Informed consent: theory and policy

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Editor's note

Dr Strong divides the argument in his paper into two questions: the first asking to what information has the patient the right; the second what policy should the physician follow in divulging that information? He examines both the theory and the policy, and through example shows how other people, such as Veatch,³ whose policy he does not altogether endorse, have tackled this problem. Dr Strong concludes that he would encourage a recognition of the limit of the right to information, the answering of those questions which do not go beyond that limit and an active involvement by physicians in determining what special information a patient needs.

Introduction

Although there has been considerable discussion emphasising the importance of obtaining informed consent prior to carrying out medical procedures, little attention has been given to the limits of the patient's right to information. We need to distinguish two separate questions:

- 1) To what information does a particular patient have a right?
- 2) What policy should a physician follow in divulging information to patients?

The former is a theoretical question, the answer to which would be based upon a particular view of the patient's right to self-determination. The latter asks for moral guidelines or rules of thumb to be followed in practice. While a theoretical principle may clarify a particular moral value, a policy must often strike a compromise between competing values in a way which is morally acceptable. Therefore, the first question is conceived as the philosophically prior one, in the sense that policy ought to be based upon considerations which include a conception of the patient's rights. Most of the discussion about informed consent has focused on questions of policy, to the neglect of more fundamental questions. In order to decide what, as a matter of policy, we shall consider to be the limits of the physician's responsibility to inform, we would do well to consider the theoretical question.

The reasonable person standard

One policy which has received considerable attention in America is that known as the reasonable person standard. According to this standard, a physician should divulge that information which is material to the patient's decision, where material information is understood to be the information which a reasonable person in the patient's position would consider to be significant.¹ Although this standard, which was developed in the legal literature, has been adopted in several leading court cases it has also received incisive criticism. The principal objection is that this standard overlooks the fact that information which is material to a decision may depend to some extent upon the idiosyncracies of the particular patient.² It would seem that a particular patient can differ from the reasonable person in his position in at least two ways: in his ability to decide in a rational manner and in knowledge. For our purposes it will suffice to focus on the second of these factors. There may be knowledge which a reasonable person can be expected to have but which is lacking in an individual patient. Merely divulging that information which would enlighten the reasonable person may deprive an individual of information he needs in order to understand the choices which are before him. Since the point of informing the patient is to enable him to understand the decision he is to make, the reasonable person standard may in some cases be counter-productive to the aim of protecting the patient's right to make his own decisions.

A modification of the reasonable person standard designed to overcome this difficulty has been proposed by Robert M Veatch.³ His proposal maintains the requirement that the physician disclose information which a reasonable person in the patient's position would find significant. What specific information that might be is left by Veatch to be determined by committees. He goes on to suggest that additional disclosures must be made when there is evidence that the individual patient would require a level of information different from that of the reasonable person in order to exercise what he or she considers self-determination. The goal proposed is to provide the individual with 'all potentially useful or meaningful information', and this goal requires that the patient be given whatever information he wants. As Veatch puts it:

If there is any reason to believe that the particular patient or subject wants more information than the reasonable citizen, then the patient or subject's own standard of certainty must apply. If a subject communicates to researchers that he wants more information of a particular sort than the reasonable person would, there is an obligation of the researcher to give that additional information, if the subject is to continue to be part of the experiment.³

Veatch's policy is proposed specifically in regard to informing the patient or subject in the context of experimental procedures. The implication which his view has in this context is that a patient who is participating in an experiment has the right to whatever information he wants for the purpose of making his decisions. If a researcher is unwilling to answer every question, then, according to Veatch, he has an obligation to drop the subject from the research. With regard to non-innovative procedures, no explicit statement of policy is made by Veatch. However, he does state his agreement with 'those who favor even more caution in getting consent for clinical care and so-called therapeutic experiments than non-therapeutic research because of the strong, sometimes coercive, interest a sick person has in maintaining the approval of medical professionals.'³ Thus, it would seem to be an implication of his view that even in the context of standard therapy the patient has the right to whatever information he wants for the purpose of deciding upon a course of treatment.

