PRACTICAL DILEMMAS OF TREATMENT DECISIONS: WITHHOLDING OR WITHDRAWING TREATMENT – FROM A CLINICIAN'S POINT OF VIEW

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Introduction

Withdrawal or withholding of treatment, especially nutrition and hydration, is a difficult issue for doctors. The ethical dilemmas for the treating team is such that there are often very strongly held views which makes discussion a sensitive issue.

The Concept of Withholding and Withdrawing Treatment

There is considerable confusion about whether there are philosophical differences between withholding treatment and withdrawing it. From a practical point of view it is worth while looking at the decision making process. First is the situation where it has been decided that a patient has a condition for which there is a treatment. If the decision has been made not to give the treatment then that treatment has been *withheld*. If the treatment is given then a time may come when a decision has to be made whether the treatment should be discontinued. If it is discontinued then the treatment has been *withdrawn*.

The difficulty arises when the decision is made to withhold the treatment to avoid the situation of having to withdraw the treatment later. This implies that it is easier not to start a treatment than to discontinue the treatment. We then have to ask – who benefits from this decision making process? There is some concern that it is not the patient who benefits as much as the doctor who avoids an uncomfortable situation. This concern was expressed by Lords Goff and Lowry[i] in the Bland[1] case in the UK. They argued

[1] Tony Bland was a young man who became vegetative following severe anoxic brain damage when he was crushed in a crowd disturbance at a football match. The application to the Court for a declaration that it would be legal to withdraw nutrition and hydration was the first case to make such an application through the Courts. The case went to the Court of Appeal and then to the House of Lords [the highest Court in

"…….We not believe that there is a valid distinction between omission to treat a patient and the abandonment of treatment which has commenced, since to recognise such a distinction could quite logically confer on a doctor who refrained from treatment an immunity which did not benefit a doctor who had embarked on treatment in order to see whether it might help the patient and had abandoned the treatment when it was seen not to do so"

In other words they were concerned that a doctor who did not give his patient the opportunity of recovering (i.e. by withholding treatment) did not have to face the rigors of legal scrutiny whereas a doctor who gave the patient treatment to see whether there would be recovery and wanted to stop the treatment when there was no evidence of recovery had to face legal scrutiny. For this reason the British Medical Association[ii] came down very firmly that the decision making process for deciding whether to withhold treatment should be exactly the same as for withdrawing treatment i.e. the decisions should be made using the same criteria. They stated "Although emotionally it may be easier to withhold treatment than to withdraw that which has been started, there are no legal, or necessary morally relevant, differences between the two actions".

The British Medical Association did, however, recognise that whilst there is no legal or moral difference between withholding or withdrawing treatment many health professionals and patients feel that there is an emotional difference, associated with 'giving up on the patient'.

They suggested that there should be greater emphasis placed on the reasons for providing the treatment rather than the justification for withholding it. They also were very clear that "Treatment should never be withheld, when there is a possibility that it will benefit the patient, simply because withholding is considered to be easier than withdrawing treatment".

England] where the final decision was made that it would be legal to withdraw nutrition and hydration. The Law Lords however did stipulate that all future cases should also go to the Court for a declaration.

Process on Approach[iii]

So if the situation does arise where does the treating clinician start? The approach is likely to be different in various parts of the world. In many countries the role of the family in the decision making process is essential whilst in others the decision is considered to be purely a clinical decision.

The subject is complex and for clarity this paper considers the specific situation of decision making to withdraw nutrition and hydration in a vegetative patient.

This paper explains the approach in the United Kingdom where although families do not have a legal right in decision making it is considered to be good practice to involve them. This paper also assumes that the decision to withdraw nutrition and hydration requires a declaration from a Court of Law that to do so would be lawful.

The first step is to meet the family and find out what their views are and what their understanding is of the situation. Questions to be asked are: what do they know about the vegetative state?; do they understand the prognosis?; are there any points they want to raise about the benefits and burdens of the treatment?; are they aware of the legal process which needs to take place?; and are there other relevant members of the family who are not present but who may hold different views? At this stage the clinician's role is more to help the family understand the facts rather than advise for or against the withdrawal of the tube.

This is also the stage when the lead clinician has to make a moral decision about their own approach to the withdrawal of nutrition - if the views prevent the clinician being involved then it is essential that the care of the patient is passed to another clinician who

would be willing to withdraw treatment should the Court declare that it would be legal to do so.

Questions to be answered

The following are some of the questions which usually need answering:

- What is the diagnosis? – It is important that there is a definitive diagnosis of the vegetative state made by a clinician who has considerable experience of the condition. There have been several studies which have found a high prevalence rate of misdiagnosis.[iv,v,vi]
- Are there any factors which might be influencing whether the patient can demonstrate awareness? The Royal College of Physicians Working Group[4] on the 'Permanent Vegetative State' set three preconditions for the diagnosis of the permanent vegetative state:

    a. There shall be an established cause for the condition. It may be due to acute cerebral injury, degenerative conditions, metabolic disorders or developmental malformations.

    b. The persisting effects of sedative, anaesthetic or neuromuscular blocking drugs shall be excluded.

    c. Reversible metabolic causes shall be corrected or excluded as the cause.

