perhaps most importantly, a problem-based approach makes much more explicit the links from social and real-world causes (assault, abuse, poverty, loss, unemployment etc) through the mediating psychological processes (the ways in which we appraise, understand and respond to these events) to the emotional and psychological sequels – the identified problems. Of course, until we adopt a non-diagnostic approach to identifying and addressing emotional and psychological problems, these ideas must remain speculation. However it seems reasonable to hypothesise that, whereas medical diagnoses tend to place distance between the problems (which become a diagnosis) and the person, their experiences, and their appraisal of, response to and the meaning they attach to that experience, a problem-based approach places the experience more squarely in real-world human life.

To return, then, to the issue of communication between professionals; for clinicians, working in multidisciplinary teams, the most useful approach would be to develop individual formulations; consisting of a summary of an individual’s problems and circumstances, hypothesis about their origins and possible therapeutic solutions. As with direct clinical work, such an approach would yield all the benefits of the traditional ‘diagnosis, treatment’ approach without its many inadequacies and dangers. This would require all clinicians— doctors, nurses and other professionals—to adopt new ways of thinking. In practice, we would see letters or reports that take the form of:

“Dear Dr Freud,

I would be grateful if you could offer an appointment to my client, [DEMOGRAPHIC INFORMATION (name, age, gender, address etc)] and offer advice and, if appropriate, assistance.

[NAME] reports that she experienced [CHILDHOOD EVENTS OF SIGNIFICANCE] in her childhood and more recently [RECENT EVENTS OF SIGNIFICANCE]. She reports that she [SPECIFY RESPONSE]. Now, she reports that she is experiencing [SPECIFIC PROBLEM #1], [SPECIFIC PROBLEM #2], [SPECIFIC PROBLEM #3]. We would appreciate your help and assistance.

Sincerely, Dr Jung”

Research

Many researchers, trying to understand the causes of, and proper responses to, such distress find their activity actively hampered by the diagnostic systems currently used. This is particularly true for people pursuing more psychosocial approaches. Since the different symptomatic problems incorporated under a diagnostic label do not cluster together in meaningful ways; do not yield valid diagnostic syndromes, it is unreasonable to presume that there are common underlying pathologies that are amenable to research. In other words, since the problems do not appear systematically to be related one to another, research into any underlying process will be significantly ineffective. We can think of any number of examples; the different experiences of depressed mood, with or without accompanying anxiety; the depressive and hypomanic episodes of ‘bipolar disorder’ which appear to be in a mathematically chaotic relationship (Gottschalk, Bauer, & Whybrow, 1995) or hallucinations and delusional beliefs in ‘schizophrenia’ which may (or may not) involve dopaminergic pathways, but are clearly not driven by identical mechanisms.

Equally, the latest biological research supports the notion of non-specific links between a rather large number of genetic elements and a rather large number of quite general mental health problems (Cross-Disorder Group of the Psychiatric Genomics Consortium, 2013). Specificity appears to be rather difficult to establish in biological research

into diagnostic categories. To uncover more specific pathways from environmental trauma to the observed distress requires a much more well-specified account of the problems themselves. Whether we are researching biological, psychological or social causes of distress, an invalid diagnostic system can only ever be an active hindrance. If the diagnostic categories such as 'schizophrenia' are invalid, researchers could never uncover 'its cause'. So researchers would be better advised to study the nature of, causes of and appropriate help to be offered in response to specific, identified problems. Fortunately, this process has already begun; there is a rich literature on the social origins, biological correlates and sequelae of specific mental health phenomena (eg, hallucinations, paranoid delusions and thought disorder) stretching over the last 20 years.

