

Submission on the Name “Schizophrenia” To “Schizophrenia Enquiry, UK.”

1. Introduction

The attitudes people adopt to the word “schizophrenia” depend very much on their life experiences, whether professional, educational, or as patients. I therefore want to start this submission by describing my own background and life experiences. A long time ago (early 1960s) I was a medical student in a British medical school. I never completed the degree, because I was overwhelmed by a psychotic disorder. The only psychiatrist who had seen me when I was ill and who offered me a diagnosis named my illness as “schizophrenia” (see below for how I learned this). After that I needed to emigrate to New Zealand to get a secure university job, and have devoted my research efforts since then to the study of the theory of brain function, and its relevance to major mental disorder (notably schizophrenia). My major work on this was published in 2008¹.

In recent years, I have heard debates at international schizophrenia congresses, on whether the term should be abandoned; and, when the vote was called, I have pointedly abstained. In my view the issue is too complex for a simple “yes” or “no” to have any significance. I therefore welcome the chance to give a more thoughtful, and discursive response. I also want to preface this report by asserting that the problem with the schizophrenia diagnosis is part of a much larger issue, common to any of the diagnostic systems as currently used for psychiatry as a whole. Therefore much of what I write below (including the final conclusions) addresses broader issues of diagnosis in psychiatry as a whole.

2. Definitions and Purposes of Diagnosis in General

The word “diagnosis” means “identification of a disease by reference to symptoms etc” (OED). In general medicine, diagnosis serves several purposes, which include the following:

- (a) To provide a rational guide to individual treatment
- (b) To provide a rational indication of prognosis
- (c) To give patients a basis on which they can conduct their own self-help and self-education
- (d) To enable public health policies to be initiated
- (e) To guide researchers
- (f) To provide a basis for administrative or political decisions (financial, legal), and for collecting statistics.

3. Diagnosis versus scientific concepts.

Diagnoses are not synonymous with scientific concepts of disease. Scientific concepts should apply universally, regardless of differences in culture, language, religion etc, but diagnoses may need to be adjusted to each society’s culture, collective experience and history. In psychiatry the use of terms in each society is also influenced

¹ Miller,R. (2008) *A neurodynamic theory of schizophrenia and related disorders*, Lulu Enterprises, Morrinsville, North Carolina.

by that society's history and traditions. In particular, when historically one term has been used for abuse and stigmatization, this may lead to it being no longer acceptable in that society.

Here are some examples of such culture-specificity of diagnoses: In Japan there are at least two psychiatric diagnoses in common use which are not found elsewhere: One of them ("*taijin kyofusho*": a fear of offending or hurting others through one's awkward social behavior or an imagined physical defect) "can be understood as a pathological amplification of culture-specific concerns about the social presentation of self and the impact of improper conduct on the well-being of others"². Another Japanese diagnosis ("*hikikomori*": "prolonged social withdrawal") includes people with a variety of DSM diagnoses³, but may also be related to the culture of school and workplace bullying accepted in Japan⁴. More related to the schizophrenia-name-debate, manifestations of psychosis are shaped by the surrounding culture. The content of delusions is often closely linked to common images in the prevailing culture. In cultures where what (in the West) is called schizophrenia is viewed as demon possession, patients with this disorder will progressively shape their behaviour to match the cultural stereotype. And when miraculous "cures" are achieved by a local shaman, this can be seen as lifting the cultural overload, rather than curing the intrinsic illness⁵. In Britain and other western societies, this disorder is often seen by the general public as characterised by unpredictable violence, and a few patients with the disorder may adopt such behaviour to fit the stereotype.

The culture-bound nature of diagnoses and symptom pictures does not affect the validity or otherwise of the underlying disorders, seen as scientific concepts; but it may limit the extent to which *diagnoses* can be generalised across cultures, and how far scientific concepts can be rooted in the profile of observed abnormal behaviour or self-reported symptoms (both of which are culture-bound). In this sense, for many purposes, it is wrong to think of clinical systems of diagnosis as having scientific validity applying internationally, although (ideally) underlying scientific concepts should be international. In what follows, the scientific issues are separated from more pragmatic ones related to actual diagnostic systems. Tentative conclusions, or ways forward on the latter vexed issue, are offered at the end

4. Difference between diagnoses (and "disease concepts") in psychiatry and in general medicine.

There are several important differences here.

