THE ETHICS AND THERAPEUTICS OF DISCLOSURE IN PSYCHIATRY

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Most medical codes of ethics have historically focused on not doing harm, not taking life, not engaging in sexual acts with patients, and not revealing secrets. Little attention has been given in the past to the importance of doctors giving full and accurate information to their patients.¹

In the Hippocratic Oath, doctors are cautioned to practice with purity and holiness, which may imply veracity. At the same time they are expected to act in ways that are beneficial, with little consideration given to situations where perhaps beneficence and truth may be in conflict. The Declaration of Geneva of 1947, a modern version of the Hippocratic Oath, ignored the problem of truth all together and focused on the health of the patient which it put forward as the doctor’s primary consideration.²

In the later years of the twentieth century, there has, however, been a bioethical shift from medical paternalism in which doctors attempt to protect patients from the truth, to respect for patient autonomy and their participation in treatment-related, decision-making.³ In 1981, the World Medical Association, in the Declaration of Lisbon, explicitly conveyed that patients had the right to accept or refuse treatment after receiving adequate information.⁴ This may be largely attributed to the fact that most of the research on truth-telling in relation to diagnoses has been with regard to cancer literature.⁵ In 1961, 90% of doctors researched by Oken⁶ did not reveal diagnosis. By the time Novack et al⁷ conducted their study in 1979, the trend had reversed so that 98% reported adhering to a policy of disclosure.

THE RIGHT TO BE TOLD AS THE TRIUMPH OF AUTONOMY

Decisions with regard to truth-telling have been influenced by two moral frameworks for thinking about the ethics of disclosure and non-disclosure. One is the consequentialist model, according to which an action is considered ethically correct or not depending upon the consequences of the proposed action. If the consequence is desirable (broadly understood to promote happiness or well-being), then an action which has these consequences is determined to be ethically right.⁸ ⁹ The second, deontological approach, based on a Kantian perspective, ¹⁰ takes the patient’s autonomy and his or her rights seriously with regard to whether he or she requires disclosure and seeks to involve the patient in his or her own care.

Deciding between disclosure and non-disclosure may, however, be justified from both ethical points of view. The rights-based belief that the value of truth-telling is to be viewed fundamentally as a prerequisite for the choice of treatment, is reinforced in the ethical guidelines of the World Psychiatric Association’s Declaration of Hawaii (1977/1983)¹¹ which stated that psychiatrists needed to inform patients of the nature of their respective conditions and of the therapeutic procedures available. According to this document, the patient is to be told the truth so as to be given the opportunity to choose between appropriate and available methods of therapy.¹² The principle involved is that of respect for the patient’s capacity to make informed choices with regard to treatment.
In many instances, however, as may be the situation in certain psychiatric cases, a patient’s diminished cognitive capacity and judgement may render him or her incapable of participating effectively in medical decision-making. This acknowledgement has led to the argument, therefore, that truth-telling is to be forfeited as a right in cases of reduced mental ability. Non-disclosure has also been considered to be ethically defensible, from this rights-based, Kantian perspective, in instances where a patient explicitly requests not to be told. 13, 14, 15

On the basis of a consequentialist approach, a doctor may also decide that a patient is best served by being made aware of his or her diagnosis. However, there may be instances where being truthful is likely to cause significant distress, anguish, depression, pain and a loss of hope so that the patient’s psychological health is seriously compromised. In such cases, deception may be viewed as the more helpful and benevolent choice. 13

However, it must be recognised that consequentialism requires not only a short-term consideration of what might or might not be beneficial, but also a reflection of the implications of disclosure or non-disclosure in the future. In order for deception to be morally justifiable, it has been contended that it must be an action of last resort; it must be justifiable to the public; and the practitioner must be sufficiently cognisant of potential damage done to patient trust and clinician trustworthiness in the long-term. 16

VALIDATION, STEREOTYPES AND STIGMA

As psychiatrists experience on a daily basis however: the motivation to behave in a respectful way with regard to the autonomy and rights of the patient; the imperative of guaranteeing a long-term sense of trustworthiness; the need to maintain a therapeutic alliance with a patient; as well as the requirement that the patient be assisted therapeutically, often in contexts of personal, interpersonal and familial chaos, places them frequently in difficult situations with regard to disclosure.