The difficulty with this view is that it does not recognise any limit to the patient's right to information: it gives him at least a *prima facie* right to whatever information he wants. At the theoretical level, I suggest that this goes too far. Surely, not all the information a patient might conceivably want is genuinely relevant to the decision he must make. Furthermore, it seems to follow from this view that if the patient were to want a course in medicine, then the physician would have a duty to give it to him. But it is not at all plausible to think that the physician's duty to inform goes this far.

I suggest that the right to self-determination does not entail the right to whatever information a person wants. But what requirements for information are entailed by the right to self-determination? I believe the correct answer is that the patient is entitled to information which is sufficient to provide him with the opportunity to make a rational decision. Several remarks are required in order to explain what is meant by this. First of all, there is no suggestion here that patients should be required to make rational decisions. What is being claimed is that each patient has the right to all the information he needs in order to make a rational decision. Secondly, the information which is needed in order to make a rational decision will depend upon the particular patient's life plans and values. For

example, whether a certain unlikely side-effect is relevant to a rational decision may depend upon the plans which the patient has for himself. Furthermore, the information which needs to be disclosed will depend upon the particular patient's level of knowledge. This fact provides the basis of our criticism of the standard of the reasonable person in the patient's position. Thirdly, a physician's knowledge of medicine is not required in order to choose rationally.⁴ What is primarily needed is knowledge of the alternative courses of treatment and those risks and side-effects which have a bearing on the patient's life plans and values. Risks which are remote and which would have no significant impact on a patient's values do not need to be considered in order to choose in a rational manner. Fourthly, the foregoing remarks should not be taken to imply that the patient cannot waive his right to information by requesting of his physician that information be withheld. Finally, this view is compatible with a recognition that there may be situations in which the patient's right to information is overridden by competing moral considerations. I would not even wish to rule out the possibility that a paternalistic justification for overriding it may exist in some cases.

Choosing rationally

The view of the right to self-determination which underlies these comments is that it actually consists in two rights: the right to choose one's life plans autonomously and the right to choose one's life plans rationally. The informational component of the right to informed consent derives from the requirement of non-interference with a person's choosing rationally. The principal way in which one can interfere with a person choosing his plans rationally is to withhold from him information which is needed in order to choose in a rational manner. The physician is often found to be in a position with respect to the patient which would allow him to do this, and to do so when the medical procedure in question has a significant chance of interfering with the patient's life plans would be to interfere with the patient's exercise of his capacity to choose his plans in a rational manner, provided of course the patient has not waived his right to information.

Choosing autonomously

One might object to the introduction of a right to choose rationally as being unnecessary, on the grounds that every interference with rationality is an interference with autonomy. However, closer consideration of the meaning of autonomy will show, I believe, that this objection is unfounded. In saying that a person chooses autonomously I mean that the choice is his own, as opposed to being that of someone else. There are a variety of ways in

which a person's choice may not be his own: his choice may be the result of a threat; he may be brainwashed so as to make a certain choice; or he may be manipulated in more subtle ways so as to make the choice which others want him to make.⁵ A stock example taken from the medical context involves a physician who presents a narrow range of alternatives so that the patient will make the choice sought by the physician. It should be noted, however, that a certain amount of causal influence by others is consistent with a person's choice being his own. A choice can be one's own even though the chooser is advised, persuaded, even misinformed by others. I would think, for example, that if a physician failed to reveal certain relevant information out of neglect, perhaps due to being in a hurry or being overworked, without having the intention of leading the patient into a particular choice, then the patient's choice would nevertheless be his own. In this sort of case it seems more appropriate to speak of an interference with choosing rationally than of an interference with autonomy.