2 Kirmayer,LJ (1991) The place of culture in psychiatric nosology: *Taijin kyofusho* and DSM-III-R. *Journal of Nervous and Mental Disease*, 179, 19-28.

3 Kondo N, Sakai M, Kuroda Y, Kiyota Y, Kitabata Y, Kurosawa M. (2012) General condition of hikikomori (prolonged social withdrawal) in Japan: Psychiatric diagnosis and outcome in mental health welfare centres. *International Journal of Social Psychiatry*, 2012 Feb 23. [Epub ahead of print]

4 Caulfield, SM (2012) A Western perspective on Asia's missing millions. *Mookichik*, 28.05.2012 http://webcache.googleusercontent.com/search?q=cache:sc5b6Tg6dgJ:http://www.mookychick.co.uk/health-beauty/health-depression/hikikomori.php%2Bhikikomori+bullying&gs_l=serp.12...2403.10808.0.13374.28.21.0.7.1.1.2.61.2797.8j5j7.21.0...0.0.0ywl-o2ZWKo&hl=en&ct=clnk

5 Ellenberger,H. (1980) *The Discovery of the Unconscious: The History and Evolution of Dynamic Psychiatry*. Basic Books, p. 16.

- (a) In psychiatry, different diagnoses merge into normality with complete continuity, except when (by fiat) diagnoses are arbitrarily categorised in diagnostic systems. This is sometimes the case in general medicine (for instance in hypertension), but the continuous merging into normality is the general rule in psychiatry.
- (b) In addition, in psychiatry, different disorders merge into *one another* in much more complex and rich way than found in general medicine. As a result, using systems such as DSM III/IV, co-morbidity is very common, and, in children and adolescents, it is the general rule rather than an exception. It is more plausible (in my view) to regard this as indicating deficiencies in classification than as an indication of real co-morbidity.
- (c) Unlike general medicine, the disorders dealt with in psychiatry are often not characterised by unmitigated pathology, suffering, impairment or disability. Most mental disorders, while having varying degrees of associated impairment (sometimes severe), are also inextricably linked to psychological abilities which are *better* than normal, even amounting to exceptional talent. This fact is, I believe, insufficiently recognized by the psychiatric profession; and in any case, such positive sides of mental disorder are largely hidden by the weight of stigma felt by people so affected. One anecdote suffices here: A person who, after much trauma in hospital care, but was pleased that he and his wife were expecting a child, was cautiously advised by his psychiatrist of the risk of bipolar disorder being inherited (which risk could hardly have been news to the person concerned). Coolly he replied: "Er . . . yes, we're very much hoping so".
- (d) There is debate over whether mental disorders are "imposed upon a person" (as DSM-III would maintain), or are disorders "of the person him/her-self". In my view the latter is the more correct formulation: A generic feature of most - perhaps all - mental disorders is that they disturb an individual's sense of personal wholeness or integrity. If this is correct, the role of psychiatrists should be conceived in part as "rebuilding a person's sense of wholeness", which is not quite the same as "treating a disease", although that also may be involved. As a result, more than elsewhere in medicine, in psychiatry it is necessary for a physician to adjust his style and messages to meet the unique personality of each patient. In this sense, the generic features which are common to people with the same diagnosis, may need to give some ground to the unique features of each patient. Diagnosis *per se*, then needs to be offered in a less certain manner, with less of the authority it may have elsewhere in medicine. Indeed some patients see psychiatric diagnosis as inherently stigmatizing. This distinction is captured by subtleties of word use: "Disease" tends to imply a generic and scientifically understood disorder. "Illness" has a different shade of meaning, implying "the way a disease affects each person"⁶. In psychiatry, there is then a requirement to take into account the notion of "illness" in this sense, to a greater extent than in general medicine, while downplaying the concept of "disease".
- (e) In view of these points, I have some concern about whether the concept of "diagnosis" as used elsewhere in medicine, is really the right one for psychiatry. A somewhat different concept may serve patients' needs more effectively.

6 Kleinman, A., Eisenberg, L., Good B. (1978) Clinical lessons from anthropologic and cross-cultural research, *Annals of Internal Medicine*, 88, 251-258.

