

Pain, madness and the limits of medicine

The problem of pain poses questions pertaining to some of the assumptions that underpin modern medicine, including the conceptualisation and treatment of psychiatric disorders. Problematic issues, such as subjectivity and meaning, seem particularly critical in the domains of pain and madness, but have relevance in the broader ranges of medicine. Of central concern is the relation such issues bear to notions of scientific practice. The subjective experience of illness and the meanings attached to it need to be accounted for, and cannot be considered to lie beyond the scope of scientific thinking, as not being measurable or objectively verifiable: yet attempts to incorporate these intrinsic dimensions remain elusive, and shape some of the shifting limitations of the various definitions of what might be considered to be a scientific perspective.

The limits of an evidence-based, scientific perspective

I was recently invited to visit a new hospital in Kimberley. Part of the programme included a tour of a reconstructed mining village. There we were given brochures describing the beginnings of the mining industry in the town. The information included a report by the eminent British geologist James R Gregory, stating emphatically that he had made 'a very lengthy examination' of the districts where diamonds were said to be found. He concluded that 'the geological character renders it impossible, with the knowledge in our possession of diamond bearing rocks, that any could have been discovered there'. The Big Hole remains the richest diamond deposit ever found anywhere in the world, and changed the history of South Africa. Gregory was being entirely scientific in his report, basing his conclusions on the evidence available to him. He was also spectacularly wrong. Our forefathers similarly concluded that the earth was flat on the sound basis of their senses, and were fortunately not able to test the limits of this evidence before the development of technologies that demonstrated the fallacy of what might have seemed self-evident. At the beginning of the 21st century, with the construction of the large Hadron Collider at CERN (the European Organization for Nuclear Research), questions again arise about the limits of scientific knowledge, and the ultimate nature of matter. It is the remarkable progress of science that has pushed the endeavour to its mystifying edges, but it would not be consistent with this scientific approach to extrapolate beyond the limits of the available evidence, and claim certainty when there is no certainty, or to assume the inevitability of forthcoming answers to current mysteries.

Curiosity about pain and its lack of a clear correspondence with harm led me to attend a *ratiep* or *khalifa* ceremony in

Delft. The *ratiep* is of Iraqi and Indonesian origins, and a rite within the mystical tradition of Sufism. The ceremony involves drumming, chanting, and cutting and piercing of the body. I saw no evidence of injury, bleeding or distress, nor did I observe any evidence of trance-like or dissociative states that I thought may account for the phenomenon. Our guide emphatically insisted this was not a matter of 'mind over matter' but an expression of faith and the transcendence of the spirit. The practice gained popularity among the slaves in the Cape in the 18th century, demonstrating the belief that although the body might be owned by the slave master, the soul belonged to God, and therefore was impervious to the tribulations of the physical world. I was mystified by the experience; it confounded everything I thought I knew about pain, other than to confirm how little is known about this core phenomenon of medicine.

The limits of the biomedical model

In modern medicine the mythologies of cure seem to prevail, probably on the basis of the infectious diseases model that had successful application towards the middle and latter part of the 20th century. This model or paradigm is representative of a biomedical approach, the limits of which are becoming increasingly apparent, despite much of the triumphalism evident in some of the current claims in medicine, for example, in the expectation of a cure for schizophrenia, or the alleviation of all forms of pain.¹

The great majority of the afflictions in modern medicine, including cardiovascular disease, cancer and diabetes, are not amenable to cure, nor, again within the limits of current knowledge, is it appropriate to expect a cure, although great progress has been made in the effective management of these disorders. Yet even within the confines of the infectious diseases paradigm the notion of cure is problematic. If a cure is taken to be the successful treatment of the underlying cause, then, for example with regard to tuberculosis in southern Africa, it seems simplistic to attribute sole causation to the mycobacterium, without taking immune compromise and socio-economic deprivation into account. The application of a restrictive, mechanistic model to the majority of disorders that burden our lives, including those of pain and mental illness, is inappropriate, unhelpful and potentially harmful.

