Telling the truth to patients and relatives

Sir,
The topic of ‘Doctor’s dilemma in truth telling’ in the column “Periscope” of Indian Journal of Psychiatry,[1] was a timely reminder for serious debate on this important, but neglected component of clinical practice. I like to touch upon a few other aspects of this dilemma.

Opinion available in the literature ranges from a mandatory feedback of important clinical information to patient/family to withholding certain potentially traumatic information from the patient. The over-riding demand for absolute truth telling is in relation to informed consent.

‘Truth telling’ is a dilemma because of two reasons. First is that doctors are not formally trained in this task as a part of their routine undergraduate or postgraduate learning. And there are no well laid-out, generally agreed upon guidelines as to how to go about this task of ‘truth telling’.

Second reason is related to a certain degree of inherent uncertainty of our medical knowledge, especially in psychiatry. All medical knowledge especially psychosocial is statistical in nature with no certainties, but only differing degrees of probabilities. In such a scenario:

   a) The fact of certain degree of uncertainty itself becomes the truth.
   b) A serious question is: will this probability knowledge interfere with the patient’s and family’s hope, motivation, and determination to endeavour toward a positive outcome?
   c) Another question is: is it not our clinical duty to foster hope and confidence in patient and family?
   d) If I myself were a patient, how would I want to reposition my hope, confidence, and determination vis-à-vis the uncertain outcome?

In this context, it is prudent to borrow three concepts from ancient Indian wisdom about ‘telling the truth’ that offer operational guidelines. These guidelines are scattered across the scriptures because ‘truthfulness’ is the highest virtue of human behavior. The first concept is ‘righteousness’. The second is ‘ability of an individual to understand and benefit from a given set of knowledge (truth)’. The third deals with ‘how to tell the truth?’ These three concepts can be extrapolated to the doctor–patient relationship.

RIGHTeousNESS

General principles of righteousness are:

   a) In times of conflicts (dilemmas), choose that course of action which is righteous.
   b) In specific terms, righteousness consists of Universal compassion (Universal oneness), ensuring that anger, greed, and lust do not influence one’s behavior, and behaving toward others as toward one’s own self.[2]
   c) In more general terms, righteousness is a set of attitude and behavior that is conducive to most good in the long run to all life.
   d) What is righteous is dependent on time, place, person/s concerned, and circumstances. Thus, what is righteous in one situation need not be in another.
   e) These principles offer a framework within which decisions for further action can be taken based on other factors/variables instead of obsessional adherence to a stereotyped routine.

ABILITY OF THE INDIVIDUAL TO UNDERSTAND AND BENEFIT FROM A GIVEN SET OF INFORMATION OR ‘KNOWLEDGE’

We, mental health professionals are all aware that the ability of people to understand the implications of information follows Guassian distribution like all natural phenomena. In the same way, their ability to benefit by such understanding too follows similar distribution. In such a situation how valid are the legal and ethical injunctions?

We also tend to overlook the fact that truth (facts of ‘reality’) is often very difficult to understand and very cruel in its effect. For example, imagine a patient recovering from ischemic heart disease hearing about his son’s death in an accident, or about his comorbid cancer. Not everyone is capable of understanding a set of facts, assimilating their implications, and benefiting from them. People differ widely in this ability.

Ancient Indian wisdom stipulates that there is such a thing as an individual’s ability or lack of it to understand and benefit from a given knowledge. Sometimes, the ‘knowledge’ can be misunderstood and misused to a dangerous extent. This negative potential is best illustrated in a Sufi story.[3]

HOW TO IMPART INFORMATION TO THE PATIENT/FAMILY

This issue involves such considerations as: what to tell, how much to tell, how to tell, and whom to tell (e.g., to a chosen family member instead of the patient).

Some of these aspects are explained as components of ideal communication by a lady sage.[4] Among other requirements, the listener must be eager to learn, speech must be capable
of being understood by the listener, and the message must be useful to the listener.

It may even become necessary at times for the patient or family to be trained or prepared in a step-ladder fashion to become able to assimilate the information intended to be imparted.

During my undergraduate training (1950s), we were taught: “…best surgeon is he who knows when not to operate.....best physician is he who knows his limitations...” I believe that this wisdom still holds true. In a similar fashion, I would say “best psychiatrist is he who knows what to say, what not to say, when to say, how to say, and whom to say.” The foundations for the doctor to learn this art must be laid in undergraduate and postgraduate training.

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Sir,

Mr. V a 26-year-old male was diagnosed as a case of resistant schizophrenia with obsessive compulsive disorder (OCD) and he showed significant improvement on clozapine 400 mgs after multiple trials of different antipsychotics. He started going to his job. His OCD was already well managed on flouxetine. However, Mr. V suffered from troublesome excessive salivation and sedation. The patient’s parents were concerned with these side effects and requested to either stop or decrease the dose of medication. On the other hand, the patient was quite satisfied with his level of improvement. He was reluctant to stop the medication and face the risk of relapse. The clozapine was tapered to 300 mg/day and all the doses were shifted in the evening to manage side effects. Now there was no complaint of excessive salivation in day time. But the parents were still concerned about excessive salivation in the night and increased depth and duration of sleep (approximately 11-12 h). Amitryptaline and clonidine did not help much to reduce his salivation. He was advised to use towel under the pillow for excessive salivation in the night. According to the parents side effects are more pronounced than the level of improvement. However, the patient and resident in-charge noticed definite improvement in all the areas. The parents were educated again regarding the nature of his illness, level of improvement, role of clozapine and benign nature of side effects. However, even after repeated counselling, both mother and father kept on overemphasizing the side effects and insisting to either change or stop the clozapine. The parents revealed that these adverse effects may create problem if noticed by patient’s wife after marriage, which was being planned in near future. It was planned to do detailed longitudinal evaluation of Mr. V in the presence his parents. On the basis of evaluation, the parents were made realized about the severity of the illness and impairment in the patient before the current treatment and then level of improvement in different areas (occupation, social interaction and self care) on standard scales after the use of clozapine. It was also explained that occasional expression of referential thinking by the patient is at the ideas level, not at the delusional level. The parents were told that patient’s compliance is also a sign of improvement. The parents were undermining the benefits probably because the embarrassing side effects like excessive salivation which could be noticed by their prospective daughter-in-law. They were asked to anticipate the adverse consequences in patient’s marital life including divorce if Mr. V relapsed on stopping clozapine.

At last this case could be managed successfully after repeated counselling and education of both the parents especially regarding their concern related to social issues like the patient’s marriage.

Sir, in Indian context where the parent’s decision in treatment is equally important, it is very important to convince and educate the key family members by different ways regarding the need of regular medications and about the side effects for successful management of schizophrenia.

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