Their area of medical concern relates to the difficulties people bring with regard to their understandings of reality, the world and themselves in the world. Furthermore, in certain instances, when people come to psychiatrists for help, they seek validation for their point of view. Presenting them too soon with a diagnosis which calls into question their view of reality may, in some instances, result in their leaving treatment prematurely. Flexibility and sensitivity is required with regard to how to disclose and when to disclose.

This is true in all areas of medicine; however a person with a heart difficulty can separate their sense of themselves and their view of themselves in the world from their problematic organ. A cancer can be viewed as an illness that has happened to a person. However the nature of a person’s consciousness corresponds with their psychiatric disorder.

Psychiatric patients also often have to grapple with negative stereotypes associated with their respective disorders. In South Africa, stigma in response to mental illnesses such as schizophrenia remain prevalent and influential. A particularly cautious approach is thus necessary when presenting a diagnosis that is associated with social misunderstanding and prejudice. A study carried out on the impact of a diagnosis of mental illness on stereotypes, prejudices and discrimination with a German sample, found that while a label of major depression had no effect on public attitudes, a label of schizophrenia came with attendant negative stereotypes and was associated with more negative than positive social responses. 18

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It has been pointed out that the advantage of giving patients a psychiatric or psychological diagnosis is that it may help people to understand themselves, their temperaments and their personalities. 19 It may guide people towards thinking about their strengths and their weaknesses, about how they react in certain situations, what they should avoid, what they should do more of and how they can live in a healthy and pleasurable way with themselves and others. The disadvantage of a diagnosis is that it may be associated with stigma, it may be used to blame the patient for his or her misery or it may become an excuse for the patient or family to avoid taking responsibility for their actions. 19

THE RELEVANCE OF THE RIGHT STAGE OR MOMENT

With regard to disclosure, deliberation needs to be taken concerning the stage of the disorder that the patient is suffering from. If a patient suffering from a dementia is to be told the truth, this needs to happen while he or she still has the capacity to retain information and to take necessary steps with regard to future care and financial planning. 16 20 A person suffering from a psychotic disorder is usually in no position, while in the throes of psychosis, to appreciate and utilise truthful information regarding his or her
condition. Constructive disclosure is, in such cases, best attempted once the psychosis has resolved. On the other hand, conveying to a depressed patient that their hopeless view of the world and themselves may be attributable to their condition rather than to an inherently bleak reality, may, in many instances, encourage compliance with treatment. Truth-telling may be similarly helpful where distressful sensory disturbances, such as may be related to seizure activity, are ego-dystonic rather than ego-systonic.

**DIAGNOSTIC DISCLOSURE AS FEEDBACK**

It may be useful in the context of psychiatry to view the disclosure of diagnosis as a form of therapeutic feedback. Feedback is used in psychotherapeutic settings to convey information about past behaviour while influencing the likelihood and nature of its re-occurrence. It can be descriptive, as when a psychiatrist comments: “it seems that despite the fact that there are a number of improvements to your life in the pipeline, you still feel discouraged and hopeless.” It can be evaluative, as in the following: “you appear to have difficulty concentrating on the tasks presented to you and you struggle to complete them.” It can be interpretive as in: “you appear to be generalising your bad experiences with Jane to other women”. Feedback may also be self-disclosing as when a therapeutic practitioner comments: “when you speak so fast I have difficulty understanding what you are trying to tell me”.

