Special Article

Ethical and family management problems in the intensive care unit - an illustrative case

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Advances in medical technology now make it possible to maintain life in many individuals with irreversible organ failure. This often results in death and dying being a much more protracted and deliberate process. The ethical dilemmas engendered by these advances are compounded by the fact that life support techniques often render the individual unable to participate in treatment decisions. We present here the case report of a patient whose care in an Intensive Care Unit illustrates some of the ethical and family management problems commonly encountered.

Case report

Mrs. X was a 49-year-old woman with a 43-year history of severe bronchiectasis resulting in chronic respiratory insufficiency (CO₂ retention) and cor-pulmonale. She was regarded by her chest physician as having "end-stage" lung disease which required corticosteroids, bronchodilators and home oxygen. Her previous care had been complicated by her desire to regulate her own medications and, on one occasion, she had discharged herself from hospital against her physician's advice. Mrs. X was divorced and lived with her 14-year-old daughter.

For two to three weeks prior to admission, she had felt unwell, with an increase in both her sputum production and dyspnoea. On the night of admission, she was administering a bronchodilator when she collapsed at home. Her daughter gave oxygen by mask and called the ambulance. CPR was then performed until her successful

cardiac resuscitation 15 minutes after her admission to the emergency department. Antibiotics were started, in view of an obvious chest infection.

The following day, Mrs. X had equal and reactive pupils, myoclonic jerks, no response to painful stimulation, and absent corneal, gag, cough and oculovestibular reflexes. She did trigger the respirator occasionally. The electroencephalogram showed "post-anoxic encephalopathy with evidence of severe, diffuse cortical and sub-cortical dysfunction." A consultant neurologist stated that the patient could survive, but with a very high chance of remaining in a persistent vegetative state. He recommended against aggressive life sustaining measures. The attending physician agreed that the prognosis was dismal but felt that the therapy (antibiotics, bronchodilators, and mechanical ventilation) should be continued for seven days to allow "the benefit of any doubt."

The attending physician met with the family, outlined the dismal prognosis, and informed them of the medical team's decision not to initiate resuscitation in the event of another cardiac arrest. He also indicated that there were three treatment options available. First, the ventilator could be withdrawn and all therapy could be stopped immediately. However, if this was the family's wishes, then they would have to find another physician to care for the patient. The second option was a policy of supportive therapy involving the use of the ventilator but no other medications. Third, the attending physician stated his preferred approach which would be to continue "aggressive" therapy for seven days and then to re-assess the situation. If no further improvement had occurred, then aggressive supportive measures would be discontinued. The family (daughter, ex-husband and brother) agreed to the latter approach and were also in agreement with the "do not resuscitate" orders.

During the next five days there was no change in Mrs. X's neurological status although her pulmonary status

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did improve. By this time the ICU staff felt that, considering the woman's pulmonary disease, the absence of any improvement in her neurological condition, and the neurologist's firm opinion about the prognosis, there was no compelling medical indication to continue with aggressive supportive therapy. This consensus was conveyed to the attending physician who agreed to meet with the family. His note states "discussed situation with daughter and husband. They would like us to withdraw active support understanding that her CNS status is irreversible. After they have discussed this with family, we will actively withdraw supportive therapy: antibiotics etc."

A meeting of the ICU and attending staffs was held to try to clarify the management plans. Discussion focused primarily on whether ventilatory support could or should be withdrawn. The attending physician was adamant that there should be ventilatory support but agreed to reducing the FiO_2 . The patient died 12 hours later.

Intensivist's comments

This patient presented a challenge in terms of ethical, legal and social problems. When she was presented at ICU rounds the morning after admission, one of the residents felt very strongly that she should not have been resuscitated. Her disease had been regarded as end-stage and there was little more that could be offered her. Furthermore, her previous reluctance to accept medical advice and her apparent unwillingness to seek medical help during the current exacerbation of her chest disease suggested that she would not accept life support therapy. However, the feeling of the other team members was that, since most of the history was not available in the Emergency Room and resuscitative efforts had already been initiated by the patient's family, the resuscitation in the Emergency Room had been appropriate. It was also generally agreed that at this point the patient should be supported until the neurologist had had the opportunity to re-evaluate her.

