

Patient experience and psychiatric discourse

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Summary Language, concepts and frameworks employed by psychiatrists contrast starkly to those held by patients. Despite the fact that the battle to understand patient experience was won long ago, current biomedical approaches and the DSM culture prevent such understanding. Positioning patient narratives in the foreground will help translate experience, provide legitimate frameworks, create common language and interface for communication, offer powerful insights, influence clinical practice and have an impact on psychiatric theory.

Declaration of interest None.

Diligent students of psychiatry are taught to take detailed clinical histories and perform meticulous mental status examinations. They are encouraged to listen actively and with empathy. Psychiatrists are encouraged to have a positive unconditional regard for their patients in order to establish good therapeutic relationships. Yet, patient and clinician accounts of consultations differ in terms of detail and perspectives. Concepts and frameworks employed by psychiatrists in their clinical encounters contrast starkly to those held by patients and are a fertile ground for misinterpretation and misunderstanding.

Disease–illness divide

Typically, patients emphasise suffering and distress, whereas psychiatrists diagnose and treat ‘diseases’.^{1–5} The patient’s experience of sickness is translated into abnormality of structure and function. It is conceptualised using universal models in terms of disease, learnt maladaptive thinking and behaviour or problematic childhood and adult relationships. Contexts, stressors, personality and coping are dismissed as incidental, whereas the objective symptoms are counted. Medication is prescribed and patients referred for psychotherapy, if required.

The disease–illness divide is a classical example of differences in patient and physician perspectives. However, disease and illness tend to be synonymously and interchangeably used resulting in a lack of conceptual clarity. Many aspects of the distinction have been highlighted.^{1–5} (a) an absence of a 1:1 relation between disease and illness; (b) similar degrees of pathology generate different amounts of pain and distress; (c) illness can occur in the absence of disease (such as medically unexplained symptoms); (d) the course of a disease can be different from the trajectory of illness; (e) they represent differences in explanatory models and world views between doctors (disease) and patients (illness); (f) medicine and psychiatry highlight naturalistic explanations (disease, degeneration, dysfunction, infection, malignant change), whereas patient explanations focus on personalistic views (God, sin, punishment, karma, evil spirit,

black magic, supernatural, stress);⁶ and (g) many patients and their families simultaneously hold multiple and contradictory causal beliefs and sequentially and/or concurrently seek diverse treatments.⁶

Encounter texts

The clinical encounter between doctor and patient has been described and analysed. It is said to have at least four subtexts.⁷

- (a) Experiential text: how does the patient’s story and situation have an impact on their life and what meaning do they give it?
- (b) Narrative text: the medical history, which the doctor records as their interpretation of events.
- (c) Perceptual text: the conduct and recording of the physical and mental state examination to understand the issues.
- (d) Instrumental text: the laboratory results (e.g. blood tests, X-rays) used to rule in or rule out physical disease. Symptom checklists and the standardised diagnostic protocols and criteria play a similar role in psychiatric evaluations.

Consequently, the patient’s story of their experience contrasts markedly with the doctor’s account of the illness.

However, psychiatric theory recommends, and its practice results in, unequal weighting given to the different subtexts. The skewed dominance of certain perspectives, in particular the instrumental texts, tends to diminish the significance of the patient’s story and the meanings it holds for them. Such dominance makes integration of these subtexts into a larger whole impossible.⁷ It also highlights a key epistemological problem in medicine and psychiatry, namely, how subject–object relationships are worked out in clinical practice. The patient is turned into an object of clinical procedures with no real attempt being made to engage with the patient and their perspectives. The case history is reduced to a series of symptom checklists and

patient narratives find no place in healthcare discussions. It fails to elicit or understand the patient's attempt at coping with the problems or their attempts to bring about a sense of coherence and stability after the onset of the illness. Patient narratives of their ordeal are rarely documented nor do they find a place in the diagnosis and management of the condition. The narratives are trivialised, whereas the theory and psychiatric models are considered universal and transcendental. Their singularity and incommensurability are dismissed when universal theoretical formations are applied to clinical practice.

The focus of biomedicine on disease and consequently cure is very narrow and tends to ignore the reality of illness, suffering and personal meaning for the individual patient.⁵ The sole reliance on technological fixes disregards the patient's interpretation and explanation and fails to realise the significance of healing. These issues often result in patient dissatisfaction.

Body–mind–society division

Recent technological leaps have focused on the body and have made it easier to standardise clinical symptoms, signs, laboratory results and treatments. Such evidence is also aggregated in systematic reviews and meta-analyses. However, similar standardisation and reliable assessments for the mind and society are difficult resulting in sidelining of individual experience and social contexts. The reliance on such advanced technology centred on the body has skewed the focus and has changed the format in the practice of clinical psychiatry. This is particularly true as one moves from the community and primary care to specialist and tertiary care.

