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The duty to be *Well*-informed: The case of depression

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ABSTRACT

It is now an ethical dictum that patients should be informed by physicians about their diagnosis, prognosis and treatment options. In this paper, I ask: 'How informed are the 'informers' in clinical practice?' Physicians have a duty to be 'well-informed': patient well-being depends not just in conveying adequate information to patients, it also depends on physicians keeping up-to-date about: (1) popular misunderstandings of illnesses and treatments; and (2) the importance of patient psychology in affecting prognosis. Taking the case of depression as an entry point, this paper argues that medical researchers and physicians need to pay serious attention to the explanations given to patients regarding their diagnosis. Studies on lay understanding of depression show that there is a common belief that depression is wholly caused by a 'chemical imbalance' (such as 'low serotonin') that can be restored by chemically restorative antidepresssants, a claim that has entered 'folk wisdom'. However, these beliefs oversimplify and misrepresent the current scientific understanding of the causes of depression: first, there is consensus in the scientific community that the causes of depression include social as well as psychological triggers (and not just biochemical ones); second, there is significant dissensus in the scientific community over exactly what lower level, biological or biochemical processes are involved in causing depression; third, there is no established consensus about how antidepressants work at a biochemical level; fourth, there is evidence that patients are negatively affected if they believe their depression is wholly explained by (the vague descriptor) of 'biochemical imbalance'. I argue that the medical community has a duty, to provide patients with adequate information and to be aware of the negative health impact of prevalent oversimplifications—whatever their origins.

It is now an ethical dictum that patients should be informed by physicians about their diagnosis, prognosis and treatment options. The move to informed consent and patient education embraces the commitment of the medical community to patient autonomy in healthcare decisions. In this paper, I ask: 'How informed are the 'informers' in clinical practice?' Physicians have a duty to be 'well-informed': patient well-being depends not just in conveying adequate information to patients it also depends on physicians keeping up-to-date about (1) popular misunderstandings of illnesses and treatments; and (2) the importance of patient psychology in affecting prognosis.

Taking the case of depression as an entry-point, I contend, there are ethical problems and health risks if physicians fail to disclose relevant information to patients. The statistics with regard to the prevalence of depression make it a pertinent condition to examine: depression is estimated to be the most prevalent mental disorder worldwide (it is gauged that 1 in 20 people will suffer from depression in their lifetime), and WHO figures predict that depression will become the second most common cause of disability in the world by 2020. Patient understanding of the causes of depression include the popular notion that symptoms are simply (ie,to say, wholly) caused by a 'biochemical imbalance' in the brain (such as a lack of serotonin), and that antidepressant medications restore this balance. This 'pop-conception' of depression and antidepressants is unlikely to reflect accurately on most physicians' or psychiatrists' explicit understanding of depression;^{2–7} Dr Tony O'Neill (senior lecturer in psychiatry at Queen's University) memorably told me that the 'low serotonin' theory of depression was like trying to explain Shakespeare with the letter 'p'. But what is at stake is the scientific consensus: there is agreement in the scientific community that the causes of depression are complex and not completely understood and scientists have adopted a broad 'biopsychosocial' model of mental disorders: on this view biological, psychological and social factors are all deemed to be relevant in the aetiology and treatment of depression.

Patients who believe that depression can be caused by, among other things, 'biochemical imbalances' embrace a simplification of depression. The notion that 'biochemical processes' are relevant to depression is representative of the biopsychosocial model, as this entails an understanding of the contribution of multiple causal factors (at different levels of analysis) in precipitating depression. However, if patients believe that depression is wholly caused by 'chemical imbalances' or a 'chemical imbalance' their views are not in keeping with up-to-date science; correlatively, the belief that antidepressants work by restoring imbalances (such as 'low serotonin') is much contested: in fact, there is a great deal of controversy in the scientific community over how different antidepressants work.2 In short, patients who endorse the theory that a biochemical imbalance wholly explains their depression do not thereby endorse a theory that is sanctioned by the scientific community. In what follows I will argue that the popular conception of depression as wholly caused by biochemical imbalances is such a crude oversimplification of what is known about the

