

Death, dying and the neurosurgeon: a trainee's perspective

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Abstract

Neurosurgical trainees face many challenges, both personal and professional during their training. By far and large, undergraduate and postgraduate medical training prepares you for the academic commitments faced during one's training. However, precious few have had formal training in dealing with the dying patient or for that matter in helping bereaved relatives cope with impending loss or the death of a loved one. This article will attempt to highlight some of the aspects of death and dying from the perspective of the neurosurgeon and hopes to make useful suggestions on coping strategies for the patient, the relatives and indeed the physician.

CLASSIFICATION OF LOSS AND PERSONS AFFECTED

Coping with loss in the field of neurosurgery can be artificially divided into three main categories, the patient, the patient's relatives and the caregiver. Within each of these categories lie two broad artificial sub-headings; expected and unexpected loss. A compassionate approach is required to deal with all concerned within each of these areas. Unexpected events are naturally more difficult to cope with than events that are planned for in advance. Support systems are required for each group, regardless of age and experience of dealing with loss, be it loss of independence, terminal illness, death and dying. An attempt to classify illnesses into these groups is illustrated below.

Figure 1

Table 1

| Group | Unexpected deaths | Expected deaths |
|---------------------|--|---|
| Patient | Traumatic brain injury Pulmonary embolism Infection Seizures Intracranial bleed Degenerative spine disease Alcohol consumption | Malignancy |
| Patient's relatives | Seizures Intracranial bleed Alcohol consumption Traumatic brain injury Pulmonary embolism Infection Seizures Degenerative spine disease | Malignancy |
| Caregiver | Traumatic brain injury Pulmonary embolism Intracranial bleed Seizures Degenerative spine disease Alcohol consumption | Traumatic brain injury Pulmonary embolism Malignancy Intracranial bleed Seizures Degenerative spine disease Alcohol consumption |

This table illustrates that the caregiver because of the heightened familiarity with different illnesses are more likely to understand the risks of loss involved. This means that in order to cope with potential loss of life, the first step is education.

THE IMPORTANCE OF ADEQUATE PRE-OPERATIVE PREPARATION

Pre-operative and non-operative preparation begins when one first meets the patient and the patient's relatives. A complete history and understanding of the nature of the patient's illness and a balanced perspective of the risks to the patient's independence and life need to be communicated at the earliest opportunity, in order for them to adequately prepare for the difficult readjustments and decision making processes ahead. The importance of having family support at the time of consultation cannot be under-estimated. It helps the caregiver to gain an insight into the patient's and his next of kin's social background which is all important in helping to make decisions in the best interest of the patient. The issue of a living will and an insight into life insurance cover and disability cover can often be inferred during these sessions. In short, help the patient and their relatives prepare for the worst but hope for the best, within the confines of realistic expectations (Ref). Of course there will be times when the opportunity for this kind of preparation is lost, as occurs in the case of trauma.

DEALING WITH AN UNEXPECTED EVENT

My way of helping the patient and relatives cope is to find out first whether they understand the nature of events that

led to this point and what the consequences of the trauma have been. By doing this, one gets more history that may be directly relevant to the patient's management, such as obtaining the mechanism of action of spinal trauma, or finding out the exact time of brain injury versus the timing of the first scan. This also sets the stage of involving the patient and their relatives in the decision making process of therapeutic options, which goes a long way to relieve the sense of helplessness felt when a total stranger steps in to look after their loved one. It also gives the caregiver the opportunity to identify the named next of kin and establish what support services may be needed to get them through this trying period of their lives. Such services include the Specialist Liaison Nurse Team, the local Chaplain, the bereavement officer and the Patient advisory Liaison service if necessary. Occasionally legal services and the police may be needed in cases of trauma and finally, it is always helpful and reassuring for the family to have a named caregiver to whom they can receive updates on their loved one's condition. Personally I counsel each patient and their relatives to take things one day at a time in serious trauma given the relatively unpredictable and sometimes rapid turn of events, for better or for worse that can take place. This is a very important point to be stressed at this stage. In cases where the situation is clearly hopeless, there is the opportunity to identify what the patient's wishes would have been as far as tissue and organ donation are concerned and whether they would want to be resuscitated, ventilated or not. There are times obviously when a medical decision will need to be made about the appropriateness of this.

WITHDRAWAL OF TREATMENT

Bad news is best delivered in small doses over time. It is important to remember that people do have different coping strategies and are already under considerable stress. Speaking to them about a hopeless outcome despite medical therapy is best introduced early. Withdrawing active therapy that does not improve the patient's illness must be considered when there is a danger of the patient suffering unnecessarily and losing their dignity. Such a decision is never taken lightly and should never be taken alone.