The individual patient experience, which has to be viewed through its immediate context (such as social class, economic status, caste, minority grouping, gender, sexuality and religion) is ignored. History, culture, development, specialist care, pharmaceutical and health insurance industries and politics, the broader filters influencing patient experience and perspectives, are considered inconsequential, although illness narratives are also shaped by cultural, spatial and historical practice. The evaluation of a patient's concerns within a psychologised and patronising relationship also poses problems but is not recognised. Psychiatrists rarely acknowledge philosophical difficulties inherent in the diagnosis of mental illness.

Part perceptions

The conceptualisations of disease and illness have many similarities:^{1–5} (a) both are conceptualisations and models, which explain the sickness episode; (b) both are complex, dynamic and total phenomena; (c) both derive from and help construct clinical reality; and (d) both are culture specific and value laden. Consequently, psychiatrists and their patients inhabit different worlds. The clinical method objectifies patient problems in order to enable clinicopathological reasoning. However, this process has very limited engagement with patients. The need to individualise care, which is the essence of clinical practice, is difficult as the language to bridge the disease–illness divide is non-existent.

Doctors employ technical language and body/disease centric information, which is useful only to other doctors, whereas patient experience and language useful to patients is dismissed as unimportant by medicine. Biomedicine does not have a language for sickness⁷ and such perspectives are rarely written in case notes. The patient's story is frequently interrupted by the shortage of time, a limited resource. The need to medicalise the social and personal distress of everyday life in order to provide medical and psychiatric care demands the use of medical and psychiatric labels.⁸ Symptom checklists and standardised diagnostic and treatment protocols, driven by evidence-based medicine, insurance providers and legal issues seek to control practice with the aim of protecting patients or financial interests.⁷

Randomised controlled trials are the cornerstone of evidence-based medicine. Yet, the results of a single randomised controlled trial or a systematic review of many trials provide evidence about the efficacy of treatments (i.e. 'the treatment works somewhere') without necessarily providing evidence of effectiveness in clinical practice (i.e. 'the treatment works widely').⁹ Extrapolating or generalising knowledge gained from randomised controlled trials to other individuals and to many different settings is essentially problematic as it requires much more evidence, which is often unavailable.

Evidence in medicine has a positional quality. Differential weighting is given to the patient's subjective evidence, which has no scientific basis, compared with the physician's objective evidence, which can be replicated. The context and specificity of the physician–patient situation and interaction and its social position and location demand a re-examination of the issues. The oversimplification of the psychiatric framework and its resultant straightjacket mandate the inclusion of patient experience and perspectives. Patient and service user interest groups need an organisational system to talk back to medicine and to psychiatry and to have an impact on medical knowledge. Such forums need to open up questions including the role of pharmaceuticals in the selective focus on symptoms, diagnosis and classification of psychiatric disorders, and on evidence-based medicine.

Many questions remain unanswered.⁷ How can patient experiences be translated? What are the forums available for such translations? At what level does experiential knowledge have an impact on medical knowledge? Can patient experience have an impact on psychiatric theory, pedagogy and research? The inherent differences in structure and function between patient and clinician perspectives and the incommensurability of their frameworks results in problems in communication and in understanding. Can clinician perspectives be used to make patients more comfortable? Is it about sharing medical knowledge? Or contextualising categories? Can patient experiences be generalised? Can patient experience be legitimised?

Which psychopathology?

The meanings and approaches to psychopathology have changed over the past century. Psychopathology now refers to mental phenomena/symptoms/phenomenology (descriptive), to syndrome/diagnosis (clinical) and to the meaning of

personal experience (structural).¹⁰ It is more commonly used for easy communication between mental health professionals; to categorise patients into different diagnoses. These functions tend to trivialise the term 'psychopathology' and move it away from the original aim of the discipline to understand the nature of subjective experience. Such approaches conceal major problems in the definition of terms and conflate the separate issues related to disease and illness. Jaspers' approach to phenomenology emphasised empathetic understanding of subjective experience.¹¹ The current approaches, which focus exclusively on 'form' to the complete exclusion of 'content', trump all attempts at an empathetic understanding of issues. The current use of observable/objective phenomena, based on Schneider's pragmatic approach in differentiating schizophrenia from bipolar illness,¹² improves reliability at the cost of the understanding of subjective experience. The DSM tradition, which in 1980 represented 'best effort', has now become 'ground truth', ignoring the psychopathological tradition and the social context.¹³ Its use in non-clinical areas (such as legal responsibility, third party payments) changed the character of psychopathology and reduced its clinical function in understanding patient experience.

