

"How do we say enough is enough? End of Life issues in a pastoral context."

(A talk given to the annual Catholic and Anglican Clergy day, 2011.)

When I was first asked to give this talk I pondered for the short time that was given me, regarding what might be the topic. I wanted to talk about something that might be of practical benefit to you in your pastoral work. It would be easy to talk to you about euthanasia, or about stem cells, and you might leave here better informed. But it might not be of practical assistance to you.

So I suggested that I talk about what is sometimes called "end of life" decision making. By that I do not mean decisions about ending someone's life. But I do mean decisions the consequences of which are that someone will probably die quicker, but where the intention is not to end someone's life. How do we say "enough is enough"?

One of the reasons I chose this topic is because it is one of the ones about which I am most frequently consulted. So I was thinking that if I am asked about it, it is quite possible that a good many of you will also be consulted by a terminally ill person, family members of the ill, or by hospital staff, when they are wrestling with this type of decision.

The second reason for choosing the topic and for the wording of the topic, 'how we speak about these things' was because in my experience I have found that we have lost the language with which to talk about such matters. By 'we' I mean Christians who think in terms of a tradition that holds that every human life is sacred. Because we have lost our language, we tend to adopt the language being forged by the secular society, and that language will often lead us to places we would rather not go.

So after that explanation let me begin by giving a scenario.

"The patient was 67 years old and profoundly mentally retarded (with an IQ of 10 and a mental age of approximately 2 years and 8 months). He had been institutionalised all his life and was unable to communicate verbally. He was diagnosed as suffering from acute myeloblastic monocytic leukemia, an invariably fatal disease. The normal treatment is chemotherapy which offers a 30%-50% chance of remission lasting from 2 to 13 months. The treatment itself has serious side effects, including pain, discomfort, pronounced anaemia, bladder irritation, loss of hair, bone marrow depression, and, in rare cases, death. Apparently a majority of competent patients suffering from the condition elect to undergo chemotherapy in the hope of remission."ⁱ

The brother and sister of this man, who have enduring power of attorney for their brother, have come to you and asked your advice regarding the treatment. In particular would it be ethical for them to refuse the chemotherapy on his behalf. If so, on what grounds? How would you go about explaining it?

Now I am going to leave that case just there while we consider the theory and then how we might talk about this case to the brother and sister.

We begin with a general ethical principle regarding respect for human life. In the context of health care we can express that principle as follows:

If a person is ill he or she is obliged to seek help to maximise their chances of recovery and to minimise the effects of chronic disability or handicap. If illness is life-threatening a person should seek to avert the threat.

I am not going to argue for this principle with this audience. I am simply taking it as a given.

The negative norm, which I would consider a moral absolute is: You should not directly attack the good of life – there is no such thing as a life unworthy of life.

The positive duty rules out one kind of bad practice, what is referred to as “undertreatment.” “Undertreatment” can be defined as the failure to take appropriate measures to treat symptoms or the condition itself, when those measures could bring real relief and are not considered too burdensome or intrusive.

The language that is often used here to justify lack of treatment is that of *futility*. Medical personnel, family or even the patients themselves, might say that treatment is futile because they are going to die anyway; or because they will not be restored to the level of functioning that they consider desirable. We need to be very careful of the use of the language of futility here. Often what is meant is that the person’s life is judged to be futile. This is a judgment often made about those who are in a coma, a state of post-coma unresponsiveness, or suffering from dementia. It is a judgment about the meaning of someone’s existence. I do not believe that we can judge the meaning of someone’s life. We cannot judge someone’s life to be “futile”.

However there is a correct usage of the word futile, and that is when it is properly applied to the proposed treatment. A treatment is futile when the treatment does not achieve its purpose. So if the treatment is aimed at cure, when cure is no longer possible, then that is futile treatment. Sometimes the continuation of chemotherapy, for example, may be futile because of the progression of the cancer. Artificial nutrition is aimed at giving nutrition. But if the body processes have already begun to break down such that food is no longer being digested, then artificial nutrition is futile as it is not achieving its purpose.

In the case that I outlined, chemotherapy could not be classified as futile. The purpose of the chemotherapy in this case, is not to cure but to slow down the disease, to gain remission. There is a chance that the chemotherapy could achieve that, so it is not futile in the proper sense of the word.

I have spelt out our positive duty and that it rules out undertreatment. But like all positive duties it has limits. Consider the following case.

Mr John Corbett had no family. Soon after his retirement he was admitted to hospital on several occasions suffering from different conditions.