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causes of depression that it can be regarded as a deception: it renders other causal factors redundant and it promotes the false claim that there is consensus in the scientific community about all the relevant biochemical causes of depression. I argue that there are two significant reasons why physicians should be motivated to better inform patients about the causes of depression. First, if patients have inadequate understanding about what causes depression and about how treatments are known to work, this threatens their autonomy in decisions about treatment options. Physicians have a duty to be open and honest in therapeutic encounters and to ensure the adequate disclosure of relevant information and to ensure patient understanding of that information. In order to achieve these goals, physicians need to keep updated about common 'folk' misunderstandings about depression; they also need to ensure that they are not complicit in promoting misleading beliefs about what is known about the causes and the treatment of this disorder. Second, there is now a body of research which shows that patients who perceive depression to be wholly caused by a 'chemical imbalance' also appear to have a negative view of their prognosis: they are less likely to seek other forms of treatment, or to make lifestyle changes, that may prevent future relapses. 13-15 The popular notion that a known 'chemical imbalance' fully explains depression may even inhibit patients from taking responsibility for their own well-being. It has also been argued that even when ill we should not relinquish duties to ourselves: there may be a moral imperative to look after one's health and some patient-physician encounters may not foster this obligation. 16

I begin by considering some possible origins for the explanatory potency of the 'chemical imbalance' theory: in so doing, I highlight some potential problems with current patient guidelines on depression in the USA and UK issued by the American Psychiatric Association ('APA') and the National Health Service ('NHS') respectively. I then consider the health consequences of patient endorsement of the 'biochemical imbalance' theory by drawing on recent studies of how this theory affects patient psychology and actions. Next, I discuss the importance of adequate guards to ensure patients are given relevant information in physician encounters. I list different circumstances in which physicians may fail to provide such disclosure and examine the range of ethical consequences that result. Given the prevalence and rise in depression, I conclude that it is incumbent on the medical community—to provide patients with truthful information—and to be mindful of the negative psychological impact of misinformation. 17 18

THE 'CHEMICAL IMBALANCE' THEORY

At the outset we might ask: How prevalent is the view that depression is exclusively caused by a 'chemical imbalance'? Studies in the UK and USA suggest that this theory of depression is widespread and endorsed by laypersons: in fact, there is evidence to suggest that this theory is endorsed more often by patients suffering from depression than non-depressed individuals. 19 20 This finding is especially troubling given that there is a lack of consensus in the scientific community about the biochemical processes that are implicated in depression, and there is no clear understanding of the role of particular neurotransmitters (such as serotonin). In addition, there is not yet consensus over how antidepressants work, nor whether they are significantly more effective than placebos even for cases of moderate depression.^{2–7} 8–12 ²¹ The adherence of these views among laypersons is likely to stem from multiple factors. It cannot be ignored that direct-to-consumer advertising in the USA (via television, newspapers, internet and other media) appears to be

responsible for considerable influence on the lay public.²² ²³ However, in the UK (where such advertising is forbidden)—as in the USA—the rise in prescriptions for antidepressants may in itself have influenced patients' misunderstanding: the nomenclature 'antidepressant' may also be responsible for the natural tendency to assume that depression is targeted via a 'magic bullet' drug in the same way that antibiotics are known to target bacterial infections. The simplicity of the explanation should not be overlooked either: it is a seductively neat theory for the lay public to grasp and one that is easily remembered. The theory also seems to be destigmatising for the individual with depression. In a disorder such as depression, whereupon the individual's self-esteem is very often significantly diminished, the notion that depression is really just a 'biological disease' like any other is a comforting claim: the patient can be reassured that they are not to blame for their 'biochemical imbalance'.

