

Debate

Involving patients in Do Not Resuscitate (DNR) decisions: an old issue raising its ugly head

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Author's abstract

A recent paper in this journal (1) suggests that involving terminally ill patients in choices concerned with Cardio-Pulmonary Resuscitation (CPR) produces 'psychological pain' and therefore is ill-advised. Such a claim rests on anecdotal observations made by the authors. In this paper I suggest that drawing conclusions in ethics, no less than in science, requires a rigorous framework and cannot be relegated to personal observation of a few cases. The paper concludes by suggesting that patients, if we acknowledge their valid interest in making their own choices, must themselves be allowed to make a prior choice about choosing. Those who may not wish to choose may properly be relieved of this burden and may allow another to choose for them. Routinely allowing others to make choices for competent adults, however, is likely to decrease communication with the dying patient and to introduce an atmosphere of suspicion and fear and to exclude the competent patient from his/her rightful place in the community.

Discussing plans of action with patients and obtaining their informed consent as much as possible has become a commonplace ethical precept of recent medical practice. It has become the standard of medical care, unfortunately not only because doctors have come to realise that to do otherwise is ethically unacceptable but because the law, at least in America, has firmly insisted upon it. One would not think of trimming a patient's toenail or of removing an appendix without obtaining such consent. Yet, when it comes to making some of the most critical end-of-life decisions there has often been a reluctance to involve such patients in the decision, even though it is the patient him/herself who inevitably is the person most importantly affected. Doctors have often felt that involving patients directly would cause 'psychological pain' (1) and have thus felt justified when they have failed to consult the patient, either consulting only the family or, at times, making such decisions entirely 'on their own'. Sadly enough, when it is pointed out that failure to involve patients

may be legally problematic, doctors, in my own experience, have not infrequently appealed to the fact that patients who are not resuscitated are unlikely to bring suit and that agreement from relatives had generally been obtained.

The fact that there have been second thoughts when it comes to obtaining patient's consent for DNR orders is not surprising and may, all things considered, be a healthy sign. It may be an attempt to move from a mindless application of rules and principles to a more humane and thoughtful use of such rules and principles as guide-posts instead of as strait-jackets; on the other hand, it may simply constitute a backlash against which a new rule ('do not directly involve patients in such decisions because it causes them harm') has been mindlessly applied. A move back to a time when patients were never or hardly ever consulted and when doctors reigned as the final arbiters of their patient's fate (doing everything, of course, 'for the patient's good') is not one which most thinking persons would welcome. Knowing that we are 'the captains of our fate', rather than surmising that we are the pawns of another (no matter how benevolent that other might be), is what most adults, at least in Western culture, want.

As medical practice is conceived today, doctors are properly seen as advisers who advise patients on the means necessary to obtain a commonly agreed upon end. The 'bio-medical good', in pursuit of which patients seek out medical care, is seen as only one (and not necessarily the highest) in a hierarchy of personal goods (2). Doctors, seen in this fashion, are geographers who can point out the terrain and delineate desirable ways of reaching a desired goal; they are not the ultimate directors of the enterprise who determine the goals. Clashes between doctors and patients can be solved in a variety of ways including, as a last resort, a termination of the relationship.

Painting such a picture is easier than translating it into medical practice. Medical interventions carry the potential for doing harm. This is true whether we speak of injecting penicillin for pneumococcal disease or of doing coronary bypass surgery. This potential for doing harm cannot be shrugged off. The potential for doing harm forms one of the important considerations when it comes to the advice doctors give or the

Key words

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decisions patients ultimately make. The advice is given to and the decisions made for specific patients but the 'facts' of the matter are derived from a careful study of many similar cases and are then subjected to statistical analysis. Such information is crucial when it comes to assessing the 'risk' which any intervention may pose. We know that injecting penicillin, or doing bypass surgery, carries a perceptible and statistically quantifiable risk. This is critical knowledge but it is not in itself sufficient for planning a course of action for a specific patient. A plan for a course of action must apply such data to the particular situation posed by a particular patient at a particular time. When this is repeatedly done in a thoughtful manner it may form the grounds for even sharper distinctions and delineations: we may, for example, be able to identify specific groups at greater or lesser risk. A small series of terrible failures (the three patients in our practice who had an anaphylactic reaction after receiving penicillin or the four who failed to come off bypass during bypass surgery) or stupendous successes (the elderly patient with heart disease, septic shock and pneumococcal meningitis who survived to take a trip around the world or the cardiac cripple who after bypass surgery travels across the country to participate in a debate) do not afford a sound basis for further judgements even though such experiences cannot help but flavour the way we approach future cases. Anecdote is not a safe or a proper guide to behaviour. Our individual experiences are useful to ourselves and to others as guidelines only when they are assessed in the context of a larger body of rigorously examined experiences with similar cases. Such considerations do not apply only to technical matters; they are equally valid when it comes to our ethical judgements. Methodologically, our approach to 'ethical' problems does not differ rationally from the way 'scientific' problems are approached (3).