The problem of pain is confounded by a crude dualism that remains prevalent in modern medicine despite being without a scientific foundation. A simplistic, dichotomous definition of pain as being physical or psychological, for example, has damaging consequences. Neglect of psychological dimensions, commonly depression, which is virtually intrinsic to pain, yet treatable,

leads to woefully inadequate treatment or mistreatment through unnecessary physical interventions. Neglect of physical factors, seen all too often in persons with psychiatric illnesses, can have potentially disastrous consequences. A young woman referred to me in a community health care clinic was reported to have a history of a psychiatric disorder, but was then presenting with a headache. A bizarre, unwarranted and dangerous assumption seemed to have been made that the headache was in some way a symptom of the psychiatric disorder, or 'psychological'. The young woman had become disembodied by this diagnostic inference. The assumption was dangerous because the headache bore all the features of raised intracranial pressure, most probably caused by an intracerebral bleed. Some of the difficulty might arise in the conflation of nociception with pain. The pathophysiological basis of pain is fairly well elucidated, including both the sensory discriminatory and the affective motivational components of the phenomenon. But that does not explain pain. A vast range of pain experiences can derive from a shared identifiable biological basis. Pain is the articulation or end-point of a complex array of biographical biological cultural emotional and cognitive factors. This conceptualisation has important consequences for management. Physical problems require physical remedies: more complex problems require more complex and therefore individualised approaches. Pain is a subjective phenomenon, and a failure to acknowledge this is likely to ensue in ineffective management.

Acknowledgement itself is a complex phenomenon: in some way it includes the understanding that pain is private and that the person suffering from pain has endowed the experience with meanings, and has to some extent developed ways of making sense of it, and thus coping as well as possible. Various attempts have been made to define the phenomenon of pain, in the past twenty years shifting from reductive mechanistic formulations to a more recent emphasis on the emotional and subjective qualities of pain. One strategy to delink nociception from pain is to reconstruct chronic pain as a form of suffering.² This again has important implications for management. It is the experience of many clinicians involved in the field that a priority in the treatment of pain is the acknowledgement of this suffering, prior to any attempts to alleviate the symptom. An unexamined assumption prevails that a patient attends a pain clinic for the sole aim of having the pain relieved, and it has come as a surprise, to this writer at least, that there are those who in some way need the pain, and certainly for it to be acknowledged, as if in some non-articulated way, as a means of making sense of, and thus mitigating misfortune. Failure to understand that the presenting symptoms represent to an extent a construction on the part of the person suffering from pain is likely to lead to disenchantment with medical care and the resentful anger and resignation familiar to

many of us working in the field. Declaring that there is 'nothing wrong', when examination and investigations have yielded no observable pathology, is clearly platitudinous and patronising nonsense, and will do nothing to reassure the patient.

The limits of diagnoses

In a similar way there is a gulf between the pathophysiological substrate of psychotic disorders, the observed phenomenon, and the felt experience thereof. Dysregulation of dopamine, serotonin and glutamate transmission, or dysconnectivity syndromes, or any other hypotheses do not explain the symptoms of schizophrenia. How disorganisation at molecular or neuronal network levels should lead to the experience of others inserting thoughts into one's mind is a mystery. In this respect the diagnosis of schizophrenia, enshrined in the *DSM-IV* and elaborated in a clutter of rating scales, may be considered as an example of a premature and inadequate diagnostic reductionism, squandering, for the sake of reliability in assessment, an intrinsic and heuristic complexity. Although some of our more scrupulous colleagues may construe the term as a potentially useful, albeit tentative, provisional hypothesis, in the light or shadows of current knowledge, the *DSM* apparatus has led to the reification of the construct, and again, it is argued, this has potentially harmful consequences. Asked to account for their symptoms, a familiar answer given by many of our patients is 'I think too much ...'. A diagnosis of depression in this context seems impoverished, and to provide meagre explanatory power for the patient and his or her family, and is thus not particularly meaningful or helpful.