The scientific community currently adheres to a multilevel model of the causes and treatment of depression (the 'biopsychosocial' model of mental disorders): as such, any description of depression that omits psychological or social factors as triggers for depression and its treatment does not provide patients with a comprehensive account of their illness. Thus, talk of 'chemical imbalances' should always be supplemented with descriptions which include the significance of other causal and treatment factors (including, eg, other forms of psychological therapy, and social and environmental modifications to the depressed individual's life). In those cases where the medical community promotes simplistic 'magic-bullet' explanations for depression as caused by a 'biochemical imbalance' it is promoting a misleading portrayal of current scientific knowledge and debate.

To what extent, then, might it be gauged that physicians present such misleading information on the causes of depression? While there are evidently serious methodological and ethical impediments to assessing this very issue, current guidelines for patients, issued by the APA and the NHS may provide a window into consultations. In the USA, the APA's 'Healthy Minds, Healthy Lives' resource lists 'biochemistry' as the first on its list of causes of depression²⁴ and in the section on 'Medication' antidepressants are listed first: the website claims, 'Antidepressants may be prescribed to correct imbalances in the levels of chemicals in the brain.'24 The APA website also advises that 'Several factors can play a role in the onset of depression' which is in line with the prevailing scientific, biopsychosocial model. Insofar as the website provides this information it is scientifically representative. However, the website also declares, 'Abnormalities in two chemicals in the brain, serotonin and norepinephrine, might contribute to symptoms of depression'.24 While there is nothing false about this information per se, it does not provide patients with a representative account of the current scientific research—that is to say, there continues to be significant debate on fundamental issues such as the role of specific neurotransmitters in depression, and with respect to how antidepressants work.^{2–7} 8–12

In the UK the patient-centred 'Health A-Z' website of the NHS includes a section on 'How antidepressants work' which claims, 'It is thought that antidepressants work by changing the levels of a group of chemicals in the brain called neurotransmitters' and 'increasing the levels of neurotransmitters is a gradual process.'²⁵ Again, these claims are not representative of the field of research on depression and may reinforce in the public simplistic (and controversial) conceptions of their illness.

Given that the aetiology of depression is still not well understood, especially at the biochemical level of explanation, more needs to be done to counter the tendency to provide popular 'bio-babble'²⁶ explanations among the public. The underlying processes involved in causing depression are extremely complex, and in fact, not well understood but conveying this to patients is highly important.

HEALTH IMPLICATIONS

Before I examine the ethical concerns with regard to informed consent in the case of depression, it is important to discuss the serious health implications of pop conceptions of depression on patients suffering from depression. A mounting body of research shows that patients who embrace the view that depression is wholly caused by a 'biochemical imbalance' theory tend to expect a worse prognosis: 13-15 they also embrace the belief that non-pharmacological interventions and lifestyle changes are 'ineffective'. 19-21 This research also reveals that these patients are less likely to blame themselves for their depression (than patients who embrace a more medically representative biopsychosocial theory of depression). 27 28 But such patients are also significantly less likely to take measures to adjust their cognitive and behavioural patterns, to seek to remedy any lifestyle or precipitating factors for their depression, more likely to believe that their depression is beyond their control, and more likely to perceive it as less curable. 13 27 The hegemony of the 'biochemical imbalance' explanation for depression has profound impact on patients' knowledge of their illness, and it appears to promote a damaging (false), essentialist understanding of patients as 'inherent depressives'. 14 15 20 21 27 28 The scepticism with regard to other forms of treatment and other factors that may influence or cause depression, may incur serious long-term health impact on patients including the ability to avoid potential relapses.

There is also evidence that, far from benignly eradicating mental health stigmatisation by presenting it as a 'brain disease' caused by a 'chemical imbalance', this theory appears to promote stigmatisation among the non-depressed public. ¹⁹ ²⁰ In short, what might be deemed from the armchair to be a trivial—even benevolent—deception, this misconception may have significant impact on patient stigmatisation and future wellbeing. Finally, it might also be argued that patients have a moral obligation to preserve their health. ¹⁶ The seductions of the 'biochemical imbalance' theory seem to foster ethical irresponsibility with regard to patients' own health, placing a passive dependence on the medical community to respond to patient symptoms without expectation of patient responsibility for their health management.