It is best to involve two senior members of the medical team, a nurse and the next of kin in the decision. The way in which treatment is withdrawn must also be discussed. The GMC has published clear guidelines on these issues (www.gmc-uk.org/guidelines/library/withholding_lifeprolonging_guidance.asp#gmc_print). Those of particular relevance to the neurosurgeon are summarised thus:

Doctors have an ethical responsibility to protect their patient's health and to seek their patient's best interest by offering treatment where the benefits outweigh the burden/risk of treatment and avoiding treatments of no benefit.

.... In cases of acute critical illness where the outcome of treatment is unclear, survival from the acute crisis would be considered in the patient's best interest.

Life has a natural end....doctors should not prolong the act of dying with no regard to the patients wishes or a reassessment of benefit vs burden/risk of treatment or no-treatment. This includes the appropriateness of CPR.

Adult competent patients can express their wishes in advance directive eg living will or verbal instructions to the doctor. Doctors are legally bound to respect their wishes.

Any patient decision , when competent, with respect to treatment is legally binding

When the patient is incompetent, the doctor is legally responsible for the decision making process.

Junior doctors may conscientiously object to the decision to withdraw care and in so doing should inform the consultant and withdraw from the patient's care. An equally competent replacement must be found as to not compromise patient care

In the case of a life threatening emergency, when a delay can result in a poor outcome, a decision can be made in the absence of information about the patient's wishes

In establishing best interest: always take reasonable steps to determine whether an advance directive was given by the patient, whether the patient had expressed their wishes to anyone and finally be careful not to inform those who the patient may not have wanted to tell about their condition.

Seek a consensus about withdrawal of care and how it is to be done. If a consensus cannot be reached, seek informal advice from an independent multidisciplinary clinical team and or ethics committee. If this fails seek legal counsel.

All decisions must be clearly documented including all those consulted in the patient's records. Adequate communication of these decisions especially during shift changes is paramount. Remember that these decisions should be reviewed when it is appropriate to do so.

Clinical audit on withdrawal of treatment should be carried out and education on handling these issues should be carried out

Withdrawing treatment is quite clearly a complex area and fortunately for the neurosurgical trainee, our neurointensivist colleagues are more heavily involved in such decisions. To be completely ignorant however about this however is foolhardy.

BRAIN DEATH AND THE NEUROSURGEON

All neurosurgeons have to deal with patients who are diagnosed with brain death. Unfortunately, to date, no worldwide consensus exists as to the criteria for brain death. The preconditions for diagnosis of brain death include the following:

The patient's condition is due to irremediable brain damage of known aetiology

The patient is deeply unconscious

The patient is being maintained on the ventilator because of spontaneous respiration has been inadequate or ceased altogether

The exclusions include

The presence of depressant drugs eg. Narcotics, hypnotics and tranquilisers

Hypothermia (<35 C)

Reversible circulatory, metabolic and endocrine disturbances

The performance of these tests should be done by two medical practitioners registered with the General Medical Council for at least 5 years, one of whom must be a consultant. Both should be competent in the field of neurosurgery or critical care and neither should be a member of the transplant team. Two sets of tests are carried out and the time interval between the tests is not stipulated. The legal time of death is when the first set of tests has been completed and death is certified at the end of the second set of tests.

Clinical assessment of brain stem function include

No papillary responses to light

No corneal reflex

No vestibulo-cochlear reflex

No motor response to central stimulation

No gag and cough reflexes

No respiratory movements during apnoea testing

These brain death criteria do not apply in children under the age of 37 weeks and it is rare to confidently diagnose brain death between 37 weeks and 2 yrs of age. Details can be found on the Intensive Care Society Website at www.ics.org.uk.

ORGAN AND TISSUE TRANSPLANTATION

The Intensive Care Society has produced guidelines on organ and tissue donation in the brain stem dead and non-heart beating donor. These guidelines can be summarised as follows:

Age: There is an age restriction of 85 years for brain stem dead donors. No definitive age restriction exists for potential non-heart beating donors and tissue donors. The following age restrictions apply for different organs and tissues

Figure 2

Table 2: Age restrictions for organ/tissue donation

| Organ/ Tissue | Age limit |
|------------------------|----------------|
| Heart and heart valves | Birth - 65 yrs |
| Non cardiac organs | Any age |
| Skin and bone | > 17 yrs |
| Corneas | > 2 yrs |
| Tendons, ligaments | 17 – 50 yrs |

Transplant co-ordinator : Discuss all potential cases with the transplant co-ordinator

Absolute contra-indications: HIV and CJD are absolute contra-indications for organ transplantation and tissue donation. Hepatitis B/C, HTLV, Syphilis, unknown CNS disease, haematological malignancy, Alzheimer's and unexplained confusional state are added to the list for Tissue donation.

The family: After the first set of brain stem tests, the transplant co-ordinator and the critical care staff will discuss the options of donation with the family. A documented "lack of objection to donation" must be made.

