

Case Commentary

Karen L, a 29 year old woman was well known to her local hospital for her severe asthma and her non-compliance with therapy, including discharge from hospital against medical advice. Her frequent hospital admissions included three overnight intensive care admissions, but she had never required artificial ventilation.

One evening she was taken to hospital by ambulance with life-threatening asthma. When she arrived in Casualty, she was semi-conscious from lack of oxygen and unable to communicate. Due to the seriousness of her condition, she was given a general anaesthetic and placed on a ventilator in intensive care. Further investigations showed she had a pneumonia in one lung, which had given her a septicaemia (blood poisoning) in addition to her asthma, and treatment was commenced for all of these conditions.

Karen's mother and father arrived shortly after their daughter's admission. Her sister, who also had asthma, visited once that night but refused to enter the intensive care unit as it brought back too many unpleasant memories of her own admissions to the unit. Subsequently, only the mother and father visited Karen. It was explained by the medical and nursing staff to all members of the family that although Karen was seriously ill, and may die, that she did have a good chance of surviving with intensive care

therapy, and returning to her previous quality of life. The parents were initially agreeable to her treatment. However after four days, despite being informed of their daughter's small but sustained improvement, they requested that all treatment be stopped, and their daughter be allowed to die. They stated Karen would not want this treatment and they did not believe, despite medical assurances to the contrary, that she would survive. The medical staff refused to agree to the parents request on the basis of her good (although uncertain) prognosis.

Over the next week her parents met daily with medical staff demanding the cessation of therapy. The parents also met three times with the hospital administration seeking to override the intensive care doctors. This was unsuccessful. Meanwhile, Karen who remained on a ventilator, but non-communicative due to sedation, continued steadily to improve with treatment. Two weeks after her admission the sedation was stopped, and she was successfully weaned from her ventilator. She spent a further two weeks in a medical ward before returning home. Subsequently, her behaviour markedly changed and she achieved a better quality of life than she had had for many years. She became highly compliant with her therapy and obtained her first regular employment. She also left her parental home and moved to another city, where for several years she had no further hospital admissions.

COMMENTARY ONE

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*Oh! Let us never, never doubt
What nobody is sure about!*

The Microbe
Hilaire Belloc

These words of Belloc are appropriate because uncertainty "infects" all areas of medicine, not least of all the intensive care unit (ICU) and uncertainty as well as the pneumonia was also infecting this case. Her wishes were not clearly known (although her parents were strong and vocal advocates of what they thought she would have wanted) and her prognosis was far from certain - at least in the first few days of her illness. What was certain, was that if treatment had never been started, or was withdrawn at the time of the parents' requests to do so, Karen L would have died. This combination of unknown patient wishes, an uncertain prognosis and the life of an individual being at stake, frequently occurs in intensive care medicine.

Unknown patient wishes

In this country a competent patient has the right to refuse any treatment including life-saving treatment. If the patient is incompetent then the ultimate responsibility for any decisions lies with the specialist in charge of the case. All ICUs have their share of "booked" admissions (usually following elective surgery) which carry the possibility, at least before admission to ICU, of the patient actively participating in the decision making process. Unfortunately it is far more common that the patient arrives after a sudden, catastrophic illness or accident, unable to communicate, leaving the family and staff struggling to know what exactly the patient would have wanted done or not done. In the case of Karen L, it could be argued that her known record of non-compliance and self-discharge from hospital might form a basis for believing she would refuse treatment, if she could speak, but many causes for her previous behaviour could be possible which would invalidate such reasoning. The fact that following her treatment Karen left the family home and had a much better quality of life could mean that her family was dysfunctional. The doctors treating

her could have been aware of this and therefore may have reason to believe her parents were not acting with Karen's best interests at heart. Such a circumstance would be rare: families usually do act in good faith for their loved ones. Living wills and power of attorney are very rarely encountered in Australasia, and leaving aside their lack of legal status, are not necessarily useful, for many intensive care specialists can recall patients who have changed their mind and requested treatment when faced with the stark reality of certain, imminent death.