The great volume of literature devoted to the subject of schizophrenia has yielded surprisingly limited results. In the first decade of the 21st century the ultimate causes, the pathophysiology, and the effective treatment of the disorder remain elusive. These limitations are of course not confined to schizophrenia, and apply to other psychiatric disorders and many general medical conditions, the particularity of psychiatric disorders being that they pertain to the most complex dynamic system in the universe. In more recent years there have been calls for a return to phenomenology, or an examination of the experiences of schizophrenia, rather than of schizophrenia as an abstract construction.³

Phenomena as constructions

As for the phenomenon of pain, the clinical features of schizophrenia, in particular the passivity phenomena, may be interpreted as attempts on the part of those suffering to describe and possibly explain the experience, albeit in a bizarre and at times incomprehensible way. In the terms of this formulation biological events, for example dysregulation of monoamine

transmission in the meso-limbic and meso-cortical circuitry, and dysconnection of neuronal networks, confound the subject. In the struggle for reconstitution the person strives for meaning in the form of metaphors, which, given the nature of the pathology, are concretised and idiosyncratic. These disorganised endeavours are read by the observer as evidence of psychosis, rather than disorganised ways of coping with the phenomena. This might be considered inconsequential, but in terms of management the shift is critical in refocusing attention from the indeterminate underlying pathological processes to the attempts on the part of the subject to make sense of the phenomenon, so as best to cope, as do those struggling to live with pain.

The diagnostic concept of pain syndromes, or schizophrenia, requires levels of understanding that extend beyond the criteria of standard diagnostic systems. The diagnosis of schizophrenia does not of course explain the phenomenon of schizophrenia. Seeking common features in the apparent disparity of clinical features a pattern may be discerned. Delusions tend to be represented by passivity phenomena, the sense of not being the author of one's own actions. Hallucinations are perceptions of events generated internally but experienced in external space. Thought disorders represent a failure to monitor the effectiveness of one's own utterances: social withdrawal a loss of self-efficacy, or of being in the world that is often evident in self-neglect. Loss of volition in a similar way suggests an impairment of agency, coupled with the loss of the emotional drive to action. A common denominator of these apparently disparate phenomena is a disorder of the self, or the relationship of the self to the external world. A core notion of the self is the assumption of the self as being conscious, and of there being a fundamental distinction between inner and outer worlds: in this respect schizophrenia may be regarded as a disorder of self-consciousness. The definitions of consciousness are varied and elusive, but broadly include a sense of subjectivity, of the self interpreted as unitary and continuous and of intentionality and autonomy. It is the disruption of these functions, which might be considered to represent the core of what it is to be human, that constitute the phenomenology of schizophrenia. What it means to be humanly conscious is uncertain, and whatever that might be seems to be the very faculty that becomes disorganised in schizophrenia, the substrate of these processes possibly being in the neuronal integrity and functional connections of the prefrontal, temporal and limbic cortices and their subcortical connections. Conceptually it is possible to imagine that the processes that lead to disorder of the sense of self in relation to the world, render the self void or ineffectual. Perhaps understandably the world then becomes perceived as either meaningless or menacing. The person living with schizophrenia becomes engulfed by the outside world. Confronted by this world, experienced as noise, the sufferer strives to make sense of the experience and to

restore order and meaning. The sense of loss of the integrity and continuity of the self is interpreted as, for example, possession by an evil spirit or control by a computer device in the brain. These explanatory metaphors are derived from social, cultural and spiritual beliefs and customs. Clinicians will be familiar with the shift, with gradual recovery, from the statement 'I know it sounds crazy but it's true' to the less immersed more reflective 'I felt as if ...'. It is not inconceivable that in the foreseeable future functional neuroimaging will be able to reflect these relatively subtle shifts with the recovery of integrity.

Treatment implications

The problem of chronic pain provides a possibly informative model for re-evaluating the basic assumptions underlying current philosophies of treatment. In fairly recent years a paradigm shift has occurred in the treatment of chronic non-malignant pain, representing a change in emphasis from the notion of cure, in terms of a relatively restrictive biomedical model, to the principles of rehabilitation or reintegration according to a broader systemic or biopsychosocial approach. This shift in thinking is born out of a realistic appraisal of the limits of a biomedical model in a high proportion of general medical conditions. The assumption made is that the presenting features are symptoms of specific underlying causes, and that by the identification and treatment of these underlying causes the symptoms can reasonably be expected to remit. Chronic pain is more appropriately conceptualised as a problem in itself and as such the proper focus of attention, taking into account the probability that the precipitating and perpetuating factors are multifactorial.