In this paper I shall claim that in the circumstances of medical practice as they exist in the Western world today to fail to involve patients in end-of-life decisions is generally, but perhaps not always, a form of morally intolerable crass paternalism. Further I shall claim that such failure may, in fact, have psychologically rather harmful overall effects on dying patients. By paternalism I shall understand a way of behaving in which a person or persons seek to protect others from a course of action believed to be harmful to them. Such a definition is, of course, insufficient to deal with all the moral dimensions of paternalism. Protecting an unknowing other from harm is quite a different matter from forcing one's own vision of the good upon another who happens not to share the vision. But it suffices for my current purposes.

I shall differentiate between what I shall call 'crass' paternalism (called 'strong paternalism' by Joel Feinberg) and what I shall, with Professor Feinberg, term 'weak' paternalism (4). I shall define crass paternalism as preventing a person (A) from implementing a well-informed, deliberated and

articulated choice because it is believed by (B) the person acting paternalistically, that such a course of action would be 'harmful' to A. The decision of what is and what is not harmful is made by the person acting for the good of another regardless of that other's values. An example would be transfusing a staunch Jehovah's Witness who refused to accept blood or force-feeding competent adults against their wish. Weak paternalism, on the other hand, is designed to protect others from involuntary, or ill-informed, action which puts them at grave risk. Not to practice weak paternalism may be to abandon others to their, strangely defined, autonomy. Forcing a hysterical patient to hold still while a severely bleeding artery is ligated or forcing a young child to take medicine would be examples of weak paternalism, not doing so would be examples of abandonment to a strangely defined autonomy – strangely defined because true autonomy cannot be based on ignorance.

Things are not quite that simple, however. There would seem to be a continuum which ranges from extremely weak paternalism (as when one gives medicine to a protesting infant) to the far crasser forms. Beyond these lies total disregard on the one hand (in which one will simply watch silently while another comes to severe and unknowing harm without even attempting a warning) and, on the other hand, forcing another to undergo something that one oneself would not want to have done. Examples of both of these are, unfortunately, not rare. On the one hand, persons are not always warned of disaster ahead even when it is possible to do so; on the other hand, persons are sometimes forced to undergo interventions which those forcing the intervention would reject for themselves. (I have personally been present on occasions when doctors have kept patients alive, sometimes against the expressed wishes of patient or family, and yet have remarked that they hope that 'no one ever does such a thing to me'. Such actions go beyond even crass paternalism.)

I shall argue that failure to discuss end-of-life decisions with competent patients is under most but not all circumstances, a form of crass paternalism. Giving competent patients no chance to express their wishes in a given situation is not only generally not respecting their wishes but is not even giving them a chance to say that they wish the doctor to make such decisions for them. The only justification offered for such paternalism is that it prevents harm to the patient who would otherwise be caused 'psychological pain'.

The belief that involving patients in end-of-life decisions would cause them psychological pain and make their dying more difficult must rest on several prior assumptions. These may include 1) that dying patients are unaware of their dying or, if aware of it, would prefer not to discuss it with others; 2) that facing the issue of dying and making choices about the way we would choose to die is a worse alternative than either allowing another to make these choices for us or making no specific choices at all; and 3) that others

(health-professionals and families) could make such choices for the dying patient because they would 'know what the patient would want'.

Not involving competent patients in end-of-life decisions, of course, opens the door either to (i) continuing mindlessly all treatments which offer the slightest hope of prolonging life itself merely because such treatments are available or to (ii) allowing the choice to be made on the basis of another's values or on the basis of what amount to 'guesses' about the patients own wishes and desires. Hiding facts from the patient (shouldn't such facts belong to the patient?) and engaging in a type of subterfuge in which competent patients are treated as though they were no longer competent, is held by those who oppose discussing such issues with patients, to be 'kinder' than compassionately engaging in such undoubtedly painful discussions. But kinder to whom? The painfulness of these discussions may often be at least as painful for the health-care team as they are for the patient involved and evading such discussions may well be more than simply a kindly act done in the interest of another.