Once the attending physician and family had been persuaded of the uselessness of continuing with aggressive therapy, discussions centred on which forms of therapy could and should be stopped. The attending physician was strongly opposed to stopping ventilatory support even though the patient did occasionally trigger the respirator. He felt, and the ICU staff agreed, that she would probably die quite rapidly once mechanical ventilation was discontinued. While he and a number of the residents were quite comfortable with stopping antibiotics and having the patient die days or weeks later from a pulmonary infection, the probable temporal relationship between stopping mechanical ventilation and the patient dying seemed to give it a completely different ethical flavour.

Throughout Mrs. X's hospital stay there was confusion as to who the legal next of kin was. Clearly, the 14-year-old daughter could not fulfil this function. Most regarded the brother, who had had only infrequent contact with the patient, as the legal next of kin even though the estranged husband appeared to be acting as family head. He had obviously maintained close contact with his ex-wife. Fortunately, all three were present at meetings with the attending physician and all three seemed to agree with the proposed management plans. The state of confusion is well exemplified by the last note on the chart: "There is some concern as to who is legally able to sign autopsy consent. Both husband (separated) and brother are and were agreeable to autopsy and would recommend now getting husband's signature as well (as brother's) to be sure."

Social worker's comments

Social work assessment in a critical care environment provides the treatment team with pertinent data concerning family composition, lifestyle of the patient, and the impact illness and hospitalization in the past has had on family functioning. Family cohesion and pre-existing conflicts significantly influence their ability to cope with the stress of a life-threatening illness and play a role in decision-making. Information concerning the family's intellectual capacity, emotional stability, social structure and previous exposure in medical settings can assist the physician to establish the most appropriate degree of family participation in decision-making.

Initial contact with the patient's family members served to clarify the nature of her relationship with Mr. X. He had identified himself as her husband to gain entry to the Intensive Care Unit. Although separated for eight years, Mrs. X had initiated divorce proceedings only one year previously. She had been awarded custody of their daughter but problems related to access were essentially non-existent. The daughter described her parents as "friends."

When the attending physician met with the estranged husband, daughter, the brother and sister-in-law, and the social worker, after outlining treatment options, he asked each person "What do you want us to do?" The patient's daughter flinched in response to the question and reluctantly stated, "I want what my dad said." Throughout the hospital admission, the family group demonstrated a moderate degree of anxiety in response to reviewing the medical problems and struggled with the attending physician's interest in involving them in the planning. Their questions indicated confusion and uncertainty, e.g., "Does the doctor want us to tell him what to do?" and "What will happen if we make the wrong decision? Will she still die?" Their verbal skills were limited. Simple medical vocabulary required explanation and interpretation

following each discussion with the attending physician. It was clear they held very traditional expectations for the doctor as decision-maker.

Physicians have obvious constraints on the amount of time they can devote to family members. A social worker or a chaplain, who will meet frequently with the family, can help provide continual practical and emotional support as well as reinforcing information already received from the physician. They can provide more frequent opportunities for the discussion of fears and concerns. Such identification of concerns and areas of confusion will make future meetings with the physician more productive.

Bioethicist's comments

Moral questions arising in the Intensive Care Unit serve within bioethics as a paradigm for the proposition that decisions reached "in the heat of a medical crisis" may profit from a separate, reflective consideration.¹ If nothing else, such examination may reveal the inevitable constraints upon decision-making imposed by the ambiguity and uncertainty endemic within the ICU.

