Follow-up: should the elderly woman have been put on a ventilator against her wishes?

We would like to provide follow up and comment on the case study regarding putting a patient on the ventilator against her wishes (1).The dilemma that the daughter and son-in-law, both physicians, had faced was the decision to place this patient on a ventilator despite her repeatedly expressed abhorrence for such a treatment. They asked her at the time that she was gravely ill, hypoxic but seemingly in possession of her faculties if she still held the same views or if she now felt that she would agree to a ventilator if the hospital doctors advised it. She changed her mind and said that she would be willing to abide by the decision of the hospital doctors, including a ventilator if needed. Accordingly she was taken to a tertiary care hospital where she was admitted to ICU, placed on a ventilator for three days and weaned successfully to make a complete recovery. She returned to her activities of daily living in a short time. Surprisingly, she later told her relatives that she had no recollection of the conversation where she changed her earlier decision of refusing ventilator under any circumstances and again exhorted them never to put her on the ventilator again.

The ethicists would say that the relatives did the right thing in asking her again if she wanted to change her earlier decision. The patient in full possession of his faculties has the right to change his mind even after a "Living Will" declining ventilator etc has been made and submitted to the doctor and the hospital. However, an ethically correct decision does not guarantee a good outcome. In her case, the ethically correct decision turned out to be the correct medical decision also but that may not happen in every instance. She could have died a lingering and painful death after being on the ventilator for several days. Would we then have felt as confident of the ethics of asking her if she had changed her mind? Would we have wondered if we made a mistake in asking such a question of a person who was hypoxic and encephalopathic and perhaps not able to make decisions? As it turned out later she must have been encephalopathic as she had no recollection of making the decision to go to the hospital and on a ventilator and has only vague memories of the first day in the hospital. Surely, the bad outcome would have made us doubt the wisdom and ethics of asking such a question of a person who may not have been medically fit to answer.

What one learns from this case is that there are grey areas in ethical decision making as there are in medical decision making and as often happens, it is the outcome of a situation that allows us to either pat ourselves on the back or kick ourselves in the rear. As physicians we would like to spot clues that will help us make the right decision, both ethically and medically, before the outcome becomes known. For only then can we offer sound advice and make medicine more a science than mere inspired guesswork.

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Trust her inner voice

The ethical dilemma herein is resolvable on the basis of two non sequiturs : The avoidance of a ventilator does not always spell death. Insisting on it is no guarantee of survival. It is incidental that Mrs. SBG managed to recover - because of the ventilator, or, may be, DESPITE IT.

It is ethical to pay heed to a sprightly 80 years old, to trust her inner voice, and even to concede that she be allowed to embrace death of dignity at home, in case of an exit while struggling against a ventilator, in an alien setting, much against what the patient had patently expressed, merely endorses Bigelow's comment of mid 19th century- " Most men form an exaggerated opinion of the powers of medicine".The 1986 Oxford companion to medicine, writing about the role of doctors, echoes Bigelow-" It needs to be more generally recognised that most of medicine is about relief of, and comfort in suffering and in main very little to do with saving life."

An editorial in the *New England Journal of Medicine* (305: 1467-269,1981)entitled "The toss-up" bears eloquent testimony to the rationale of the above. It is common experience that, on a given case, the proposed diagnostic or therapeutic thrust ranges from extreme conservatism to surgical ultra- radicalism. After attributing such divergence in medical thinking to the idiosyncrasies of the physicians, the authors propose: 'perhaps all these factors are involved in clinical controversies, but we propose that one explanation has not been sufficiently recognised: that it simply makes no difference which choice is made. We suggest that some dramatic controversies represent" toss-ups" - clinical situations in which the consequences of divergent choices are, on the averages, virtually identical. 'the identicality of the consequences, no matter what the investigations and what the therapy, is a result of the basic fact that the problem being tackled is beyond the limits of technology.

Bottomline: We would have honoured the dictates of Mrs. SBG, avoided the ventilator without being unethical.

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A competent patient can decide

In the case of the 80-year-old lady with COPD, if clinical examination suggested that the lady was alert and capable of deciding about whether she would consent to use of mechanical ventilation, I would go by her decision, and discuss this with the daughter and son-in-law. However, a less traumatic mode of therapy called "non-invasive ventilation" is now available, which does not entail inserting a tube into the patient's trachea. Most patients who have received mechanical ventilation are really distressed by the presence of the tracheal tube and the inability to talk, cough or consume food / water while the tube is in place. Some of these are avoided by non-invasive ventilation. However, this can substitute for conventional mechanical ventilation in only a few, very limited conditions. Fortunately, the

present case seems to be one such situation.