- What is the prognosis for recovery? If there is any potential for recovery then it would be unwise to proceed to withdrawing treatment. The difficulty is deciding what level of 'recovery' would warrant treatment being continued and below which treatment could be withdrawn. It is a general principle of medical ethics that it is not an appropriate goal to prolong life at all costs, with no regard to its quality or the burdens of the treatment[2].

- What is the life expectancy if nutrition and hydration are not withdrawn? The decision making process is likely to be different if there is only a short life expectancy because of frequent acute illnesses compared with a long life expectancy in a medically stable but unconscious patient.
- Has everything been done to achieve improvement? Removing nutrition and hydration is such a serious decision that it should not be made if the patient has not had an opportunity of optimal treatment. The evidence of misdiagnosis described above was all due to the diagnosis being made by inexperienced clinicians (vegetative state is a rare disorder) who lacked the expertise to assess appropriately and to provide an appropriate disability management programme.

Is it in the Best Interests of the Patient to Withdraw Treatment?

Where the treatment is not benefiting the patient then the treatment is not in the patient's best interest. This, however, is a complicated debate in nutrition an hydration where it is clear that the 'treatment' is having the desired effect in providing maintenance of healthy tissues. The difficulty is whether it is benefiting the patient in the broader sense that it cannot achieve consciousness or any return of the 'person'.

Discussions about *best interests* often consider it in the terms of "is it in the best interest of a patient who is unaware of his or her internal or external environment to continue tube feeding?". The obvious answer may seem to be 'no' but it must be questioned whether the patient has *any* interest rather than a best or worse interest. If this is the case then the decisions are being made for the benefit of others, a dubious decision making process.

Best interests require us to know what the patient would have wanted:

a. Is there an advance directive or advance refusal[vii]? Whilst these indications of what the patient considered they would want to happen to them if they became

mentally incapacitated would seem to be a clear directive they can only have an influence on withdrawal or withholding of treatment rather than an insistence on having the treatment. Advance directives are also often unclear, especially when dealing with rare conditions such as the vegetative state, and it can be difficult to know whether the patient was making an informed instruction. Nevertheless where there is an advance directive it should only be ignored on very good grounds.

b. What factors in the patient's life would influence the patient's decision making process – did they have strong religious or cultural views, or had they expressed the views about other end-of-life situations in other people.

Much of this information is going to be obtained by relatives. In many countries relatives do not have any legal right to make clinical decisions on behalf of the patient and therefore asking them to do so has no legal validity. Indeed it places the relative in a difficult position – if they ask for the nutrition and hydration to be withdrawn they will feel responsible for the death of the patient; if the ask for the tube to remain in place then they may feel guilty about the prolonged state of unconsciousness. It is reasonable to ask the relatives what decision they think the patient would have wanted making, though it is of note that there are often conflicting replies from different members of the family..

Team Involvement

Withdrawing nutrition and hydration is a major decision for all members of the clinical team caring for the patient. It is usually important to involve nurses and therapists who are actively treating the patient in the discussion about withdrawal of nutrition and hydration. What are their views about diagnosis, appropriateness and effect on the team morale which are worth taking into consideration?

Supporting the Family and Team

This is not a comfortable situation for anyone. Whilst the lead clinician has an important role in supporting the family and certainly providing clinical and legal procedure information it is recommended that formal counselling support is available for the family. A family is made up of a group of people with complex interrelationships[viii] whose ability to cope depends on the relationships and behaviour before the onset of the brain damage, the nature and severity of the injury, and the availability of a supportive community[ix]. Supporting families is not easy since there are many emotional reactions which need to be understood and coped[x] with including anger, hostility, denial, guilt, overprotection, anxiety, depression and social isolation.

It is important that the involved staff, whether the patient is in hospital, nursing home or at home, should have access to counselling services. It is also good practice to discuss with the team as a group the pros and cons of withdrawing treatment so that they do not feel that their moral views have been ignored.

Practical Process for the Unit

There are several practical issues for the unit worth considering. These include:

1. Caring for the patient in a single room to help to maintain the confidentiality of this very sensitive issue and allow privacy for the family
2. Identify the staff who are morally willing to be involved in the care of the patient. Some staff will have strong moral and cultural views and these should be respected. These staff should be given an opportunity of moving to another unit during this period.
3. If necessary seek the advice of the local palliative care service.

What will happen when the tube is removed?

The removal of the tube is a simple procedure but seems to be such a big step to take. Once the tube is removed the care is straightforward good general nursing care of the dying patient.

Some believe that giving sedation or analgesia would meet any concerns that the patient may feel pain or distress. The advice of a palliative care service would help in this process.

It is important that both nutrition and hydration are removed. Death will be due to the effects of dehydration rather than of undernutrition. To provide fluids but not nutrition will prolong the dying phase by weeks or months.

Death usually occurs within 10-14 days and it is usually peaceful.

Conclusion

Withdrawal of nutrition and hydration in the vegetative patient is not any easy decision to be made. It creates many anxieties within the family and the treating clinical team. Great skill, caring and sensitivity is required to ensure optimal support for patient, family and staff.

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