5. The Scientific Issues

(a) *Validation of concepts.* In my view, no classification system for mental disorders currently in use can remotely be considered to be validated by proper scientific reasoning. Admittedly the main classes of disorder may have fairly good face validity in practice, but the subdivisions of these main classes are very often controversial. Sometimes even the main “fault lines” in current classification systems are in contention (e.g. the distinction between psychotic disorders and dissociative disorders). I have written elsewhere about what is needed to produce properly-validated concepts of disorder in psychiatry⁷. It is worth quoting here the words of from Carl Wernicke, a pioneer in neurology, but who worked at a time when academic psychiatry had not yet split off from neurology. In the preface to his 1894 textbook on psychiatry he wrote as follows:

[Psychiatry] is an area that is backward in its development, and even now stands at the point where all the rest of medicine was, about a hundred years ago. You know that at that time an evolved pathology in the modern sense, i.e. one that was sustained by pathological disturbances of individual organs of known function, still did not exist; and that accordingly people ascribed the status of classes of disease to certain symptoms that recurred quite often, albeit in the most varied groupings. With that attitude, medical knowledge of disease did not extend far beyond the knowledge that we now find disseminated among the lay public, when it treats coughing, palpitations, fever, jaundice, anaemia, and emaciation as actual illnesses. This is precisely the current attitude to psychiatry, at least among the majority of psychiatrists. For them, certain particular symptoms form the actual essence of the disease. Thus a depressed mood in the broadest sense is the essence of melancholy, an enhanced mood with an excess of movements, that of mania etc. People now differentiate a whole number of such types of putative disease. Since, however, in nature, the combination of symptoms is by far more diverse and complex, it is necessary to construct an artificial context sometimes more widely, sometimes more narrowly, which is done by different observers in very different ways. In spite of all the efforts to artificially bring all the cases of illness into one form that fits within a framework, there remain a great number of cases that cannot be correctly forced, and in no way fit the frame. (Wernicke, 1894⁸, Preface; *translation: John Dennison*)

Of course, since Wernicke’s day our knowledge of mental disorders has increased greatly; but I suggest that on the most fundamental issue, namely validating basic concepts of mental disorder with the sort of reasoning used elsewhere in the natural sciences, there has been no progress.

(b) *Examples of the resulting confusion.* The current state of confusion can be illustrated from most areas of psychiatry. Here are some examples (omitting reference to confusion over “schizophrenia” which is discussed later):-

⁷ R.Miller *Concepts of Mental Illness and an Invitation.* (www.robertmiller-octspan.co.nz)

⁸ Wernicke, C. (1894) *Grundriss der Psychiatrie in klinischen Vorlesungen*, Georg Thieme Verlag, Leipzig.

- (i) It is the experience of many patients that they receive a variety of different diagnoses from different psychiatrists for one disorder, and the diagnosis may shift over time. Ever-more emphatic claims by psychiatrists that “mine is the *right* diagnosis”, cut no ice; indeed such claims bring psychiatry into disrepute.
- (ii) The high prevalence of co-morbidity (at least using recent current DSM criteria) has already been referred to. A cynic might say, with little exaggeration, that the most serious risk factor for *any* psychiatric diagnosis, is to have another one!
- (iii) It is suggested that psychiatric diagnoses serve commercial interests (e.g. health insurance and pharmaceutical industries), rather than needs of patients. Diagnoses seem to be “made up” to serve such interests.
- (iv) For one diagnostic entity - attention deficit/hyperactivity disorder (ADHD) - it is asked: Is it really a mental disorder? . . . or is it a normal personality variant, which is a disorder only in certain social environments (especially those created in schools)? Perhaps more attention should be given to unhealthy school environments as a public health initiative rather than treating ADHD as one for personal health care (and medication with ritalin).
- (v) Another diagnosis - dyslexia - is certainly disabling, given that our culture relies heavily on the written word; yet it is well understood that people with dyslexia often have unusual talents in other areas, which enables them not only to hold their own, but even to achieve pre-eminence⁹.
- (vi) In Britain the government tried to foist the term “dangerous severe personality disorder” as a diagnosis on the psychiatric profession, despite it having neither legal nor medical basis, this to be used as a basis for pre-emptive detention of people who had committed no crime. The same was attempted in New Zealand, and, I have been told, was stopped only when key psychiatrists put their own jobs on the line over the issue. Political interference with psychiatry is made easier because few of its *other* diagnoses have secure scientific status. It is good that there are people with sufficient integrity to stop this, but one cannot rely on that. One needs other safeguards.
- (vii) In New Zealand, the government-backed campaign (with which I work) “*Like Minds Like Mine*” aiming to combat stigma and discrimination related to mental illness, has received acclaim around the world as a public health initiative. Persons with lived experience of mental illness played a major part in shaping and then in implementing this campaign, yet it *avoids* diagnostic labels, preferring instead direct first-person accounts of lived experiences. Thus, in some areas, the idea that diagnosis is essential to define mental disorders is being overtaken by events, and by public awareness.