Of particular interest was the view of a resident that Mrs. X should not have been resuscitated, as her previous behaviour suggested that she would not accept the life-sustaining therapy administered. This view echoes a major theme in contemporary medical ethics and law: the patient's right to choose the form and nature of his or her medical care, including the right to informed consent or refusal. In this case, though, there were no direct patient instructions regarding the current episode. Staff had learned that the patient had resisted earlier treatment by discharging herself from hospital. However, patients with chronic diseases tend as a group to be relatively non-compliant, so that the significance of this patient's previous resistance to therapy was difficult to assess. In any event, it could not be said that the patient had given an "informed" refusal. Those who thought that Mrs. X's prior behaviour indicated a refusal of treatment were also influenced by her dim prognosis. In light of the prognosis, it seemed that a reasonable person might well have refused aggressive measures. This latter argument though should stand alone, and not be influenced by speculations concerning Mrs. X's prior, veiled intentions.

The issue of clearest bioethical relevance in this case is proxy consent. Since the patient was unconscious upon arrival and continued so for the duration of her remaining life, a decision needed to be made on her behalf. Unfortunately, the principles of proxy consent, and the selection of a proxy decision-maker, come into conflict in this case.

Proxy consent as a bioethical issue involves a combination of substantive and procedural questions.² Substantively, on what basis should a decision be reached?

Should we seek to decide in the best interests of the patient, according to the patient's prior wishes (or request), or in some other fashion? Procedurally, who should serve as the proxy consentor, and should the proxy's decision be subject to review (and, by whom)? Even the seemingly mechanical choice of the next of kin as a proxy is problematic. For example, what should be done when two next of kin of the same degree of closeness (for example, two children or two siblings) disagree?

The next of kin listed on Mrs. X's chart was her ex-husband. The next of kin in law was her brother; and the next of kin in fact was her daughter. The choice of any one of these three possibilities would reflect a different view of proxy consent. Some feel that proxy choice should be made in accordance with what the patient would have desired had she been confronted with the choice. This view implies that the proxy chosen should be that person with the most intimate and accurate knowledge of the patient's recent wishes and life style. In this case, the daughter would most closely satisfy this requirement. Another view maintains that in choosing a proxy, we must attend to that person who will have the most stake in the decisions. "Responsible" choice, in this view, must be sought from that person who will be responsible for the consequences of the choice. Should this view be adopted, it would seem that Mrs. X's ex-husband should serve as the proxy, for the major "unfinished business" that her death will leave is the rearing of their daughter. If we are concerned to ensure that the proxy has no conflict of interest arising from the treatment decision, then paradoxically the brother's claim to serve as proxy (already legally secured) would be strengthened by the fact of his geographical separation from his sister.

In the face of these multiple uncertainties and conflicts, it is hard to say what would have been the "best" resolution. Practice in this case reflected a compromise of sorts. All three potential proxies were involved in treatment discussions, and decisions were reached in accord with their consensus. For legal purposes, the consent of the brother was obtained; but at the time of autopsy, consideration was given to the idea that both Mrs. X's brother and her ex-husband should sign autopsy permissions. This compromise resolution was bought, however, at the expense of a potentially high psychological cost, especially on the part of the daughter.

The framing of the treatment alternatives by the attending physician seems an instance in which concepts were drawn from another, essentially irrelevant quarter, in an effort to resolve this case. Although the family were told that there were basically three available options, they acceded to the attending physician's preferred approach of aggressive respiratory support including antibiotics

for seven days. This represents the length of time needed for the antibiotics to achieve their maximum effect. We see, however, that principles of general medicine were, to a considerable degree, out of place; for although her pulmonary function did improve, a decision was made at the close of seven days to withdraw aggressive therapy nonetheless. The determinative factor was the patient's neurological rather than pulmonary status. In the midst of neurological uncertainty, the relatively clear principles of antibiotic practice offered a convenient guide.