Current practice

The apparent sophistication of the current superficially scientific approach has changed practice. The fact that current biomedical approaches focus on reliability without regard to the validity of most categories, which are yet to be established, is rarely highlighted. Although the atheoretical nature of the current diagnostic criteria is trumpeted, their biomedical underpinning are obvious. It has reduced clinical interview to a checklist, which focuses on knowledge of the criteria rather than skill and understanding of the patient and their context. Although psychiatrists are exhorted to employ multiple models (such as psychoanalytic/dynamic, cognitive/behavioural, social/contextual)¹⁴ to understand the patient, current practice tends to reduce the process to biomedical approaches.¹³

The introduction of the category of major depression^{15,16} with its symptom count, side-stepped many contemporary debates about depression (such as disease/reaction, normal/abnormal, psychotic/neurotic, category/dimension, biological/psychological).¹⁷ The removal of emphasis on stress and context and the subordinate status of adjustment disorders medicalised categories of depression.¹⁸ Even as psychiatry mandates the examination of cultural issues and the need for a cultural formulation, their position in the DSM-IV appendix suggests their secondary status.¹⁹ The DSM argues for a universalist approach rather than support an individual or contextual analysis.

Current practice, as described, appears to the older generation of clinicians as a caricature of the ideal; a straw man erected only to be knocked down. Yet, the description fits the practice of the DSM generation. Although the arguments and debate for a multimodal approach was won long ago, the fact that the DSM's biomedical juggernaut has dominated practice on the ground and decimated other approaches is not difficult to appreciate. The generation gap

in clinical approaches is difficult to understand, let alone bridge.

Current training

These issues, although occasionally highlighted in psychiatric literature, are rarely discussed in current clinical practice and pedagogy. The younger generation of psychiatrists, raised in the DSM tradition, consider the diagnostic system and criteria as an authoritative text.¹³ The universal and uncritical use of such operational definitions for psychopathology and diagnosis for teaching undergraduates and residents has meant that the classics in psychopathology are largely ignored. The use of such criteria in board examinations, which certify all training, have spawned the need to memorise its contents.¹³ This has translated to knowledge of the criteria rather than a focus on the skill and understanding required for clinical interview and patient care. The original intended 'gate keeping function', which intended to set minimum standards, is lost and these texts have become the resource and reference material for clinical psychiatry. Although one could argue that such an approach reflects bad practice rather than current psychiatric thought, its persistence and dominance in most clinical settings argues otherwise.

Research priorities

The focus on interrater reliability in research has mandated the use of operational diagnostic criteria to the near complete exclusion of other approaches to mental health and illness. The drivers of psychiatric research (such as biomedicine, pharmaceutical and insurance industries) prefer objective and behavioural criteria to subjective and illness experience. Consequently, checklists have become the new standard in psychiatric research. Convincing residents and trainees otherwise is a daunting task. Strong advice based on weak evidence of practice as reflected in current psychiatric research is usually not accepted. This is not the failure of individual teachers but of the new culture spawned unwittingly by the DSM.¹³ Current trainees, children of the internet revolution and its explosion of information are reassured with DSM's certainty. Grasping at such straws provides a certain stability and orientation to manage the information overload.

Moving forward

There is a need to recast and reframe patient experience and to create a new language to influence the mainstream psychiatric discourse. The story of the elephant and the blind men comes to mind. The issues involved are complex and difficult to comprehend. The limitation of the current approaches includes the use of symptom checklists, which provides part perception and not the holistic picture.⁸ It medicalises all personal and social distress, employing a framework that is incommensurable with patient perspectives and concerns.

The clinical encounter is similar to figure-ground illusions (such as Rubin vase/profile illusion) and is biased by 'perceptual set' and individual interest, which make one

interpretation stronger than the other. It involves higher cortical functioning based on stored information on vases and profiles (or diseases and illness). The incommensurability of the patient and clinician framework demands rapid shifts between perspectives to capture the complexity of the issues.⁵ Newton's wheel, another analogy, demands rapid alternations between colours (or individual and physician perspectives, immediate context and social milieu).

Patient-centred clinical methods need to explore both disease and illness, attempt to understand the person and context, find common ground, enhance the physician–patient relationship through mutual decision-making for problems, goals, roles, etc. Treatments have to be biomedically correct and yet, universal approaches have to be contextually appropriate. History-taking, now a method for diagnosis, should be employed to explore and understand sickness. There is a need to move away from the so-called scientific certainty of the single best curative strategy when arriving at an individual and contextual diagnosis, making way for a broader emphasis on individual experience and contextual analysis. It should not be a black box approach to diagnosis. Patient-centred approaches need to be formally taught.