What is needed here is a completely new approach to psychiatric research, taking physics as the model (where the complementarity of the skills of experimentalists and theoreticians was evident from the very start). The key principle here is that explanation and validation of concepts depend on each other. The *only* way in which scientific concepts can be securely validated, such that they will stand the test of time, is when they are defined in such a way as to support strong explanatory arguments¹⁰. Those explanatory arguments would develop theories of mental disorder based not on a single said-to-be-crucial criterion, but on all available evidence joined together by a set of

⁹ Joanne Black “In their right mind” *New Zealand Listener*, May, 8-14, 2010.

¹⁰ For the disorder called schizophrenia I have done my best along these lines in my 2008 book (see footnote 1).

reasoned scientific arguments. We should therefore *stop* adding to the mountains of empirical data already available (except with rare exceptions), and *start* reading all the findings made over the last hundred years, thinking dispassionately and carefully about what they mean, and synthesising and integrating them into testable explanations of the phenomena of mental illness. I believe that there is more than enough data there to formulate those explanations, if only we knew how to pull it all together in a way that makes sense. The *exceptions* are those rare moments when, from a fully formulated disease theory, a critical prediction can be made to test the theory. *Only then* are new empirical investigations needed. In the same way, in the early natural philosophy tradition right from the beginning, there were not only empirical investigators, but also a completely different breed - Copernicus, Kepler, Newton - those we now call *theoretical* physicists. These two different but complementary types of scientist made physics the most secure of all sciences. If a similar synergy could be set in motion in psychiatric research, in my view, progress in fundamental understanding of mental illness would go further than at present, it would move faster, conclusions would be more secure, and overall it would be much cheaper; and from that understanding would come concepts of disease (and diagnoses) which really would stand the test of time.

(c) *Categorical versus dimension typology*. This has been a source of debate for decades. Given the high degree of co-morbidity of official diagnoses (or the fact that it has been necessary to impose categorization artificially on diagnostic systems to make them more plausible) it is clear that, from a strictly scientific point of view, some sort of dimensional typology is to be preferred over a categorical one. One hardly needs to prove this by adding to the empirical investigations on the topic, since a dimensional classification would inevitably contain more information than a categorical one. However, there are strong pressures to simplify any dimensional system by carving it into categories; and for some of the purposes to which a diagnostic system might be put, these are based on sound reasoning.

(d) *The concept of schizophrenia*. Here I write strictly on the scientific issues. The pragmatic ones about diagnostic systems are dealt with later.

(i) *Status of schizophrenia as a scientific concept*. The concept of schizophrenia has never been formulated in a very satisfactory way, but the concept is not completely useless. Should one then abandon this term for scientific discourse (as happened with medical terms such as hysteria, or disorders based on the “four humours” doctrine)? Alternatively, should one try to refine the concept (as Isaac Newton did with his new definitions of the everyday terms “mass” and “force”)? A related debate is on whether schizophrenia (if it exists), is one disorder, fundamentally similar in most cases, despite its being manifest in many different forms, or alternatively is a variety of different disorders, bearing only superficial similarity to each other. I believe that schizophrenia (whatever one calls it) *does* exist. There is an entity here which needs a better definition. Most cases are basically similar in my view, but with some much rarer and genetically more discrete conditions presenting a superficially similar picture.

