

The Disclosure of Information: Decisions Concerning Treatment

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Introduction

In a consultation concerning treatment decisions, the doctor and the patient exchange and discuss information. Ideally, this is shared equally with each party continually evaluating the situation facing them. Information is so central to the assessment of the patient's condition and options that it assumes key ethical significance and information disclosure on both sides becomes a key dynamic in negotiating treatment. (*SA Fam Pract* 2004;46(10): 35-36)

Information Disclosure and Disease Situations

The doctor holds significant pieces of medical and scientific information as a part of his or her past medical training and continuous professional skills development. However, the consultative process is often unequal. For example, the doctor may be aware that Mrs. X. belongs to a particular belief system, resides in a particular area, and has a husband and 3 children. The doctor has her medical records indicating her past medical history, what is to be explored, and thoughts on what might be useful to pursue in the future. On the other hand, the patient, while he or she confides to the doctor much information, does not necessarily disclose all the information about him or herself that may be relevant to the medical situation. For example, if test results show Mrs. X. has breast cancer, and she holds an underlying belief that illnesses are punishments for past 'misdeeds' (whatever their perceived significance) or bewitchments then such beliefs will influence her disease situation. This type of knowledge is vital for ethical decisions concerning the sharing of information concerning treatment decisions. In South Africa, a recent report indicates that 70% of South Africans consult traditional healers before medical practitioners.¹ So the importance of

patient's perceptions concerning their disease or illness cannot be overemphasised. As discussed by Hoffmaster, placing a patient in institutional, social, historical and cultural context influences the overall disease management and outcomes.² The philosophy of Family Medicine supports this. As de Villiers notes, "In exploring a patient's illness experience, we must specifically ask or pick up clues about the patient's ideas, expectations, feelings and fears, and the effect of the illness on the patient's functioning".³

This concept also relates to the type and amount of information patients ought to receive before they make their treatment decisions as decisions are dependent upon these and the psychological framework that they, medical professionals and society are prepared to support.

Societal Norms

In a liberal democratic society, we could broadly say that each person decides what is best for them, and pursues their own best interests and happiness. In such a society, the greatest amount of information available should be given to patients reinforcing the basis of their autonomous choice. In a medically weakly paternalistic society, "an action is taken in the best interests of a patient who cannot give fully informed consent for some reason, or who is not

afforded the possibility of free choice".⁴ In such a framework, less information and choice might be ethically supported if it is deemed for the patient's good. Strong paternalism, in which a patient's expressed wishes are overridden, is unacceptable in a liberal democratic society. Perhaps it should be noted that such perspectives are culturally contextualised. In many cultures, patients are not informed of for example, a terminal illness because it is considered that full information and choice will not be the most benefit to the overall good of the patient; the family is informed so that they can plan for patient care and support.⁵ Concerning information disclosure, the point is that societal norms are critical considerations in seeking an ethical balance between promoting choices and choosing the best patient care.

In our society, how much information ought a doctor to disclose concerning treatment options? How much is enough information, how little is insufficient? Court cases in which judgments were made against doctors providing insufficient treatment information are increasingly present in the literature. In South Africa, the ethical standards concerning information disclosure encapsulate the idea that overall, patients are entitled to make their own decisions concerning their medical care.⁶ Thus, a

doctor is obliged to provide the patient with sufficient information concerning their condition, different options available for investigation and treatment, benefits and burdens of treatment, possible adverse effects of investigation and treatments, possible consequences of not undergoing treatment and the time and monetary costs of treatment. This has support from to Beauchamp and Childress's five elements of the process of informed decision-making namely: *competence*, *disclosure*, *understanding*, *voluntariness*, and *consent*.⁷ At first glance, this may sound like an impossible burden. After all, if one were to inform a patient of all the pros and cons involved in all proposed or alternative pharmaceutical products, procedures, treatment options, investigations and so forth, the consultation would be endless. So what is meant by enough or sufficient information?

Information Disclosure Standards

Information disclosure standards for doctors have changed in response to societal perceptions concerning the practice of medicine. In the legal arena, at one time the amount of information disclosure required was held to 'The Reasonable Doctor Standard'. This standard was based upon the amount of information disclosed by medical peers undertaking similar procedures. Believing this to represent at worst a 'guild mentality', this is no longer the acceptable standard. **'The Reasonable Person Standard'** (information that a reasonable hypothetical person would want to know concerning a procedure) and **'The Subjective Person Standard'** (information reasonably desired by the patient but tailored by the doctor to meet the patient's individual situation or concerns) are both commonly evoked nowadays. While these standards form only part of the legal picture, broadly we could say that if a doctor is taken to court by a patient concerning failure to disclose information, the actions or inactions of the doctor would be held to the latter standards. In the ethical arena, a critical consideration is placed on the *reasons* the doctor provides for non-disclosure of information.

The evocation of 'The Reasonable Person Standard' or 'The Subjective Person Standard' attempts to answer this question: Under the same or similar circumstances, how much information disclosure is reasonably expected to be shared with a patient? In seeking an answer, a rule of thumb to follow is to ask this question: Under the same or similar circumstances as my patient, how much information disclosure would I need to have shared with me in order to reach a voluntary decision concerning my care?

Conclusion

When looking at patient treatment options, the idea of disclosing medical information presents challenges in our multicultural society. In decisions concerning treatment, information must not only be shared, but also communicated in a way in which it is understood by the patient in his or her bio-psycho-cultural context. Similar to the idea of informed consent, disclosure of information should be viewed as an on-going *process* involving 3 major areas of focus (assessment): the clinical, individual, and contextual components. The inclusion of these infers that the doctor is obliged to include space for and is sensitive to a patient's questions, fears, emotions; that the doctor shares new medical information when it is available; and that both the doctor and the patient retain the flexibility to revise decisions in light of new information and circumstances.✚

References

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