Another objection is that the requirement of non-interference with autonomy entails the requirement of giving the patient whatever information he wants. The basis of this objection seems to be the premise that failure to receive wanted information constitutes an obstacle to the patient's decision-making and is therefore an interference with his freedom. One approach to rebutting the objection would be to take issue with that premise; however, I find the premise itself to be quite plausible. The difficulty with this objection seems rather to lie with the presupposition that freedom and autonomy are equivalent. The sense of freedom used above can be defined as the absence of constraints to one's desires. An example has been given by Feinberg which shows that this kind of freedom is not the same thing as autonomy.

Suppose that John Doe wants nothing more than to have all his desires, actual and potential, free of constraints. He wants as many options as possible left open, especially those that are most important to him. He believes that Richard Roe knows best how to arrange this state of affairs. Hence, he puts himself under Roe's control, obeying as if commanded every piece of advice Roe gives him. The example becomes even more forceful if Doe makes this arrangement irrevocable. He is no longer self-determined, but receives rich dividends of satisfaction, having found a more effective way of getting all the particular things he wants or may one day come to want. (Self-direction is *not* one of the particular things he wants, nor is it important to him to keep open the option of one day repossessing it.) He may also want 'breathing space' and 'genuine options', in which case his benevolent director, Roe, arranges his life with these goals in mind.⁶

This arrangement has increased Doe's freedom,

since there are now fewer constraints to his desires, but at the same time it has made him less autonomous. What we might say is that autonomy has to do with absence of constraint to a particular kind of desire; namely, the desire to make one's own decisions. Although it may be an interference with a patient's freedom, in some sense, to not be given all the information he might conceivably want, it is not necessarily an interference with his autonomy.

Policy

At the level of policy, there may be a good reason generally to follow the guideline of giving the patient whatever information he wants. One might well be correct, more often than not, in adopting the presumption that each patient knows best what information is relevant to a rational decision by him. Each patient presumably knows best his own plans and values and thus could reasonably be presumed, in the absence of evidence to the contrary, to be in a better position than others to know what kinds of special information would have a bearing on his decision. I do not wish to take issue with this line of reasoning. However, I should like to emphasise that it is one thing to say that a patient has the right to whatever information he wants, and it is another thing entirely to say that he has a right to that information which he needs in order to make a rational decision and that in order to protect this right we will presume that he knows best what information he needs. The latter view allows for a limit to the patient's right to information. On this view, for example, if a researcher is unwilling to answer all of a patient's questions, it does not necessarily follow that he has an obligation to drop the subject from the experiment. If it is reasonable to believe that the subject has been given, and understands, enough information to enable him to make a rational decision about whether to participate in the experiment, then the researcher has fulfilled his duty to inform.

Whose responsibility

My theoretical account has practical implications for the question of who should take the initiative in determining what information a particular patient needs. Who has the responsibility of seeing to it that the patient receives information which is sufficient to meet his particular needs? Is it the physician or is it the patient and in some cases the patient's family? I believe that Veatch's policy does not encourage the physician to accept this responsibility. It encourages a minimal involvement with the patient, consisting in delivering the standard information and then more or less passively answering the patient's questions. Thus, his policy seems to imply an endorsement of the shift toward more impersonal health care which is a characteristic of our times. A recognition of the

limits of the patient's right to information would, I believe, encourage the physician to take a more active role in determining what information a particular patient needs. It might, for example, encourage the physician to ask a few probing questions to discover if the patient has any special plans which indicate the need for a disclosure which would perhaps not ordinarily be made.

Conclusion

I have argued for a theoretical account of the right to self-determination. Using this account, we have been able to construct what I believe is a reasonable view of the right to information. In applying this view I would recommend a policy which incorporates the reasonable person standard. Delivering the standard information is a good way to begin the process of adequately informing the patient. Going beyond this, I would encourage a recognition of the limit of the right to information, the answering of those questions which do not

obviously go beyond that limit, and an active involvement by physicians in determining what special information a patient needs.

References

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