Although a consensus had been reached on stopping antibiotics after the initial seven day trial, the proposal to remove the patient from artificial ventilation at that time was strongly rejected by most. For a patient with such advanced lung disease, it was felt that to remove her from ventilation would be tantamount to killing. The decision to continue ventilation may have been supported by a number of bioethical principles, including the distinctions between active and passive euthanasia; responsibility for acts and omissions and, perhaps, the distinction between ordinary and extraordinary means of preserving life.^{3,4} (It may have been felt that at this juncture renewing antibiotic therapy was an "extraordinary" measure, while continuing assisted respiration was "ordinary.") While there is considerable overlap between these categories, the distinction of greatest relevance is that between withholding and withdrawing treatment. Many practitioners feel that the two are of substantially different moral weight such that it is relatively easy to decide against initiating some form of treatment upon a variety of grounds (dubious benefit, substantial pain or discomfort, etc.) but, once initiated, extremely difficult to justify withdrawal. From the tenor of the discussions in the ICU, it was clear that this distinction was strongly operative. A decision upon admission not to initiate artificial ventilation would have been entirely acceptable but once on the ventilator, it was felt to be immoral to remove this artificial assistance.

The distinction between withholding and withdrawing treatment receives almost no support within the bioethics and health policy literature. The documents on euthanasia prepared by the Law Reform Commission of Canada, for example, consistently treat the two on an equal basis.^{5,6} In the United States, similarly, the President's Commission for the Study of Ethical Problems in Medicine has concluded that "neither law nor public policy should mark a difference in moral seriousness between stopping and not starting treatment."⁷

The distinction has been attacked, in the first instance, for being ambiguous. In our case, for example, when the apparatus is disconnected for maintenance or suctioning of secretions, would a failure to re-connect the machine be an instance of withholding a treatment or of with-

drawing it? The ambiguity is further emphasized when we consider that the decision to discontinue antibiotics beyond the initial seven-day period of treatment was considered to be withholding (a new run of antibiotics) rather than withdrawing antibiotic therapy.

In addition, the distinction between withdrawing and withholding treatment can result in two kinds of serious harm. First, patients for whom a treatment has grown ineffective or whose risk/benefit ratio has altered may continue to be subjected to it because the powerful burden of proof against withdrawing treatment has not been overcome. Second, for fear of being "locked in" to a decision which could prove to be costly, the distinction may cause physicians to fail to initiate treatment for some patients whose prognosis on admission is grim. A preferable course would be to initiate treatment upon a trial basis and then to withdraw treatment if, as anticipated, it does not yield good results. Therefore, the distinction may serve to freeze medical decision-making which should be fluidly reactive to the changing condition of the patient. It may unwisely make withdrawal too difficult; or withholding too easy; or both.

The popularity among medical practitioners of the withdrawing/withholding distinction can be explained on psychological rather than ethical grounds. It distances the practitioner from the death of the patient. When treatment is withheld, it seems natural to say that the patient died of her disease, whereas when withdrawn, the immediate cause of death appears to be that decision. Thus, the practitioner is relieved of a sense of guilt about the death of the patient. Yet, in view of the considerations mentioned, it seems costly to have spared the practitioner's feelings at the expense of flexible and sound medical judgement.

From the point of view of ethical analysis, the major theme emerging from the above discussions is the shortage of ethical concepts and heuristics (principles of decision making) that may realistically apply within the intensive care setting. Repeatedly, ethical questions became distorted by an analysis predicated upon concepts drawn from other fields or situations — from antibiotics to brain death — none of which were adequate for the situation presented by this patient. It is natural, when faced with uncertainty, to cling to the familiar; and it is perhaps ironic that such recent ethical issues as informed consent have become so familiar as to yield this form of comfort.

The ICU involves certain features which depart from a comprehensive and rational model of ethical decision-making. In particular, the uncertainties, ambiguities, and limited time available before a decision must be reached, speak of a situation far removed from leisurely analysis. This does not mean, however, that ethical analysis is of no use within the ICU. Rather, the point suggests that a

new understanding of ethical action under uncertainty is needed, which will take into account the chasm looming between the ideal and the practical. In theory, further information could always be sought; further clarity achieved; further developments awaited. The case of Mrs. X outlines how, in a number of ways, attempts were made to buy the time which would afford these manoeuvres. However, the task of ethics within the ICU is to delineate when an issue or problem has been resolved "well enough" and this task is ill served by analysis that insists upon optimal conditions.