The Coroner: Remember to discuss all relevant cases with the coroner. When in doubt, refer for permission to harvest.

Donor assessment: This will be carried out by the transplant co-ordinator and the patient registered at UK Transplant. A full set of medical notes, including past medical history, drug and social history is required for the assessment.

Harvesting: In the case of the NHBD, arrangements are

made for withdrawal of treatment with the family. Death is certified (NHBD) after 5 minutes of cessation of cardiopulmonary function. The family must have adequate support during this process. In the case of brain-stem death, after the second set of brain stem tests, organ retrieval can take place. The organ retrieval team then perform retrieval in the operating theatre and the family are given the opportunity to see their loved one post retrieval. The timing between the diagnosis of death and harvesting has implications for what organs can be harvested (Table 3)

Figure 3

Table 3: Maximal interval between withdrawal of treatment and diagnosis of death allowed for organ/tissue harvestingle

| Organ | Time to harvest |
|--------|-----------------|
| Liver | < 1 hr |
| Kidney | < 4 hrs |
| Tissue | Within 24 hrs |

Last Offices and Cultural competence : Leaflets about these issues are available from www.uktransplant.org.uk and can be found in Whitely, Bodenham and Bellamy's Churchill's pocketbook of Intensive Care, Chapter 16, pages 372-375. Suffice it to say that the religious and cultural beliefs of the patient and the family must be respected and time must be allowed for last offices. Some cultural groups may not believe in organ donation.

Follow-up care : It is always important to acknowledge that organ and tissue donation is a gift and gratitude must always be expressed. The family should be referred to the hospital bereavement services and grief counsellors. Feedback should be supplied about the success of organ donation as this has been shown to help families cope with their loss.

DEATH BY THE SURGEON'S HAND

Few neurosurgeons are blessed never to have lost a patient due to operative intervention. Preparing for this type of event goes far beyond just having medical protection cover (MPS/MDU). One has to deal with one's own feelings; your attending's thoughts on the matter and of course the patient's relatives who will be traumatised if the death was unexpected. One very important strategy is to attend the morbidity and mortality meeting and present the patient's case and receive a peer review of whether appropriate actions were taken. This is an important source of audit and helps to identify deficiencies of service, training and also to help educate the caregivers to prevent recurrences of "preventable" deaths. Keeping a copy of the minutes from these meetings is an extremely useful way of learning from

not only your mistakes but from others mistakes as well. It is important to remember than no one is perfect. What is expected is that one does what is reasonable for one's level of competence. Goldstone et al investigated whether surgeons should refrain from operating for 48 hours after an intra-operative death. Their results suggested that whilst mortality did not increase amongst the surgeons who continued operating, the patients post-operatively spent longer in hospital and longer in the intensive care setting. This may reflect a reduced level of confidence on the part of the surgeon or it may represent a reduced level of actual operative performance. These parameters however would be extremely difficult to measure. For many busy neurosurgeons, a 48 hour break in the middle of a busy elective and emergency service, is not a practical option and like the orthopaedic surgeons studied in Smith and Jones's paper, may consider intra-operative death "part of the job". Perhaps the simplest way of dealing with an intra-operative death is not to have one in the first place. Proper patient selection is paramount in the case of an elective patient, but in the emergency setting, adequate resuscitation is paramount. In this regard, the on-call neurosurgeon is particularly vulnerable as most of his referrals may be off-site at a District General Hospital on whom he has to depend on to stabilise a patient adequately for transfer. A neurosurgical outreach educational program in the catchment areas of neuroscience centres may reduce the probability of inadequate neurosurgical resuscitation.

THE HISTOLOGY RESULT: DELIVERING BAD NEWS.

Perhaps one of the most difficult tasks facing a neurosurgical trainee is to look a healthy-looking relatively young patient in the eye and tell them that their life is going to end prematurely. For parents, this is devastating news and it is often best for them to come to terms with the impending loss of their child, and for them to tell the child themselves. With the increasing use of Neuro-oncology Multidisciplinary Teams (MDT's) less of the burden of responsibility is falling on the trainee and more often than not, the team co-ordinator delivers the news. Regardless of who this might be, it is imperative that (1) they know the up to date scientific information about the tumour (2) what the therapeutic options are and how the patient can access them (3) they give the patient's realistic expectations and hope (4) provide an easily accessible support network for the patient and their family. NICE guidelines indicate that this information should be delivered in one (1) day of availability of results for inpatients and five (5) days for outpatients.

CONCLUSION

Confronting these issues is part of the art of medicine. Some aspects can be taught, some one learns during training. It is hoped that this article heightens the awareness of trainees and trainers alike on coping strategies for all parties concerned so that we may better educate ourselves to serve our patients needs.

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