Planning, commissioning and audit

At present, much of healthcare is planned, audited and commissioned on the basis of diagnosis - or so it is sometimes argued. That latter, slightly cynical, clause is necessary because in fact, and entirely properly, commissioning of service is not directly related to diagnosis. The UK benefits from the fact that it presently enjoys healthcare provision via the National Health Service, a comprehensive system ensuring world-class healthcare available to all, free at the point of need and predicated on the principles of universal and equitable provision. Other nations are less fortunate, and still rely heavily on either commercial provision or on services funded through insurance. In these latter schemes, diagnosis is particularly important in gaining access to services, and is therefore particularly pernicious. In the UK, diagnostic information - incidence and prevalence - are important, but not of overwhelming significance. Services are commissioned, now in liaison with local authority social services through the joint Health and Wellbeing Boards, on the basis of a wide range of parameters, which certainly includes prevalence statistics, which in turn rely on diagnostic information, but are not dominated by them. Thus, for example, the authorities responsible for commissioning services will attempt to respond to the reported levels of anxiety and depression in the community (perhaps via initiatives such as the well-known IAPT or Improving Access to Psychological Therapies programme), but also support parenting classes for parents of children with a range of difficulties, fund artistic and literary services, and commission services that support people in returning to work etc.

The point is that invalid and inappropriate diagnostic systems do cast a shadow over commissioning and planning services, just as they do over clinical practice and research. That could, perhaps, mean that some of the more extreme fears of the influence of diagnosis should be tempered. But it also means that we can easily imagine a system for the commissioning of services that was not predicated on diagnosis (the logic can't possibly both mean that diagnoses are necessary for commissioning and planning and that people already use non-diagnostic approaches in this regard). In services other than healthcare - in education, in social services, in criminal justice services - we do not rely on diagnosis. That doesn't mean that such services are aimless or random. Instead, well-developed systems of service commissioning are in place, systems based upon the identification of problems and the evidence-based formulation of a plan for responding. Currently, in the UK, there is discussion in mental health services about the basis of a remuneration and commissioning system called 'payment by results'. This approach is not a diagnostic system, and - importantly - identifies service users' problems on a non-diagnostic basis. Precisely because people with a particular diagnosis (say, for instance, 'generalised anxiety disorder' or 'schizophrenia') differ hugely in their needs for service provision, the guidance for commissioners, service managers and clinicians are based not on diagnosis but on a cluster of specific but trans-diagnostic problems and needs. These initiatives are controversial, both because they represent changes to service provision and management of health services (which, of course, involved politics) and because many people feel that it is inappropriate to move away from a diagnostic approach. In this debate, they are important because, again, they offer examples of non-diagnostic frameworks for healthcare planning and commissioning.

We do, of course, need to know the extent of the problems that we have to address, and the scale of the response demanded. We need to know how many psychological therapists, how many psychologists, how many psychiatrists to employ. We need to know what type of residential services to commission, and how many people will be needed to staff them. Even as we pose these questions, the inadequacy of diagnoses becomes a little clearer. When we think about the details, it becomes clearer too. While we do need to know the extent of the problems; how many working days are lost each year to emotional problems, for instance; how many educational psychologists are needed to support our schoolchildren; how many psychological therapists are needed, for example, it seems

equally clear that diagnostic classification will not help us here. It is clearly beneficial for all of us – for the clients themselves, for employers, for the nation as a whole – to help people with mental health problems remain in work or to find work. And of course the majority of people with mental health problems – the majority of the one in four of us – are in work. It follows that the important questions are not really answered by diagnosis at all. We can't simply assess how many people might need different kinds of services – or none at all - on the basis of diagnosis and prevalence.

It follows that commissioners and planners of services need answers to questions unrelated to diagnosis. They need to know how many people experience certain problems, the health economics of those problems, and the recommended interventions. We need to base our services on the assessment of needs. As in other aspects of public services, these are largely unrelated to diagnosis. It is a perfectly valid question to ask how many employment advisors are needed in our mental health services, but diagnostic information is an inadequate way to answer that question. Once again, real-world, pragmatic data re needed.

A new ethos

In short, then, we must move away from the 'disease-model', which assumes that emotional distress is merely symptomatic of biological illness, and instead embrace a model of mental health and well-being that recognises our essential and shared humanity. We should stop diagnosing non-existent illnesses – a simple list of people's problems (properly defined) would be more than sufficient as a basis for individual care planning and for the design and planning of services. But we also need to do more. Diagnostic reform is only a small part of the reforms needed in mental health care.

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