(ii) *Substitution of the generic term “psychosis”*. This has become common in recent years (especially in the early intervention area), and some of the pragmatic reasons for this are sound, given the public aversion to the word “schizophrenia”. However, from a scientific point of view, in my opinion, this trend “fudges” two important scientific issues. *First*, schizophrenia is more than just psychosis. Apart from psychosis (which has been called “the fever of schizophrenia”) there is a wide variety of non-psychotic traits, many of which are impairments, but some are advantages over normal. Since the

latter are present before, during and after episodes of active psychosis (which, with modern drug treatment are usually transient) these traits are probably more fundamental to understanding the disorder than are the psychotic episodes. It becomes more difficult to grasp this point if “psychosis” replaces “schizophrenia”. *Second*, even if one restricts oneself to psychosis, it is likely that there is more than one basic cause to be considered. I refer particularly to the long-debated distinction between bipolar disorder and schizophrenia. My reading leads me to conclude that there *is* more than one fundamental cause of active psychosis¹¹, but clinical evidence is not a fully reliable way to separate the different causes. This is to some extent an inference made from a wide variety of evidence, but most obviously from the fact that quite different forms of treatment (e.g. antipsychotic medicines versus lithium) can be effective in different cases of psychosis (often despite similarity of presenting symptoms). This being so, if we adopt the generic term “psychosis” in scientific discourse, we may lose the ability to make important distinctions. Whatever terms we use, we need more than one.

6. Pragmatic Issues About Psychiatric Diagnoses, and the Specific Diagnosis of Schizophrenia.

(a) *Diagnosis in general*

(i) *Do psychiatric diagnoses serve their proper purposes (as listed in [2] above)?*

As guides to treatment. The major diagnostic distinctions in psychiatry *are* helpful guides, I believe, but the finer distinctions are less so. At that level, decisions over which is the best pharmaceutical product to use (for instance in depression, bipolar disorder, or schizophrenia), are seldom made on a rational basis, but usually are worked out empirically over months of trial and error (hopefully with the patient an active participant in the decision-making process). However, for reasons given above (section 4[d]), some patients find diagnoses to be unhelpful. This is not only because of the necessarily empirical approach to finding the right medicine, but also because a diagnosis may tend to invalidate them as persons and may be perceived as inherently stigmatising. Admittedly this depends entirely on the approach adopted by each clinician to his/her patient, and so is not really a function of diagnosis itself. Nevertheless, one person I know remarks sardonically that the diagnosis preceded, rather than followed, the feeling ill (“I did not feel ill until I had a diagnosis.”)

As guides to prognosis. As a non-clinician, I do not feel able to comment much on this, but my impression is that diagnoses across psychiatry are no better as guides to prognosis than they are in the field of psychotic disorders (including schizophrenia). I comment on this in the latter field below.

To give patients a basis on which they can conduct their own self-help and self-education. This is sometimes a very useful role for diagnoses. For the more serious disorders it may be more useful for family members or caregivers than for the patients themselves; but as the lives of patients improve, partly as a result of better medicines, partly as a result of the democratization of psychiatry, patients too are becoming more actively involved in their own health care. For this, knowledge of diagnosis is crucial.

¹¹ I think I know what one of them is, and since the literature about this was all about the disorder called schizophrenia, I called my book “*A Neurodynamic theory of schizophrenia and related disorders*”.

To enable public health measures to be initiated: In psychiatry, public health measures are best conceived as a close alliance between early intervention programmes for those at risk or in early stages of an illness, and programs for education of the wider public about mental health issues. Mainly these initiatives do not depend greatly on use of specific diagnostic terms, although those who conduct educational programs should be well-informed about major diagnostic classes, because they will find themselves being asked questions of personal relevance to the questioners.

To guide researchers. Much of the research background for psychiatry is based around diagnoses in use at the time of the work. One of the difficulties about using past research literature is not that it is useless, but that one has to do a lot of further reading to discover how diagnostic terms were being used at the time. Much valuable work has thus been made inaccessible, almost as much as if it were in a foreign language. While I *do* look for a much improved system of classification, it will confound future research very severely if we now start to change our terminology in radical ways.

