

Thoughts on Giving Full and Accurate Information

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Abstract

The ethical view that patients are entitled to honesty with regard to their diagnosis and treatment is discussed in this paper. Caution is advised with regard to how the truth is to be conveyed. Medical Practitioners need to be sensitive to context; the patient's emotional needs; and the possible consequences of their grief and defence mechanisms. The effect of stereotypes in relation to certain psychiatric illnesses and the importance of facilitating any possibility of a placebo effect through allowing a space for hope are also considered.

Keywords: Ethics; Honesty; Beneficence; Stereotypes; Placebo

Introduction

'Everyone has a right to be given full and accurate information about the nature of one's illnesses, diagnostic procedures, the proposed treatment and risks associated therewith and the costs involved.' Health Professions Council of South Africa's National Patients' Rights Charter, May 2008, Pretoria.

Historically most medical codes of ethics were focused on not doing harm, not taking life, not engaging in sexual acts with patients, and not revealing secrets. They conveyed little, however, about the importance of doctors giving 'full and accurate information' to their patients [1].

Beneficence and Non-maleficence

Today, while beneficence and non-maleficence remain basic ethical principles in the medical profession, the importance of truth-telling has also been introduced into most codes. The requirement of honesty is linked with patients' legal right to be able to give informed and free consent or to refuse treatment. Hence, doctors kept the truth away from patients in the past for the purposes of protecting them emotionally. Now patient protection is viewed as requiring that people be given truthful information in order for them to participate in clinical decision-making.

How to be Truthful

However, it is essential to remember that there are various ways of being truthful. Patients may be in different emotional states; and interpersonal environments differ. Metaphorically-speaking, doctors need to ensure that important information is fed to their patients in a manner that the individual concerned is able to digest.

Consider the following examples of "truth-telling":

A young man has a certain disorder and his physician regularly reminds him that he is at risk of developing a more serious illness. This reminder does not affect his self-care in any way. He is well aware of this fact and experiences these constant, out of context, reminders as something of an assault.

Another person, dying of pancreatic cancer and aware that this is so, is energised by his daughter's care at home, only to collapse and become weaker with each visit to his physician who expresses his despair openly to him each time.

It is thus evident that doctors' duty to be truthful to their patients and the ethical requirement of non-maleficence may at times be in conflict. It is akin to the situation of a person sitting in a crowded cinema and noticing a fire. The fire needs to be reported, but to simply shout out a warning, may lead to disaster.

Just as the person in the cinema needs to consider the process whereby other people can be led to safety and informed of the fire, delivering 'full and accurate information' should always be done with a sense of the possible consequences and a sensitivity to the patient's emotional needs. A doctor who feels free to unload the truth whenever he or she feels the need, may cause psychologically vulnerable people to struggle with coping strategies and perhaps even hasten their deterioration.

Doctors have to be aware of what they say, when they say it and how they say it. Amer & Al-Zakri (2013), in a qualitative, phenomenological study exploring the nature and meaning of the experiences of Omani physicians with regard to the ethics of veracity in diagnosing cancer, make the point that communication skills are vital when giving bad news. Good communication skills enhance doctor-patient relationships and satisfaction with care.

Was Elizabeth Kübler-Ross Right?

Receiving a less than optimistic diagnosis often represents the demise of a sense of well-being and hope. Elizabeth Kübler-Ross [2] identified various stages that people pass through in response to loss, namely: denial, anger, bargaining, grief and acceptance. According to her five-stage model, it was not necessarily the case that people would inevitably pass through these stages in the above order. Nor were these, by any means, a complete list of all the possible emotions that an individual might experience in relation to the prospect of loss. Furthermore, it was noted that people's psychological profiles differ so that, again, not everyone presented with a life-threatening or life-altering loss or disorder might feel all five of the responses named above.

These qualifications notwithstanding, later investigations, such as that of Bonanno (2004), have challenged her work. Bonanno summarized peer-reviewed research conducted on thousands of subjects and concluded that a healthy, natural resilience was the main component of most grief and trauma reactions.

Use of Defences

Not everyone, however, is emotionally resilient. The type of defence mechanisms a person habitually uses or not, will affect how he or she deals with the truth. Learning that one has lost one's good health, perhaps permanently, may thrust a person into denial and inspire them to seek out alternative forms of healing which may potentially be destructive and associated with non-compliance to their medical regime.

Anyone who has ever worked in a State hospital in this country, as I have, will have been exposed to patients who abandon their treatment to visit a traditional healer, a practice which might have innocuous and perhaps even beneficial emotional consequences at times, but which also often result in a worsening of their conditions, such as when renal patients are given potions to drink that worsen their kidney functioning, or psychotic patients leave the hospital, only to come back more traumatised with burns and scars on their bodies.

Inadequate defences may result in depression and even suicide. This is well recognised with regard to HIV, so that pre-test and post-test counselling is mandatory. Where this happens with good therapists or counsellors, HIV positive patients can expect to feel contained and able to continue with their lives. However patients in the grip of other serious medical conditions need to be able to grapple with their negative diagnosis in a constructive way too.

Clues

Hence the importance of interpersonal sensitivity: The founder of the Hospice movement, Cicely Saunders (1977) said the following:

The main argument against a policy of deliberate, invariable denial of unpleasant facts is that it makes such communication extremely difficult, if not impossible. Once the possibility of talking frankly with a patient has been admitted, it does not mean that this will always take place, but the whole atmosphere is changed. We are then free to wait quietly for clues from each patient, seeing them as individuals from whom we can expect intelligence, courage and individual decisions. They will feel secure enough to give us these clues when they wish. (p 12)

The doctors in the above examples of truth-telling did not 'wait quietly for clues'. They were not guided by what their respective patients needed to know; what could wait; perhaps need not have been said or could have been vocalised sensitively at some other time.

Mental Illness and Stereotypes

When it comes to mental illness an equally careful and gentle approach is necessary, particularly when presenting a diagnosis of schizophrenia. Angermeyer and Matschinger [3] carried out a study of the impact of a diagnosis of mental illness on stereotypes, prejudices and discrimination with a German sample and 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. Telling a

person they are schizophrenic should therefore be accompanied by a good deal of emotional support and awareness of the social implications of this label.

In her article on the meaning of social responsibility, psychiatrist Moniek Thunnisen (2014) points 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. 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. Like Angermeyer and Matschinger (2003), she notes, however, that 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.

The Placebo Effect

Finally, there is another negative implication to thoughtless truth-telling. Engaging the body's self-healing processes where possible is surely a desirable outcome? Thick-skinned truth-telling is likely to sabotage any likelihood of this happening. As Faith Brynie (2009) has pointed out, the placebo effect causes real changes in the body. It is not a form of deception, but rather a product of positive expectation in which the individual anticipates those outcomes. Research [4,5] has shown that the placebo effect is an important part of the healing process. It has been studied in relation to chronic pain, depression, Parkinsons and other disorders. It has been noted that the placebo responder's belief in the positive possibilities of the therapy on the illness and on the effectiveness of the doctor involved, will enhance healing [5,6].

Conclusion

When the time emerges for giving 'full and accurate information', medical professionals need to sensitively identify and name symptoms; explain the underlying biological and perhaps psychological processes involved; provide education which explains the role of medication and whatever other therapies are indicated as useful; and maximise the positive possibilities. Any information regarding prognosis and likely mortality should be provided only on request from the patient [7,8].

Assistance with coping strategies in relation to the potential personal and social consequences of the diagnosis should be provided where necessary by referring the patient for counselling or therapy from an experienced professional on the team.

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