ETHICAL IMPLICATIONS

Informed consent is an ethical imperative: physicians have duties to provide disclosure of relevant information and to ensure patient understanding. Providing truthful disclosure in clinical practice does not entail the exhaustive process of providing a full or complete list of the current state of scientific knowledge; rather, as Beauchamp and Childress contend, it means that patients need to be *adequately* informed:²⁹ patients' comprehension of their illness should be representative of current medical knowledge and relevant to decision-making about medical care.

Given that the scientific community has not reached consensus on how antidepressants work any information that may mislead the public and reinforce simplistic conceptions is a cause for concern:³⁻⁶ ¹⁹⁻²² ³⁰ as Beauchamp and Childress argue, 'even a single false belief can invalidate a patient's or subject's consent' (ref. 29, p.130–31). In order to ensure that adequate disclosure of information is provided to patients it is

essential that the medical community is careful not to promote misrepresentative beliefs. The case can also be made that patients should be *actively* informed not just about the causes of depression but what is known about treatments. The neglect to inform patients that: (1) the causes of depression are not fully understood; (2) the causes are likely to be complex; (3) that a range of psychological and social triggers are likely to be highly significant; and (4) that there is currently lack of scientific consensus on how antidepressants work, as well as the extent of their effectiveness—can be deemed as a failure to inform patients about relevant facts with regards to depression. Indeed, examples of social or psychological factors can be given to patients in order to better educate them about the many causes of depression. Communicating this information is all the more important given the prevalence of pop-conceptions of the causes and treatment of depression. It might be deemed to be a tall order to demand of physicians that they redress popular misconceptions about health and illness, but the medical community cannot afford to ignore the zeitgeist: these are widespread misconceptions and they are ones that undermine patient autonomy and patient health. We can remind ourselves that the American Medical Association guidelines stipulate that physicians 'should respectfully disclose all relevant medical information to patients.'31 If we value informed consent—and the General Medical Council³² and the American Medical Association³³ declare that they do—then more needs to be done in clinical practice to ensure that patients understand their diagnosis in a manner that provides a truthful, understandable and representative account of medical knowledge. Providing inadequate information also poses the serious risk of damaging patient trust, and the risk may be especially precarious in cases where lay understanding lags behind the understanding of the scientific community.

There may be a variety of reasons and motivations why physicians fail to provide adequate disclosure of information in the case of depression. Each reason carries different ethical evaluations and deserves separate consideration.

Some physicians may believe that the biochemical imbalance theory deserves to be promoted at the expense of disclosing the broader biopsychosocial model of depression because they predict that this will be destigmatising for the patient. On this line of reasoning, placing explanatory emphasis on a 'biochemical imbalance' (or even naming the imbalance as 'low serotonin') may also encourage some patients to take ('restorative') antidepressant medication (especially if such patients are reluctant to do so). These actions may be motivated by beneficence: some physicians might wrongly contend that there are cases where paternalism is justified: that patient well-being may ultimately be enhanced if patients believe that their depression is simply caused by a 'biochemical imbalance'. While the prioritising of therapeutic benefit might appear morally commendable, there is no justification for failure to provide full disclosure of the relevant facts in this case. There is no tension between beneficence and transparency in the case of depression. In these circumstances, physicians have also be deemed to have failed professionally since the empirical literature which (as we have seen) shows that those patients who adhere to the theory that depression is wholly explained by a 'biochemical imbalance' may be less inclined to blame themselves for their depression but they are more inclined to be 'essentialist' about the causes of depression (and to consider themselves, as 'essentially depressive'), and to be sceptical about their prognosis and other treatment methods. The blame for this may be institutional: medical curricula still seriously neglect the significance of patients'

psychological understanding of illnesses and the ways in which this can predict patient behaviour and health outcome.³⁴ Until physicians have a better understanding of how to conceive of 'mind-body' relations (ie, to say, interlevel explanations in science) it is likely that a medically myopic, mind-body dualism will persist in clinical practice. Thus, any apparent paternalistic motivation of 'therapeutic privilege' fails by its own lights. In short, adequate disclosure in the case of depression *does not* jeopardise patient well-being: in fact, as we have seen, empirical evidence attests that it does just the opposite.