If on the other hand, the old lady is not in a condition to decide for herself during the present illness, then it would be up to the daughter and son-in-law to decide about whether or not to subject the patient to ventilation. They would have to be told about the nature of the chronic disease, the acute problem, the possible outcomes, and the possible risks and benefits of ventilation (the medical aspects of the problem). They would also have to consider the views that the patient may have expressed earlier about not wanting to go on ventilator (the ethical aspects). Their decision should be respected by the treating doctor. Ventilation could be withheld, if so decided, after properly documenting in the patient's case records, the circumstances and reasons for withholding potentially life-saving treatment.

Dilip Karnad

The doctor, the patient and the relative

Providing the medical diagnosis and identifying the drugs in question would have enhanced the case study about the doctor, the patient and the relative (1) without compromising patient confidentiality. Yet, the case study serves to illustrate how patient, "facilitator" and physician interactions can compromise principles of ethical care.

The doctor's behavior as reported by the relative: We agree that the doctor should have given due consideration to the doubts expressed by the relative and should have explained in detail his reasons for suggesting a change. Yes, it does appear that the doctor's ego was bruised: he was quite brusque and rudely bypassed the relative to talk to the patient directly while, earlier, he had been content to deal through the relative. It is often difficult for doctors to accept that people with no medical training can question their judgment. Every doctor knows that no drug is devoid of side effects. It is far better to relate the pros and cons of the options, recommend the best option, and then let the patient make the decision. A patient who is a partner in the decision-making is less likely to blame the doctor if things do not work out.

The appropriateness of changing a drug: In this situation, the opinion of the first doctor, that newer medicines are not necessarily bad because less is known about them, is quite valid. The second doctor confirmed this opinion. However, his statement that the decision to change a drug rests solely on whether the patient is currently experiencing any side effects is partially true. There may be other reasons for changing a drug. Some drugs cause side effects that are apparent only after prolonged exposure such as L-Dopa for Parkinson's disease. Other drugs such as phenytoin for epilepsy cause subtle cognitive dysfunction that becomes apparent only after the drug is withdrawn. Other drugs like coumadin are more prone to drug-drug interaction or drug-food interactions and therefore, if substituted by safer alternatives, would circumvent future side effects. Finally the response to the drug may be less than what the doctor had hoped for and therefore he may suggest a change. Since we do not know why the first doctor suggested a change of drug, to assume that he was wrong or did it only for personal, financial gain is jumping to hasty and possibly erroneous conclusions.

Patient behaviour: The dependent attitude of this educated, English-speaking patient can be frustrating for the physician. She might as well be deaf, dumb, and demented for all the participation that she provides. How does one enfranchise a person who refuses enfranchisement? Is this behavior a reflection of a fear of making a mistake and thus losing face? Does one feel better if some one else makes the decision so that one is then free to blame and criticise? The relative was unable to elicit the patient's participation in her own medical care and it seems that this dependent behaviour was customary as her children expressed no surprise at this and were willing to have the relative continue to be the decision maker. This, indeed, is not unusual in our country where "loving care" translates into family members "shielding" the loved one from the rigours of decision-making.

The doctor's dilemma It is hard to fault only the doctor for not dealing directly with the patient. It appears that he at first, tried to involve the patient. However, he adjusted to the patient's resistance and was accepted the relative as the decision-maker. Later, when he felt that the relative was making the wrong therapeutic choice, he brought his concern directly to the patient, albeit rudely.

The dilemma for the relative was that she was entrusted to make decisions for a person who, though competent, refused to make them for herself. The relative, commendably, obtained a second opinion, read some literature on the subject before expressing her reservations. It is not clear whether the relative's concern was a result of her reaction to the doctor's rudeness, or, a valid clinical concern based on her literature search. Sound, competent, medical opinion is independent of the manner in which it is proffered. Unfortunately, most patients cannot separate one from the other.

Were any principles of ethical care compromised in this case? We feel that at least two of the seven ethical principles (2) proposed by the Tavistock Group were compromised: "Principle 4: Cooperation – health care succeeds only if we cooperate with those we serve, each other, and those in other sectors"; and "principle 7: Openness - being open, honest, and trustworthy is vital in health care". The doctor was not open and cooperative with the relative who was attempting to do her best. The relative should have repeatedly involved the patient in the decision-making process, in the doctor's presence. The patient's refusal to participate in her own care withheld her cooperation and openness from both the relative and the doctor.

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References:

1. Pilgaokar A: The doctor, the patient and the relative. *Issues in Medical Ethics* 2000; 8: 129-130.

2. Davidoff F.: Changing the subject: Ethical Principles for Everyone in Healthcare. *Ann. Int Med* 2000; 5: 386-389.