Clinicians need to explore dimensions of patient experience, understand patient perspectives and consider contradictions with the medical/psychiatric model. There is a need to challenge the official discourses about the doctor–patient relationship, informed consent, and adherence to treatment by patients.⁷ The role of patient experience and the impact of their perspectives in the production of medical knowledge warrant review. The discourses on the prevalent dichotomies (such as disease *v.* illness; care *v.* cure; mind *v.* body) in medicine and psychiatry also require rethinking.

Patient and carer activism and advocacy (for example in HIV/AIDS, Alzheimer's disease) have highlighted patient issues and perspectives, challenged and changed medical knowledge and practice, influenced popular ideas about these conditions and have had an impact on healthcare policies. Mental illness also requires such advocacy and activism to incorporate the patient perspective into psychiatric practice. Although incorporation of user perspectives of people presenting with chronic fatigue may pose a challenge to psychiatry, engaging people with most, if not all, forms of mental health issues will prove beneficial. Although the 'antipsychiatry movement' of the 1960s took extreme positions about the usefulness of psychiatric treatment, their advocacy for user involvement in decision-making is valid. Different forums need to be created to translate patient and carer experience into different registers so they can have an impact on psychiatric knowledge and share issues with other people with similar conditions and situations. This would help in having their voices heard and in renegotiating with the psychiatric fraternity to have an impact on practice.

Such experiential knowledge, although personal, will have to be recast in each case. It will help translate experience, provide legitimate frameworks and create a language and interface for improved communication. The reframing of such narratives will have an impact on psychiatric care, practice, research and healthcare delivery

systems. Psychiatrists and clinicians need to constantly search for the elephant and acknowledge their limitations in fully comprehending patient experience. Although patient experience and narratives cannot be standardised using the techniques of evidence-based medicine, they provide powerful insights into mental illness and can influence clinical practice and consequently have an impact on psychiatric theory. Patient experience and perspectives, devalued and delegitimised by canonical authority, needs to be re-emphasised and integrated into clinical practice. There is a need to bring to the foreground patient experience in order for them to have an impact on mainstream psychiatric discourse. This calls for the need to re-evaluate and change the many unintended consequences of the DSM and classificatory movement.

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References

- 1 Boyd KM. Disease, illness, sickness, health, healing and wholeness: exploring some elusive concepts. *Med Humanit* 2000; **26**: 9–17.
- 2 Marinker M. Why make people patients? *J Med Ethics* 1975; **1**: 81–4.
- 3 Eisenberg L. Disease and illness. Distinctions between professional and popular ideas of sickness. *Cult Med Psychiatry* 1977; **1**: 9–23
- 4 Tseng W-S. *Handbook of Cultural Psychiatry*. Academic Press, 2001.
- 5 Jacob KS. Bridging the disease-illness divide in modern medicine. *Natl Med J India* 2009; **22**: 320–2.
- 6 Saravanan B, David A, Bhugra D, Prince M, Jacob KS. Insight in people with psychosis: the influence of culture. *Int Rev Psychiatry* 2005; **17**: 83–7.
- 7 Duggirala V, Seemanthini N. Patient questions. In *Towards a Critical Medical Practice: Reflections on the Dilemmas of Medical Culture Today* (eds A Zachariah, R Srivatsan, S Tharu): 246–65. Orient Blackswan, 2010.
- 8 Jacob KS. Major depression: revisiting the concept and diagnosis. *Adv Psychiatr Treat* 2009; **15**: 279–85.
- 9 Cartwright N. A philosopher's view of the long road from RCTs to effectiveness. *Lancet*. 2011; **377**: 1400–1.
- 10 Stanghellini G. The meanings of psychopathology. *Curr Opin Psychiatry* 2009; **22**: 559–64.
- 11 Jaspers K. *General Psychopathology*. The Johns Hopkins University Press, 1997.
- 12 Mellor CS. First rank symptoms of schizophrenia. *Br J Psychiatry*. 1970; **117**: 15–23.
- 13 Andreasen NC. DSM and the death of phenomenology in America: an example of unintended consequences. *Schizophr Bull* 2007; **33**: 108–12.
- 14 Lazare A. Hidden conceptual models in clinical psychiatry. *N Engl J Med* 1973; **288**: 345–51.
- 15 Feighner JP, Robins E, Guse SB, Woodruff RA, Winokur G, Munoz R. Diagnostic criteria for use in psychiatric research. *Arch Gen Psychiatry* 1972; **26**: 57–63.
- 16 American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders (3rd edn) (DSM-III)*. APA, 1980.
- 17 Kendell RE. The classification of depressions: a review of contemporary confusion. *Br J Psychiatry* 1976; **129**: 15–28.
- 18 Casey P, Dowrick C, Wilkinson G. Adjustment disorders. Fault line in the psychiatric glossary. *Br J Psychiatry* 2001; **179**: 479–81.
- 19 American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders (4th edn) (DSM-IV)*. APA, 1994.