The belief that discussing such issues is 'painful' to the patient is a belief which Kübler-Ross a long time ago showed not to be true (5). Her work, based on the observation of many cases, has been amply confirmed since. Patients not only were not unduly burdened by having information shared with them but seemed relieved by the fact that the possibility of dialogue with health-professionals as well as loved ones had been opened and that, furthermore, they themselves continued to be in control of their own destiny. Time and again patients who were not informed or consulted were found to be engaging in a charade with health-professionals as well as with loved ones, a game which separated them from not-actively-dying others. The assumptions that patients 'want to be shielded' seems untrue because most patients (a) were found to be quite aware of their own dying and (b) were relieved rather than burdened by the opportunity to discuss options freely and, in concert with their loved ones, to make final choices. Moreover, the belief that doctors can, with any degree of accuracy, know what their patients may want has been shown to be an error. Even when doctors have known their patients quite well, their ability to predict the wishes of these patients has had virtually no more accuracy than random chance (6). Relatives and other loved ones may have a better idea; but accepting them, without the patient's authority, as sole decision-makers for competent adults has no ethical or legal standing. Families legitimately participate in decision-making as sounding boards, as counsellors and as comforters, but in the final analysis when adults are competent consent can only be given or denied by the competent adult (7). Depriving such persons of the opportunity to make such critical therapeutic decisions when they in fact would want to make them is difficult to defend.

Basing a viewpoint which would deny competent patients the opportunity to participate in and

ultimately make decisions for themselves on 'sparing suffering' to such patients requires, at the very least, a rigorous demonstration that involving patients does, indeed, promote considerable suffering and that it does so in most persons. Even if it could be shown that such discussions entail a certain amount of 'psychological pain' (such discussions can hardly be expected to give psychological pleasure!) one would have to show that 1) refraining from such a discussion is not of itself at least as painful; and that 2) a majority of patients prefer being spared the pain to being allowed to make their own choices. Relying on personal anecdote, gathered by two investigators who may very well have approached the topic from their inevitable personal bias and conveyed their own uneasiness and distaste, inevitably stacks the cards. In the more technical realm of medical practice an experiment which stacked the cards in such a way would not (and should not) be tolerated. If we were to base our usage of drugs or procedures on a few experiences reported to us by previously strongly biased observers, we would, and rightly, receive short shrift.

Classically and for many years doctors did not share 'bad news' with the patient. Even in some modern societies this is still the case and to claim that not sharing 'bad news' or acting crassly paternalistically is 'wrong' in every cultural setting is a statement which can be defended only after a particular ethical position has been established. The expectations of the community and of the patient, and therefore, the role of doctors, in such societies are quite different from those in our own. In most societies, however, the person or persons entitled to make such decisions are clearly identified. The patient is aware of this social presumption and, presumably, is at least reconciled to it. When the understanding of different roles evolves, such social presumptions inevitably will change. Whether or not such a change is 'for the better' is difficult if not impossible to say without invoking a specific vision of the good. In our particular culture as it exists today, the competent individual is presumed to be entitled to make decisions for him/herself.

Today, making patients part of the decision-making process and giving them the final say in the specific decision made is accepted as proper medical practice. Competent patients are free to choose among various medical options and also free to decline all treatment for themselves. If this is acknowledged to be the case, then a point of view which would deny competent patients the opportunity to make such decisions when it comes to some of the most critical ones a patient can make is decidedly peculiar. However, to be or not to be involved in the decision-making process, to make or not to make one's own final decision is a prior choice patients themselves must make. Choosing not to choose is just as much a legitimate choice as is any other (8). It is, I believe, a choice which likewise is frequently, and wrongly, overridden today.

Doctors who choose not to involve their patients in cardio-pulmonary resuscitation decisions often do so

with the presumption that doing so is a form of weak paternalism calculated to protect their patients from involuntary, or ill-informed action which puts such patients at grave risk. Such a justification is, in most cases, not a warranted one. There may be exceptional cases: patients who are known to have hysterical outbursts or who have been patently incapable of coming to terms with bad news in the past. But such cases present a tiny minority; and the temptation to invoke such a reason therefore must in most cases be resisted. To choose for patients who choose not to make choices is not, on the other hand, a form of paternalism as long as the patients' capacity to change their mind and participate should they wish to do so is amply respected. Forcing patients who 'choose not to choose' to choose is also a form of crass paternalism when it overrides a patient's prior informed, reasoned and articulated wish.

Choices, when they are to be made, must be between realistically possible options. Doctors are not compelled (nor would they be advised) to use non-efficacious therapy (9). Cardio-pulmonary resuscitation as a legitimate medical procedure must have some hope of technical success before being considered as a viable, and therefore legitimate option (10). Discussing resuscitation with the patient and family with a view to making a decision about whether or not to employ CPR is grounded on the assumption that CPR would be efficacious. There are certain conditions in which it has been shown that CPR is not successful either in restarting the arrested heart or, when it is restarted, in giving patients the opportunity to recover sufficiently to regain consciousness or leave the hospital alive (11). Resuscitation, under such circumstances, cannot be considered to be efficacious. Doctors do not generally ask patients to make decisions about the employment of non-efficacious therapy. When patients are asked to give or withhold consent it is consent for potentially useful interventions, not consent for interventions which are clinically useless. Asking for consent or asking whether patients wish to refuse procedures implies that the use of such a procedure is, in the circumstances of the case, possibly clinically useful.

