Ordinary and Extraordinary Treatment: a case for review?

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The recent Englaro case has again given rise to the controversy of keeping a person alive in a persistent vegetative state (PVS) by nutrition and hydration through a nasogastric tube. The last controversial case which made a similar outcry was that of Terry Sciavo in the United States. The question to consider is whether nutrition and hydration, especially after several years in a PVS constitutes an ordinary measure to keep a person alive or an extraordinary and/or heroic one.

The difference between Ordinary / Extraordinary treatment originates from Roman Catholic Medical Ethics and was introduced by Pope Pius XII in the 50s, as a guidelines to Catholics in the face of new extraordinary means to keep people alive which were becoming more and more common. In fact before being able to keep people alive on a life support system, one was considered dead when one's heart stops beating. (This still applies for medico-legal purposes, say, when one attempts cardiac resuscitation – if the attempt fails one cannot be accused of having caused death). A Harvard neurologist introduced the Brain Death Criteria, to determine whether a person is still scientifically alive and therefore allowing removal of the body from advanced life support.

The first controversial case, ironically, was to put a girl *off* life support when she was in fact not yet brain dead[1]. Mary Quinlan was a 21 year old on life support. She had been involved in an accident. She also was Roman Catholic as were her parents. The parents thought that keeping her alive on such a system was something they could not bear. They wanted her to die in dignity. Their Parish Priest defended their case. The doctors however would not agree as she was not brain dead. The case went to court, which made historical ground when it was decided that the criteria of a social institution (in this case the Catholic religion) could over-ride scientific thought. She was subsequently removed from life support and allowed to die *even though she was not brain dead.*

At this juncture it is important to note that the definition of the Church, subsequently put through scholarly rigour[2] takes note of two particular (and important) points. First, what is to be defined as ordinary or extraordinary has nothing to do with the state-of-the-art medicine used in such cases. Blood transfusion was then considered as quite an extraordinary form of treatment. Today it is very common place. Yet we still note the controversy over Jehovah Witnesses, which to them is an extraordinary measure. What is ordinary for one person, such as having CPR, may be considered extraordinary for another. In this regard, having an Advance Directive (or living will) can be very helpful.

This brings up the second point – the relatives. The burden of the relatives is considered very important in determining whether treatment is ordinary or extraordinary. Therefore if the relatives have to go through extraordinary measures, such as selling a house, or extreme psychological distress, as in the Quinlan Case, then the treatment is considered extraordinary.

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It is here that cases become controversial, although in reality they should remain confidential. The fact that respect for confidentiality seems not to take place here implies that we are still in an evolutionary phase of understanding these cases, and there is still to be found a balance between what is important to the patient/relatives, and what is important to society.

Roman Catholic moralists have however traditionally argued, as in the Quinlan case, that moral obligation demands only the use of 'ordinary' means:

Extraordinary means of preserving life are all medicine, treatments, and operations, which cannot be obtained or used without excessive expense, pain or other inconvenience for the patient or for others, or which, if used, would not offer a reasonable hope of benefit to the patient.[2]

Whilst it is important to note that the statement, accepted as 'dogma' nowadays, as it follows directly from the declaration of Pope Pius XII, includes 'others'. The Quinlan case showed how true to the word this is. When it comes to nutrition and hydration however there is still controversy among ethicists.

Many ethicists consider nutrition and hydration to be so basic as to always constitute an 'ordinary' measure. Just as much ethicists however still believe that this is not the case. These arguments arise on whether to *start* a person in a PVS on hydration and nutrition. Definitely a person in such a state cannot be considered to experience hunger in the psychological state. Any nutrition and hydration does not give any satiety or satisfaction. It is simply to keep the physiological status of the body. The Englaro case showed, as opposed to the Sciavo case, how much life can be being held on a thread with nutrition. Jonsen, Siegler and Winslade, following Catholic moral teaching, propose that since controversy exists, both positions are ethically permissible and there is legal ground for both[3]. Certainly, Jonsen is a renowned Catholic theologian in the U.S.

What is unfortunate about these cases is that all forms of confidentiality are lost; people become overly emotional and judgemental about the relatives, and the application of the moral rule of what constitutes extraordinary is lost to public scrutiny and opinion. Some countries may decide to legislate to make things easier. This of course will remove one's right to having advance directives about one's own care, which seemed to be the issue in this case as well.

There will hopefully come a time when we can have a structure which protects both patients and family, keeping the dignity of the situation. This would have to include some form of scrutiny to avoid abuse. Certainly if we decide that both options (giving or withholding nutrition and hydration) are both morally permissible, such policing would not be necessary. For many, living in a PVS for over seventeen years is extraordinary in itself. Other than contact with the person who feeds them two or three times a day, these people usually remain alone all day.

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There is a growing literature and evidence on people in PVS. Some drugs have been shown to improve their condition and even bring them back to a relatively normal life. Classifications are continuously developed with further understanding. Indeed many do recover within the first six months. After that the chances are very slim and deteriorate with time. There are exceptional cases and it may be the case that one will be able to identify these with further knowledge on these cases obtained by the use of imaging techniques. There is certainly not enough evidence at the moment and one has to respect that there is an evolutionary phase for both definitions (ordinary and extraordinary treatments). Does nutrition in cases of PVS become extraordinary after a few years? Should we allow the person to die in dignity or leave them in this abyss, if abyss it is?

Conversely PVS has been around since the early seventies, when it was described by a neurosurgeon from Scotland. It is a side-effect of modern medicine, and we are still in the evolutionary phase of understanding even the classification, let alone the state itself. In the meantime should we be 'prudent' and give physiological feeding to these people and keep them in this abyss for seventeen years; or should we build an evidence-based literature which guides us as to when, early in the process, feeding would be considered extraordinary? For the family it is always difficult, but as with life support systems, there will be those who, as in the Quinlan case, would see any advancement as a technology which interferes with the natural dying process. There will be others who, even after the relative is brain dead, will object to the removal, thinking that since their heart can be kept beating, then there is still the possibility of a miracle. We have moved forward with life support systems, and chances are that we will move forward in PVS.

References

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