Gretchen Kerns was assigned as Mr. Corbett's primary nurse. Over several weeks, they developed a bantering, congenial relationship. Mr. Corbett frequently referred to himself as "a disaster that found a place to happen" and commented that "Jolly Jack, the Grim Reaper, is coming to get me - the slow way. That is sure not the way I want to go". Then Mr. Corbett suffered a stroke and was readmitted to the hospital. This time, there were no jokes and bantering. When Ms. Kerns inserted the IV to provide antibiotics for a bladder infection (a three-nurse fight), Mr. Corbett made loud guttural noises, wept, and fought the familiar nurse with flailing arms. When he refused to eat, clenching his jaws and moving his head from side to side, he was force fed a pureed diet from a syringe until a nasogastric tube was inserted (a four nurse fight). When Mr. Corbett developed congestive heart failure, his hands were restrained so that nasal oxygen could be administered. It was almost a relief to the nursing staff when he became semicomatose.

Still, it took some juggling to keep Mr. Corbett going. His blood pressure dipped and soared, the liquid diet caused diarrhea, and his arthritis caused contractures. When he suffered a respiratory arrest, he was resuscitated. The staff were praised for their fine work. When Mr. Corbett suffered a second arrest 3 days later, some of the staff began to doubt the wisdom of their efforts. Yet Mr. Corbett improved, to the point where he could shout guttural sounds again and fight off Ms. Kerns and the other nurses with his fists. Then his kidneys began to fail, and he was dialyzed. Eventually, he "stabilized" with dialysis three times a week although his blood gases, electrolytes, cardiac enzymes, urine cultures, and whatever else was tested were always abnormal.

One day his blood pressure dropped steadily, his physician indicated that they should "let nature take its course". A do not resuscitate (DNR) order was written, and the physician said "goodbye" to the patient. Ms. Kerns, however, refused to follow the order. "You can't do that. We've brought him back before-twice. We can pull him through again. Let's give him some dopamine", she said. She argued with the physician, the rest of the staff, and her supervisor, claiming that everyone

deserves to be resuscitated and that she could not participate in euthanasia-"It's morally and legally wrong", she said. The physician obliged Ms. Kerns and rescinded the DNR order. Two days later, Mr. Corbett had a third arrest. Ms. Kerns and the resuscitation team performed expertly. "God gave us the technology to preserve the lives of our patients", she said.

Two months after the first arrest, the sixth resuscitation attempt failed, and Mr. Corbett died. "We did the best we could", Ms. Kerns said proudly. "We gave him the benefit of everything we had to offer". Other members of the nursing staff were bitter. One said, "When I get to heaven, I'll explain to God that I did the best I could for every patient. But who's going to explain to Mr Corbett?"ⁱⁱ

Now I would say that Mr Corbett was subjected to "overtreatment". Overtreatment can be defined as: continual use or commencement of procedures aimed at cure where that is no longer possible, or use of burdensome and intrusive procedures which are of no real benefit. Mr Corbett was being subjected to intrusive procedures which, although bringing him back from the dead, were not curing nor relieving his symptoms.

So how do we walk the line between undertreatment and overtreatment. Many will talk about the *quality of life* of the patient, or their own quality of life, and make a judgment on what they consider an acceptable quality of life. However, the corollary of that is that there is such a thing as a life no longer worthwhile. Others will simply talk of autonomy and say that it is up to the patient to decide, and if they are not competent, then someone who can speak for the patient might decide. However they offer no real criteria for making these judgments.

In our tradition we used to speak of ordinary and extraordinary means. How many here have heard those terms used? Look around and see how many hands are up. Looking at that you might be tempted to say, look everyone knows those terms. You would be mistaken. You are in the minority. Those terms used to be fairly common currency. They appeared in medical dictionaries as well as ethical textbooks. However, today you will find that fewer and fewer people in the medical profession are familiar with those terms. Last year I did a series of seminars in various Catholic health and aged care facilities. I asked that question at every seminar. About 4 out of every 100 people were familiar with those terms. That came as a bit of surprise to me. That did not worry me too much because I do not use that terminology either, but it did make me think about what was the language they were using to discuss these matters. Most of them had taken on board the language of "quality of life". I am going to suggest an alternative.

I said that there are limits to our positive duty. The limits can be expressed as follows: there is no obligation to have a treatment which has little or no chance of succeeding = no futile treatment; there is no obligation, other things being equal, to undergo treatment that imposes excessive hardship (burdensome).

If we look back at the usage of “ordinary” and “extraordinary” we discover that ordinary meant obligatory, and extraordinary meant optional. But what made something extraordinary treatment? Its burdensomeness. So today we talk about the benefit and the burden of the treatment proposed.

The doctors immediately say, ‘Good, give me a list of burdensome treatments’. Of course we cannot do that. It will depend on the circumstances.