I am not suggesting that patients or families should not be told about CPR when CPR is not efficacious. There is a difference between informing patients and families about circumstances ('unfortunately under these circumstances CPR would not be feasible') and giving them a choice between two viable courses of action. Unfortunately, doctors, like all of us, are apt to shroud decisions based on values under the guise of the 'technical'. The decision not to do CPR because it would not be possible is one made on technical grounds and after a careful review of the literature dealing with the appropriate circumstances. It is not a decision that the patient 'would not want to live this way' but, rather, it is a decision that whether or not he/she would want to live this way resuscitation is not, technically speaking, a viable option. When resuscitation is felt to

be inadvisable because of the quality of the patient's life, competent patients must generally make these choices for themselves. Such choices are based on the patient's own perhaps idiosyncratic values rather than being decided upon and being made on the basis of another's values.

It has been shown repeatedly that most patients are perfectly aware of their own imminent death. This statement apparently holds for many children as well as for adults. Involving dying patients in decisions maintains their standing as members of the community; denying them this opportunity, no matter how gently or lovingly it is done, emasculates dying patients and reduces their standing in the community. Doing so may also introduce a great deal of fear: patients today and in the way medicine has been structured in America are secure in the knowledge that all critical decisions will be openly made and discussed. The knowledge or even fear that this may not be the case is likely to produce anxiety rather than comfort in those used to and wishing to make their own decisions. Knowing that my family and doctor may make such decisions behind my back would not be a comforting thought. It would add fear and suspicion and would cloud my relations with both family and caregivers. Converting a nurturing environment into one perceived to be, or feared to be, threatening does not promote the patient's ultimate comfort (12).

Resolution

Ethics cannot be reduced to invariably applicable rules. The rule 'always discuss end-of-life decisions with competent but dying patients' is a rule which must brook exceptions, just as the rule 'never discuss end-of-life decisions' with such patients must. Patients must have the opportunity to make decisions: not only the decision of whether or not to be treated but also the decision to make or not to make such decisions.

In general in our society most competent patients want to be involved in the critical decisions affecting their own destiny. Therefore, when a patient is unknown to us the presumption must be that such patients would want to be involved. When competent patients are not consulted by their caregivers prior to having such critical decisions made, the burden of justifying why such patients should not be involved is a burden born by the caregivers (8). Saying that one thought that in general doing so would increase suffering in such patients, especially since such a claim rests mainly on anecdotal information apparently obtained by already previously biased observers, does not suffice as a justification. At the very least such a claim needs substantial and convincing proof not only that suffering is increased but that, all things considered, most patients would wish to be spared such knowledge and such decisions.

When decisions must be made, the context in which they occur is all important. Doctors are ill advised to leave such decisions until the last moment. Action with patients, in the course of their illness, can and

should include not only the making of choices for their immediate care but also the making of choices for foreseeable eventualities. This can proceed by engaging such patients in a continuing dialogue which seeks, first of all, to ascertain the extent to which the patient wants to be involved and the person or persons he/she would want to make choices with them should they remain competent, or for them should they become incompetent. If patients want to make their own choices, they should be informed about the possible course their disease may take and about the foreseeable major complications likely to occur. Flexible plans of treatment can then be established. Above all, such a dialogue should be an ongoing one in which patients, health-professionals and family freely discuss more than the immediate problem at hand. In this process, patients not only feel involved rather than feeling powerless but also continue in a very important way to be members of the community. They are not abandoned to another's wishes no matter how well intentioned such others or their wishes may be. Patients who do not want to be involved (and some patients indeed do not want to be) should be given that opportunity but should also be told they are free to change their mind. Gently asking from time to time whether patients do or do not want to participate when critical decisions must be made would continue to present them with such an opportunity without forcing their participation.

Solutions to ethical problems cannot be stereotyped or predetermined. They must be mindful to and sensitive of individual variations which are likely to occur in any setting. However, the general rules which apply to particular setting must be no less rigorously derived and analysed than must the general rules which apply to more technical questions. Anecdotal observations as a method of informing either technical or ethical judgements, important as they are in fleshing out and at times in casting doubt on prior overall judgements, cannot serve to form the sole or even the most important ground of general judgement.

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