It has been argued that the symptoms of schizophrenia are inadequately interpreted as mere symptoms of underlying but as yet incompletely understood pathological processes. The alternative formulation is that these phenomena represent a struggle to give form to formless biological events and to construct meanings, in a state described as 'aberrant salience',⁴ being an attempt to live with an anomalous set of experiences that might otherwise be intolerable. The very processes that are implicated in the pathology of the illness are recruited to develop other restorative representations. In this respect the paradigm shift is the need for this process to be acknowledged and supported, in terms of the goal of restoring control and selfhood, rather than merely cancelled. Clinicians will be familiar with the ambivalence shown by patients in regard, particularly to pharmacological interventions, and which may be an insufficiently acknowledged factor in the high rates of non-adherence to treatment observed in schizophrenia. As for the barbarians at the gates,⁵ delusions may offer some sort of a solution. A void, created through the successful alleviation of symptoms, does not necessarily represent a feasible alternative. In this respect it may be more appropriate

and more likely to promote adherence if anti-psychotic treatments were described as neuro-modulatory. This shift in approach, from the elimination of symptoms to finding ways of helping people to find meanings and ways of living with schizophrenia and pain, is reflected to an extent in the growing interest in cognitive behavioural or interpersonal therapy methods of dealing with these problems. Yet again a limiting dualism is evident between psychological and biological approaches and undermines a more appropriate and effective integrative model. A tension persists between learning to live with the symptoms and eliminating symptoms: it is surely understandable to wish the pain and the delusions away.

This argument emphatically does not represent a critical position with regard to psychopharmacology or the analgesia of chronic pain. It is merely an attempt to redefine and articulate the realistic goals of treatment, and this seems to require reaching beyond the phenomena to address the existential concerns of people living with schizophrenia and pain. The appeal is to focus attention on the context of treatment, and the individual needs of the patient, which for the clinician may too often be the unquestioned assumption that the psychotic symptoms or the pain are negative experiences and therefore require treatment. Alternatively it is argued that the person, not necessarily intentionally, forms delusional beliefs in the process of reintegration, and hence may regard pharmacological treatment as a denial of his or her tentative reality, and an interruption of a potentially healing process. The remedy is not then to withhold treatment but to negotiate meaningful goals of treatment in the context of a mutually respectful therapeutic alliance. This is not being merely orthodox, or consistent with what might be regarded as standard, good or ethical practice; the argument is that such an approach is an integral and critical component in the management of psychotic disorders and pain.

One line of evidence may be drawn from the impact on the course of schizophrenia of different interpretations of the phenomena across cultures, including the culture of the scientific method. Standard Western psychiatric practice requires the identification by an objective observer of a specific cluster of operationally defined signs and symptoms for a diagnosis to be made. No meaning is attached to the symptoms, and treatment is

aimed at their elimination. In this respect the patients' experience is essentially irrelevant and is treated as anomalous or invalid. This contrasts with other belief systems or cultures where psychotic symptoms are invested with social meaning and ordained by tradition. Hearing voices becomes listening to the ancestors, for example, and in this way is transformed from a pathological event to a more validating, integrative experience.

Possibly relatively subtle shifts may be evident between addressing the problem in itself, the underlying factors giving rise to its expression, and the ways of dealing with it. But it is argued that these shifts in focus have important consequences in terms of management. In a similar way an elision is made between the problem in itself and its measurable scientifically verifiable aspects, leading to an identification of the problem with what in the light of subsequent knowledge might be mere approximations. It is inappropriate to construct this argument in a dichotomous way, as what might be considered scientifically valid or not, but to suggest that some of the rigour and clarity of the scientific method includes the endeavour to map out the edges of knowledge, and in a modest, less defined way, to acknowledge some of the limits of understanding madness and pain. Nor should this be regarded as defeatist, but a challenge to find imaginative and effective ways of helping people to cope as best as possible with often unimaginable states of mind.

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