The issues raised by this particular case, then, are not to be numbered among those limited questions (including the whole-brain definition of death, informed consent, and the ethics of research) which have achieved a degree of consensus amongst bioethicists. In most cases, in fact, controversy regarding patient management among clinicians will be reproduced in bioethical discussion, albeit with different concepts and terms coming to the fore. The fine-grained questions to which an intensivist needs to reply – "What should be done to *this* patient at *this* time" – cannot be resolved by anyone other than the intensivist.

If bioethics does not yield a firm "bottom line" for these cases, what then is its contribution? We have seen several aspects of the case that may represent confusion rather than controversy. Why was a decision about patient management decided by principles of antibiotic therapy when the patient's neurological rather than pulmonary status was of decisive concern? What basis was there for the bias against withdrawing as opposed to withholding treatment? In general, what were the operative and realistic goals of treatment in this case, and was, for example, the continued use of the respirator rationally related to these goals? Who should be involved in these decisions? – For example, was the role to be played by the daughter made clear to her; and was it, indeed, clear in the minds of the staff? Though there is no univocal *bioethical* answer for this case, it might be that a "bioethical consult" on this case would have clarified the issues enough for the staff to have resolved the issues *themselves*. In this task of facilitation and clarification, the distance between the bioethicist and the medical realities of the case furnishes a necessary degree of objectivity.

It is also important to note that these issues are not resolved within current law, nor are future reforms likely to do much to resolve them. This is brought home by an examination of the recent Working Paper and Report issued by the Law Reform Commission of Canada, entitled *Euthanasia, Aiding Suicide and Cessation of Treatment*.^{5,6} Discussing the dilemma mentioned above of substantive principles for a proxy consent, the Commis-

sion writes that treatment decisions "should be based on two criteria. The first is a criterion of a medical nature and concerns the utility or non-utility of the administration of treatment. The second criterion is based upon the wishes of the person prior to becoming incompetent . . ."⁵ The Commission, in other words, recognizes the dilemma and invites us to live with it. The situation is no better with respect to the procedural aspects of medical decision-making for the incompetent. "A formal decision regarding treatment must be made by the physician on the basis of medical facts and expertise, but it can and should be made after consultation with the family, the spouse, next of kin or tutor, or guardian. Such a decision can also be made and normally is, after an independent second medical consultation. It may be made or contributed to by an interdisciplinary hospital committee."⁶

The law can speak for a limited purpose alone. It, at best, represents a minimum of social morality. As the Commission writes, "It is not within the scope of criminal law, which can only dictate a general standard of conduct, to say exactly how that decision [to treat or not, and in what way] should be reached, what advice may be sought and who may participate in the decision-making process."⁶ It could not indeed have gone much further. In medicine, as in other areas of life, there must surely remain a distinction between right conduct and conduct which is not criminally culpable.

Conclusion

While the case of Mrs. X is more complex than the usual, it is by no means unique. Certainly the individual problems and issues, medical, social and ethical, are all commonly encountered in the Intensive Care Unit. Our aim has been to highlight some of these problems and to illustrate the roles that the social worker or chaplain and bioethicist can play. Successful patient management requires a multidisciplinary approach, including the assistance of a social worker or chaplain and ready access to a bioethicist.

The social worker or chaplain can provide valuable insights about the patient and the family while offering emotional and practical support. As well, they can help the family express their concerns and formulate their questions for future meetings with the medical team and can reinforce the medical information after such meetings. While the direct and active role of the bioethicist in decisions that need to be made in "the heat of the moment" may be limited, more leisurely discussion before or after the event can help delineate decision options and at the same time help develop ethical concepts appropriate for the intensive care environment.

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