The burden may be:

physical, which refers to pain and discomfort -- before anesthesia many treatments we consider normal today, would have been considered physically too burdensome;

psychological (includes cultural and personal sensibilities) -- this might refer to the stress of being away from one’s family and familiar surroundings, or it might be cultural taboo regarding a man being examined by a woman doctor;

moral – the classic case here is the Jehovah’s Witness refusing a blood transfusion;

economic – we might tend to think that this is rarely the case here in Australia, but it is very prevalent. People are dying waiting to see specialists in our public hospital system because they cannot afford to see them privately;

for oneself or others, (but does not mean that ‘others’ can relieve themselves of the burden of care);

in light of the patient’s condition -- the patient’s condition is relevant, but this is not a judgment on the quality of life, but an assessment of the consequences of treatment for someone in this condition.

There is subjective element of the judgment of burdensomeness, especially when one is judging for oneself.

Let us apply this to the case with which I began.

First of all there would be the physical burden. Although that may be bearable for a competent patient, it was argued that a patient with an IQ of 10 would be unable to

co-operate with the treatment and would therefore need to be physically restrained as well as put up with the pain. Further, there would be a psychological burden as the patient would be disorientated by the treatment and would find the pain unintelligible. The benefit to the patient might only be to extend his life for a short period, and to actually increase his suffering for that period.

These are the kinds of things that need to be considered in deciding what is best for this patient. In talking with the brother and sister you could ask them to consider or to ask the doctors, how will their brother handle the treatment? Will it cause him pain and discomfort? How much benefit will it give?

In the actual case, given the condition of the patient and the side-effects of the treatment, it was decided that he ought not be subjected to it.

It has been my experience that people, relatives and patients themselves, find the language of the benefit and burden of the treatment helpful in making such decisions regarding treatment in these end of life circumstances. First of all, it removes them from making some kind of judgment on the value of life of the person that they love. They are able to focus on the treatment and assess its value. It also gives them a language which they can use in talking to the medical personnel. Medical personnel are able to give a reasonably objective answer to questions such as: how will that treatment help or benefit my mother, father ...? What kind of burden, suffering will it inflict upon them?

This kind of language is helpful for the competent patient when you are talking directly to the patient, and for the relatives who might have to make a decision for a non-competent patient. One of the most difficult cases is that involving a young person. Parents find it very difficult to let go and say enough is enough. I was involved in a case where there was conflict in the family. One parent was ready to let their young child go, the other wanted the doctors to continue treatment. When we spoke to that parent, not simply in terms of the prognosis, but in terms of the suffering that the treatment itself was inflicting upon the child, then that parent was able to let go. The parent realised that not treating was not killing their baby, but allowing the child to die.

Finally this way of thinking and talking is helpful if someone is considering completing an advance health care directive.

I am just going to say something about advance health care planning because it is relevant to this topic and once again is something about which you may be consulted.

There is big push going on from various quarters for people to make some kind of arrangements for their future health care in the event that they should no longer be in a position to make their wishes known. There is an interesting and complex history behind this movement but I won't go into that with you today.

In Queensland people have four options. They can appoint an enduring power of attorney, that is, they nominate someone who will have the legal right to make health care decisions on their behalf if they should no longer be competent. Secondly they can complete a legally binding advance health care directive. Thirdly, they can appoint an enduring power of attorney and leave them written evidence of their wishes, but not as a legally binding document. Fourthly, they can do nothing, which everyone has done until recent times. In this case, if it becomes necessary, the law designates who becomes the decision maker according to a hierarchy established by the Act.

Various people promote the Queensland model of an advance health care directive. Some bureaucrats think that it is the best thing since sliced bread. I think it is terrible. It is a very blunt instrument and it is educationally abysmal.

The worse sections are those which name certain conditions and you are invited to nominate by ticking a box what treatments you do not want if you are in such a condition. There is not education given as to why you might refuse treatment. Someone who was well informed could use the Queensland Directive, but they need to be well informed and be aware of its shortcomings. Some of the problems with the directive become less so when someone is already terminally ill and has a good idea of his or her prognosis and treatment options.

Some years ago the Australian Catholic Bishops Conference and Catholic Health Australia set up a group to look at this issue and they produced two documents. One is a guide to people considering future health care planning. The other is for medical professionals who are confronted with an advance health care directive.

Both these documents are available on the CHA website. The preferred model is that of appointing an enduring power of attorney and discussing your wishes with them, leaving them a written record if you wish. But the documents give some consideration to the reasons why someone might say enough is enough – reasons relating to the burdensomeness of the treatment proposed.

ⁱ The Report of a Working Party, *Euthanasia and Clinical Practice*, The Linacre Centre, London, 1982.

ⁱⁱ Adapted from, Veatch, Robert M & Fry, Sara T. *Case Studies in Nursing Ethics*, Jones and Bartlett Pub, Boston 1995. Pp. 160-161.