The timing, form and manner of feedback are all important. Feedback, whether in the form of diagnosis or not, requires judgement as to when it is to be delivered and in what situation. Emotional processes surrounding feedback exchange are critical with regard to its reception, acceptance and incorporation. The emotional state of the patient needs to be taken into account at all times so that potentially troubling information is only fed to a patient when he or she is in a position to deal with it with equanimity.

All feedback is more likely to be constructively digested within the context of a strong therapeutic alliance. Feedback in general is more likely to be accepted if it has an influential source, combining expertise, credibility and personal relevance. Negative feedback of any kind, such as that which a serious psychiatric diagnosis may represent, is best presented alongside some sort of affirming commentary on the patient. Resistance to negative data is less likely if it is preceded by positive information. Diagnostic feedback should therefore be presented in the context of a discussion of the patient’s strengths, resilience factors and weaknesses, with mention of their strengths preceding the negative aspects of their condition. All of this is especially relevant if the patient in question has a Narcissistic Personality Structure as such individuals are more likely to question negative feedback and to view the doctor who presents it is as less than competent.
THE CONSTRUCTION OF DIAGNOSTIC FEEDBACK

Psychiatrists, furthermore, need to construct diagnostic feedback by tailoring it to the cognitive abilities of the patient involved; sensitively identifying symptoms; explaining the underlying biological and perhaps psychological processes involved; providing education which explains the role of medication and whatever other therapies are indicated as useful; and maximising the positive possibilities.

DISCLOSING TO FAMILIES

It has been suggested (at least with regard to Alzheimer’s patients) that the ideal situation for disclosure is in a joint meeting with patient and family together, in which facts about the disease are followed by a discussion of resources and plans for future care. In a South African psychiatric context, in which stigma with regard to mental illness is rife, it is suggested that, where possible, patients be consulted with regard to whom they would like diagnostic information shared with. In addition to stigma, many patients come from family contexts dominated by a lack of resources, inadequate housing, overburdened family members and a plethora of interpersonal antagonisms and the frequent trauma that often characterise such situations.

THE UNCERTAINTY PRINCIPLE

Finally, an important tenet with regard to disclosure also needs to be born in mind: this is the uncertainty principle. Absolute truth and hence absolute certainty is rarely achieved in medicine. Psychiatry is no exception. Much change is taking place, at present, with regard to understandings surrounding various disorders of mental health.

Precision medicine is revealing that biotypes do not correspond to the traditional diagnostic entities of Schizophrenia, Bipolar and Schizoaffective Disorders. Current diagnostic categories, not only relating to the psychoses, but also relating to Autism Spectrum Disorders, Attention-Deficit Hyperactivity Disorder, Depression and Anxiety are in the process of being revealed to be imprecise and more biologically heterogeneous than they had hitherto been understood to be.

COLLABORATION

With this in mind, an open, honest presentation of information as it is perceived and known, is to be advocated.

A COLLABORATIVE RELATIONSHIP SHOULD BE CREATED IN WHICH FEEDBACK REGARDING DIAGNOSIS IS VIEWED AS UNBIASED, IS CLEARLY FORMULATED, TAILORED TO THE PATIENT’S SUBJECTIVE EXPERIENCES OF HIS OR HER DIFFICULTIES AND DELIVERED IN A CLIMATE OF FREE CHOICE SO THAT IT MAY BE RECEIVED, CONSIDERED AND PROCESSED.

It may be that several attempts will need to be made with regard to conveying diagnostic feedback. Receiving less than optimistic information may represent the demise of a sense of well-being and hope and patients may pass through various stages of denial, anger, bargaining, grief and acceptance - not necessarily in this order. Assistance with additional support and coping strategies in relation to the potential personal and social consequences of the diagnosis should be provided by referring the patient for individual psychotherapy and family therapy, if this is appropriate. Good support groups, where they exist, should always be utilised to help patients gather more information, share stories of similar experiences with others and develop a sense of emotionally-strengthening connection and identification with people grappling with comparable predicaments.

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