Uncertain prognosis

Every medical prognosis has a degree of uncertainty attached to it. While various predictive systems have been developed in an attempt to reduce this uncertainty, they are severely limited in giving accurate prognoses for individuals (they are more relevant for groups of patients), and are no better than an experienced intensive care specialist at making predictions as to who will survive or not. Predictive systems do not assess the quality of the patient's survival, which often is the important issue to both the families and carers. In Karen's case,

the doctors felt she had good chance of both recovering and having a reasonable quality of life, and this strengthened their argument for not complying with the parents' request. A prognosis, once given, is not fixed but dynamic. Time-related factors such as therapeutic response, secondary complications and iatrogenic events can alter it and as Karen responded to therapy this decreased the uncertainty of her recovery, further strengthening the doctors' position. Sometimes treatment has to be commenced so that a prognostic assessment can include these temporally-related factors such as response to therapy.

Life-and-death stakes

None of this is made any easier knowing that the stakes frequently involve a person's life. This means a high level of evidence and belief is required that a treatment would not benefit a patient before the non-provision or withdrawal of that treatment. However the issue goes beyond that of the immediate patient in front of me. What of the other intensive care patients, past, present and future, who will require a share of the ICU pie? Putting huge amounts of resources into one patient now may potentially deprive other patients, either currently in ICU or those in the future, of care which may benefit them more than that given to the immediate patient. A "fair share of care", defined by the likelihood of survival with its degree of uncertainty, the quality of that survival and its degree of uncertainty, and an estimate of the patient's wishes is the complicated, intuitive calculus that takes place. No wonder I find Belloc so appealing!

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COMMENTARY TWO

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When I read this case study, it seemed so clear that the professionals had acted correctly, that I found myself a bit puzzled about what interesting moral issues it could raise. But a philosopher can usually find something to say. The most obvious issue is the question of when we should accept decisions of parents (or family more generally) about treatment for someone who is unable to communicate their wishes. Where these decisions are in accord with medical advice, we rarely question their propriety or even to what extent they reflect what the patient would want. Where they are contrary to medical advice, we (rightly) scrutinise them much more carefully. Where a decision has consequences as serious as withdrawal of life-support has, we might not grant families the right to make it, particularly against medical advice.

But there are familiar cases where families have been allowed to decide that life support be withdrawn, such as the cases of Karen Quinlan and Nancy Cruzan in the USA. How does this case differ from those?

One crucial difference is in the prognosis. For both Quinlan and Cruzan there was really no expectation (even very small) of survival without continued life-support, let alone recovery. Karen L is judged to have a good chance of survival, except by her parents. I think that the professional view should prevail in this case, but we need to be clear about what this implies. The judgement I am referring to is about prognosis, and this is properly within the expertise of professionals. The further judgement about what to do in the light of any prognosis is not normally a matter of professional expertise. This is because it incorporates questions of the value and priorities an individual places on likely consequences of treatment. The view that people have a right to reject treatment, even at the cost of death, reflects this point. Were Karen herself to be requesting that her treatment be stopped, then a professional view that this was a wrong decision should not

prevail. (Or, more precisely, it should not prevail if Karen had been given and understood the medical information relevant to her decision, including the professional assessment of her prognosis.) But I don't think Karen's right to reject treatment transfers to decisions made on her behalf by her family, at least not where the cost to her is so high. (The seriousness of consequences constitutes one pertinent difference between family requests for treatment which professionals judge futile, and requests to stop treatment professionals judge possibly useful. Honouring family decisions in one case need not commit us with respect to the other.)

So, what licenses our putting aside Karen's parents' request is its consequences for Karen (probably death) and it being based on a view of the likely outcomes which is contrary to expert opinion. These would not similarly licence ignoring such a request made by Karen herself.

But isn't it possible that Karen's parents really are representing her views? This is possible, but we have little reason for thinking that Karen would want treatment stopped. Her history of non-compliance is some evidence that she is likely to reject medical treatment. But there are no reasons to think that in the past death has been so clearly one of the consequences she has faced and accepted in rejecting treatment. Where someone is not able to convey their own views, we should work with an assumption that they would choose what any other reasonable person would choose. Most reasonable people would not reject life-support in the situation described. Karen's parents' choice seems based on an unreasonable belief. Of course, Karen might share that belief, and beliefs will be reasonable as well as their choices. So I think that the possibility that Karen's parents' decision does reflect the one she would make does not constitute a reason for accepting it.