To provide a basis for administrative and political decisions (financial, legal), and for collecting statistics. Here I have to say that the artificial categorization of diagnoses appears to serve interests of administrators and financiers of health services more than (or even against) the interests of patients and their families. Validity is then sacrificed on the altar of reliability (which is what is needed above all for these decision-makers, remote from the clinical coal face). It is no coincidence, in my view, that the DSM-III/IV systems adopted in the USA are the most severely categorical, given that healthcare there is mainly private practice, even though DSM-III was set up primarily for clinical not financial purposes. I *do* accept that categorical systems of diagnosis are needed for financial and legal decision-making, and for collecting statistics; but they should not then be allowed to become dominant in clinical practice. This, I believe is what happened with the ICD system. Originally it was set up to collect statistics on causes of mortality, for international comparisons. Today it is used for many other purposes, including clinical ones. There is worrying style underlying such trends, which has been accelerating for several centuries (in fact since shortly after the scientific revolution of brought about by Newton and others). This is to think that just because one has a *number* to assign to something, in the social, political or (here) health policy areas, it is a *ipso facto* a robustly measured quantity, and a basis for precisely-reasoned decision making. This *is* a fallacy, which has been exposed, yet it will not die down.

(ii) *Can one develop a practically-useful dimensional diagnostic system?* I think this is possible, but it may mean developing a concept different from that of “diagnosis” as used elsewhere in medicine. A precedent for this comes from systems for educational assessment. Traditionally, in British and Commonwealth universities, first degrees are graded categorically (First, Upper Second, Lower Second, Third), but many wise educationists have wanted a more informative and descriptive record of each student's abilities - a sort of “qualitative transcript” of each student’s strengths and weaknesses. This parallels psychiatric assessment, where there may be vulnerabilities and strengths inextricably combined. Thirty years ago, in Britain there were attempts to develop such a “qualitative transcript” system for national exams in secondary schools, but in due

course administrators came in and carved it up into categories¹², which was exactly what the innovators were trying to avoid. However, in psychiatry, it might be possible to develop a similar sort of “qualitative transcript”, for use in explaining to patients, their families and other professionals what each patient’s vulnerabilities and strengths are. It would help patients specifically because it would help them towards self-knowledge. This must be a crucial part of the healing process for many patients, in restoring their sense of personal wholeness. In this sense, diagnosis would serve the patient’s needs, but for reasons quite different from offering rational guidance to a prescribing physician: Diagnosis and the psychotherapeutic aspect of a clinical relationship would become part and parcel of the same therapeutic process. In principle this would also be better from a scientific point of view, being more use to researchers than an artificially-categorized system. Administrators, and the financial and legal people, and those who collect statistics, would doubtless still need to categorise the system; and so one would need to consider ways to safeguard a non-categorical system for clinical purposes, protecting a “qualitative transcript” system from artificial categorisation by administrators. I see no reason why different systems cannot be used for different purposes. This happens already to some extent: Some terms in psychiatry (“insanity” in many jurisdictions, “psychopathy” in British practice) are already in widespread use in legal practice, without their needing to be used *clinically* in psychiatry.

(b) *The schizophrenia diagnostic label.*

(i) *Reliability.* Validity of the schizophrenia diagnosis (a scientific issue) was considered above. The *reliability* of the schizophrenia diagnosis is a more pragmatic issue of relevance here. I accept that the schizophrenia diagnosis cannot at present be made very reliably. Each new psychiatrist may change a patient’s diagnosis. In part this is an inevitable consequence of trying to enforce categorical diagnostic systems, as used elsewhere in medicine. A qualitative or dimensional system could be used to match clinical realities more closely.

(ii) *Does the schizophrenia diagnosis serve useful purposes (as defined in section [2] above)?*

Does it guide rational treatment? There are many answers to this; a diagnosis of schizophrenia is useful as a guide “only in part”. The diagnosis is useful to indicate the value of antipsychotic drugs for a patient, but the effectiveness of these drugs depends just as much on the manner in which they are prescribed (including - but not only – individualised adjustment of dose). The diagnosis may also guide psychotherapy aimed to help patients come to terms with both psychotic episodes and their aftermath, and enduring trait impairments. Apart from this, the therapeutic relationship should endeavour to lift the burden of stigma which many patients feel; and there are many other therapeutic interventions at the social level. These interventions have little need of exact diagnoses. Attitudes of psychiatrists on this issue vary greatly. Many psychiatrists *do* believe the diagnosis to be stigmatising.