In other cases, physicians may fail to provide full disclosure to patients because they believe that this *is not important*—they may fail to perceive the ethical implications of not providing adequate information and ensuring that such information is understood. This is something that may be rectified by improving medical ethics education. It should also be pointed out that, once again, such physicians will either have disregarded or missed the findings on the health impact of patients' understanding of depression, and (yet again) this displays some neglect in terms of the importance of patient psychology.

Some physicians may fail to provide adequate disclosure because they are medically misinformed about the causes of depression: they may believe that depression is caused by particular neurotransmitter deficiencies. In these instances it may be that physicians are not remiss with regard to the importance of patient autonomy but they are remiss in their duty to keep medically informed. Given that depression is the most prevalent mental disorder in the world it is unacceptable for physicians to neglect to keep up-to-date with findings that have a huge impact on patient understanding and well-being.

On other occasions physicians may fail to provide adequate disclosure to patients out of expediency. If we can assume, in such instances, that physicians know that they have a duty to ensure informed consent but routinely decide not to take the time to ensure an informed discussion with patients about their illness, then they unacceptably fail to take seriously their moral obligations of respecting patient disclosure and autonomous decision making.

Finally, it might be argued that on some occasions patients may be adamant that their depression is wholly caused by a 'biochemical imbalance' (they may even cite 'low serotonin', for example). Such patients may be insistent that they receive a prescription from their physician for antidepressants. How should physicians respond in these cases, assuming that the patient does not lack capacity to understand? In these cases the physician still has a duty to persist in providing adequate disclosure about depression and what is known about antidepressants: as Beauchamp and Childress assert, 'If ignorance prevents an informed choice, it may be permissible and even obligatory to promote autonomy by attempting to impose unwelcome information' (ref. 29, p.131). In all cases physicians must strive to fulfil informational obligations.

BETTER INFORMED 'INFORMERS'

In conclusion, physicians have a duty to provide adequate information to patients about depression including treatment options. Disclosure of information can be deemed adequate when physicians have provided relevant, representative information about the diagnosis, the range of treatments and how these treatments are thought to work. In the case of depression, physicians need to be mindful that popular simplifications of the causes of depression and its treatment threaten patient autonomy and they may hamper patient prognosis in the long term. Physicians have a duty to be 'well-informed': patients have a right to adequate

information about their illness in order that they might make independent well-informed choices about treatment. But the duty to be 'well-informed' also depends on physicians keeping to-to-date about: (1) popular simplifications of illnesses and their treatments; and (2) the importance of patient psychology in affecting prognosis. First, physicians cannot ignore the fact of the matter that there is a popular belief among patients in the UK and USA that depression is wholly explicable by 'brain biochemistry' (nor, indeed, that some medical and pharmaceutical communiqués have promoted this misconception) and that the scientific community has reached consensus on these causes, as well as on the treatment of depression (including how antidepressants work, and the extent of their effectiveness). Second, more needs to be done to overturn the dichotomy between 'nice to know' (psychological facts) and 'need to know' (biomedical facts) in medical education and continuing medical education.³⁴ The diagnosis of an illness does not take place in a psychological vacuum: physicians need to be better informed about the variety of ways in which physician communication, diagnoses, explanations for treatment and other cues can influence patient health and health-promoting behaviour.³⁵ The incidence (and indeed, the rise) of depression should provide an important reminder and incentive to physicians that they cannot afford to disregard their ethical duties. Physicians have an ethical duty to be wellinformed, and medical education and continuing medical education must strive to achieve this.

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