12 Broadfoot, P. (2001) Empowerment or performativity? Assessment policy in the late twentieth century. In: *Education reform and the state: Twenty five years of politics, policy and practice*. R. Phillips and J. Furlong, London, Routledge/Falmer, pp. 136-155.

They may say to a patient (or they imply it) “we’ll not call it that, hey, because it won’t help you get a job”. Alternatively, they may avoid bringing up the topic of diagnosis, as would arise naturally in most other areas of medicine (see my own recollection below). Some psychiatrists are clearly more afraid to tell this diagnosis than their patients (who are closer to its reality) are to hear it. Some psychiatrists however have a very different approach. One I know, in reducing a patient’s anxieties, sometimes finds it useful to use the line “Don’t worry; it’s just ordinary schizophrenia”.

Does it give a useful guide to prognosis? Here the arguments can be made strongly. The term schizophrenia was developed from Kraepelin’s *dementia praecox*, which, even by definition, referred to patients with very poor prognosis, those who did not recover sufficiently to leave his institution. This is an utterly pessimistic way to define any disorder, and flies in the face of the proper commitment of any healing or caring profession. It is now well understood that schizophrenia is not a form of dementia, and that the prognosis is not one of unrelenting decline of mental capacity. Although this is well understood by many professionals, for some it is not, and amongst the general public, the view that schizophrenia is a hopeless condition is more common (though varying from country to country). Apart from these considerations, in today’s healthcare scene, I do not believe that making the diagnostic distinction between schizophrenia and bipolar or other psychotic disorders makes much difference in terms of the prognosis which the diagnosis implies.

Does it guide patients’ self-help and self-education? Patients have diverse attitudes to the schizophrenia diagnosis. Some welcome the diagnosis. Family members in particular welcome *knowing* the diagnosis (hard though the message is), after long periods of growing confusion and anxiety. Many patients think the diagnosis is itself stigmatising (“more of a sentence than a diagnosis”). However, some patients know the diagnosis before they are told. My own story is relevant here: For several years after my first breakdown no-one mentioned any diagnosis. At last a bold registrar (but not the consultant in charge) broached the subject, by asking me what I thought was the nature of my illness. I told him what I thought; so, it was me who first used the S-word. He had judged me well, and he then showed me the same diagnosis typed in the case notes. Since then, I use the diagnosis, especially at international schizophrenia congresses somewhat like a war veteran uses a military medal; and as a result I have learned a great deal about the attitudes and mentality of the run-of-the-mill research psychiatrists!

Is the schizophrenia diagnosis helpful for public health campaigns? The argument is often made that the word and diagnosis of schizophrenia contribute to stigma against people with severe mental illness, and so should no longer be used. However, this is a self-fulfilling prophecy: The more one says it, the more it becomes so. Not talking about a hard reality does not soften that reality, but only adds to the confusion.

One temptation should, I believe, be resisted – to abandon the word schizophrenia just because of vocal opposition from the more strident consumer activists, always looking for simple answers to very complex problems. By dictating the terminology, they *can* determine the nature of the debate, but not always in a helpful direction. In making this point, I do not want to undermine the consumer movement in psychiatry. The move to democratise health care, which started twenty years ago in the field of HIV/AIDS, grew out of very courageous activism by those at risk, and is

now an exciting international movement, which is transforming all areas of medicine. However, consumer activism loses credibility if its intellectual foundations are shaky. In offering the above critical comment, I therefore hope to strengthen the intellectual base for more solid consumer activism in the mental health area.

At least in Britain, the issue has to be seen in the context of British media, which may have been instrumental in giving this word such a stigmatizing insinuation. If that is the case, any alternative terms would soon be picked by the same media, and acquire the same connotations. To regard the word “schizophrenia” as the real bogey-man can be regarded as a sort of “displacement activity”. The target should not be the word “schizophrenia”, but the malign practices of public media. This is a difficult task, but not impossible if intelligence and commitment are brought to bear on the issue. What is needed is a large-scale, well-funded and intelligently-planned public education campaign, maintained in perpetuity (just as maintaining effective sewage systems is a continuing public health commitment in the field of infectious disease). Probably emphasis on the word schizophrenia would not be helpful in initial stages of such a campaign (although this may vary from country to country). I do not believe the word should be deliberately avoided, since it is a “flag” or “signpost” which can guide desperate individuals and families to services which can provide help. If the campaign was becoming successful, more difficult issues could then be broached, with explicit introduction of the term schizophrenia. The recent trend to replace “schizophrenia” by “psychosis”, or “early psychosis” was commented on above. This *is* useful for some purposes (especially in making early intervention programs acceptable to young people for whom a psychotic illness is developing). Again we must conclude that different terminology is to be preferred for different stakeholders. However, these decisions are ones based on pragmatic considerations in each society, and should not be confused with the underlying scientific debates.

Is use of “schizophrenia” helpful to research”? Comments made in section 6 (a),[i] above (“To guide researchers”), have special relevance to the debate over the name schizophrenia, and need not be reiterated.

To provide a basis for administrative and political decisions (financial, legal), and for collecting statistics. Until the science has progressed to the point where differential diagnoses amongst psychotic disorders are a more reliable guide to rational treatment and to prognosis, there is little to be gained by retaining schizophrenia as separated from other diagnoses for psychotic disorders.

7. Practical Recommendations

- (a) *Redirection of research:* Psychiatry desperately needs a new long-term research strategy, a solid theoretical strand, complementary to the deep-died empiricism which has prevailed, and become a rigid dogma, in recent decades. Only in this way can a really solid classification system be built, from which more useful diagnoses can arise.
- (b) *Diagnostic systems in general:* One system cannot serve the interests of all stakeholders. We need different (but related) systems for different stakeholders:
 - (i) For scientists/researchers: a dimensional system is preferable for most purposes.
 - (ii) For financial/legal purposes: Any dimensional system would need to be chopped into categories.

- (iii) For purposes of collecting statistics: The system also needs to be categorical. If international, it needs to be based as far as possible on scientific principles, not on society-specific ones.
 - (iv) For clinical purposes: In encounters between a physician and his/her patient, there should be some careful negotiation, to gauge what would be in the best interests of each patient. Some patients would be helped more by an explicit diagnosis, others by avoiding diagnoses unless asked for. Some would value open discussion about just how fraught the debate about diagnoses is amongst professionals. In the future it is likely that the writing of medical records will involve some degree of partnership between doctor and patient. These negotiations will then become rich opportunities where diagnosis and psychotherapy can occur simultaneously. All this is the “art” rather than the “science” of psychiatry. Perhaps most useful would be an informative qualitative transcript, of the person’s strengths and vulnerabilities, to substitute for a formal diagnosis, this being an intrinsic part of the therapeutic relationship. Even in our far-from-complete current state of understanding, this could be done, based on principles of normal personality theory (and ways of assessing personality) and its extension into abnormal personality.
- (c) *With respect to the Schizophrenia Diagnosis*
- (i) From the scientific point of view, we are by no means ready to rename this disorder.
 - (ii) Scientifically, acute psychosis in schizophrenia (though not necessarily its long-term aftermath) is plausibly seen as an abnormal state, to be defined categorically. However, enduring traits aspects of the disorder are best described dimensionally. How separate this constellation of traits is from other diagnoses is not yet known.
 - (iii) For some purposes, terms other than schizophrenia would allow better engagement with the public in relation to this disorder.
 - (iv) I do not favour revolutionary abolition of the term schizophrenia, partly because we would lose contact with the rich existing research literature. I favour a more evolutionary approach, a transition to a different style of diagnosis, perhaps laying less emphasis on formal diagnoses, or even substituting another concept for “diagnosis”. This cannot be done overnight “at the stroke of a pen”.
 - (v) For the time being, the term “schizophrenia” is useful for some purposes. At the clinical “coal face”, where all the subtleties of the “art” of psychiatry are in play (as opposed to possible scientific approaches to the discipline) the diagnosis may be less useful than for these other purposes, or for diagnoses in other areas of medicine; yet even here the term has its place, to be judged by each clinician on a patient-by-patient basis.

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3.06.2012.