

The Intensive Care Unit, Emergency Room and Brain Death Week 3

Emergency rooms (ERs) have been with us longer than I can remember as places where the acutely ill were triaged by family physicians and surgeons before admission to hospital. However except in rural areas, family physicians have long since left the ER, initially unwillingly but in recent decades, gladly for the more controlled hours of office practices, which is the norm in the era of Family Health Care Teams (FHCTs) in Canada these days. ER practice has become recognized as a specialty in its own right requiring several years of training beyond medical school. The change was necessary given the complex diagnostic and treatment skills required in the modern ER. The move to emergency specialist care, while welcome from the technological and management points of view, had its downside. Physicians and patients in the ER are strangers to one another and as a result care is often much less personal than it was in earlier times.

When I grew up in London, Ontario in the 1940's and 50's there was a good chance that your own family physician saw you in the ER – often consulting with other physicians as needed – admitted you and looked after you or at least oversaw your care in hospital and finally discharged and followed you thereafter. What's been lost in the transition to ER specialty care which came into widespread fashion in the late 60's and early 70's in Ontario, has been continuity of care by physicians who know us and especially where end-of-life issues were concerned, know our wishes and respect them, without recourse to 'directives'.

Intensive Care Units (ICUs) followed in the wake of the polio epidemics and the clear need for specialists to manage those who needed ventilator care – at first with iron lungs and soon thereafter the first of what eventually morphed into the sophisticated computer controlled modern day ventilators we're so familiar, complete with all their bells and whistles. Not surprisingly, many of the first generation ICU specialists were anesthetists well familiar with the complexities of ventilator support, given their key role supporting ventilation during many surgical operations. Soon the field attracted specialists from internal medicine, keen to apply their newly acquired understanding of the problems of how to deal with failure of one

or more of the bodies systems such as the heart, blood pressure regulation, kidney function and the acute effects of trauma, mostly from motor vehicle accidents. They knew less about the nervous system but neurosurgeons and neurologists stepped into the breach to support threatened brains, spinal cords and peripheral nervous systems caused by trauma, infection and acute autoimmune attack. These days even ICUs have sub-specialized into Neurointensive Care, Acute Heart and Stroke units. There's no doubt that these, now highly specialized services, save lives and beyond that provide much better outcomes for patients threatened with an array of acute problems. But those successes come at a price. Sometimes ICU units create their own problems such as infections acquired within the unit, wasting of muscles and even a poorly understood as yet disorder affecting the peripheral nervous system, either or both of which may make it very difficult to wean a patient off their ventilator. The latter problems were first recognized by a colleague of mine in London Ontario, Dr. Charlie Bolton, much of whose work was initially ignored or disparaged but has now entered the mainstream of understanding of the many complications of care in ICUs. And those aren't the only problems created by ICUs. Beyond all the noise, comings and goings of staff, constant checks and rechecks and bleeping of various devices, it's very difficult to get any rest in ICUs.

I well remember looking after one patient who was totally paralyzed except for flickering of her eyelids and tears. She suffered from Guillain-Barré Syndrome (GBS), a post-viral acute autoimmune-mediated peripheral neuropathy). Over the next several weeks she slowly recovered. One day, soon after she was up and about we talked about her experience. She told me that it was the most frightening, painful experience of her life, made worse by any movement of her body, suctioning her trachea and well intended staff, who non-the-less behaved as if she was unaware and talked about her as if she wasn't there. When she fully recovered I asked her to come back to share with the staff her experience in ICU. It was an eye-opener for the staff and we subsequently invited her back on several occasions to talk with new patients afflicted with the same problem, their families and staff. Most ICU staff members are fully aware of this kind of problem these days but in the hubbub of a very busy ICU it's all too easy to forget what the patient is going through or even there in that maze of tubes and monitors. And there's the problem for those at the end of life who find

themselves in ICUs and ERs. They weren't made for intimacy of the kind of care hospice can provide.

Yet despite all the depersonalization it's so hard to avoid in ICUs and ERs, patients in the last weeks and days of their life too often find themselves in these specialized units and subject to too many ill advised and unnecessary tests and interventions. That's the dilemma and one some of you will no doubt be familiar with because of experiences with a family member or friend. These specialized units are simply not geared to end-of-life care but thank goodness they're there when we need them for the specific problems they manage so well. The staff in the ER and ICU is highly dedicated and trained to look after acute medical problems – just not end-of-life problems.

Brain Death

For much of history, an end to breathing and a beating heart, marked death. And so it remains with one exception: brain death in its various shades. There is for example the slow deterioration of brain function, which occurs in many neurodegenerative diseases such as Alzheimer's disease, in which in the later stages, all vestiges of self-awareness and awareness of others may be lost. All that remains in the last stages may be a hollowed out, wasted brain capable of little more than sustaining the most vital of functions such as breathing in which most of the rest of the bodily functions go on autopilot.

The prognosis for patients in the late stages of neurodegenerative diseases such as Alzheimer's disease or frankly any of the neurodegenerative dementias, who lapse into a wakeful but unaware state or unresponsive coma, unrelated to the adverse effects of drugs, or some reversible water or electrolyte imbalance, is very poor. They remain in a vegetative or near comatose state for the rest of their life, a state, which may be prolonged for many months and even several years by tube or even spoon feedings. This was the case with Aunt Betty who I referred to in an earlier column.

It is the latter death in all its stages that most of us fear for ourselves and our loved ones and about which those of differing cultural and religious

beliefs argue about whether what remains is worth sustaining. This 'vegetative' state - wakefulness associated with eye opening but empty of what many associate with being human, has become a battleground for some these days. The brainstem is working but not much else. Should those so afflicted, with no hope of recovery, be sustained or allowed to die peacefully with only such care as needed to prevent suffering? Is there a place for assisted death in these or other cases discussed below?

What about acute injuries to the brain, such as the sometimes severe brain trauma that may accompany motor vehicle or motorcycle accidents or perhaps a bad fall or the hypoxic (lack of oxygen)/ischemic (lack of circulation) injuries which may follow cardiac arrest and cardiopulmonary resuscitation (CPR)? Not surprisingly, the young fair surprisingly well following traumatic brain injury (TBI) and CPR although the experience of the US and allied forces in Afghanistan and Iraq suggest that even the young may experience long lasting debilitating sequelae following blast and other brain injuries. The picture is much less rosy in later life for recovery from TBI and CPR. For example in the later decades, too often, CPR either fails to restore the circulation or succeeding, leaves victims with severe brain injuries from which few recover without severe and lasting behavioral, cognitive and sometimes speech deficits. Similar prognostic differences for recovery from severe stroke, infections affecting the brain such as bacterial or viral meningitis and/or encephalitis exist; older folk fare much worse than their younger brethren. In common parlance, few want to become a 'vegetable' devoid of all but the vegetative functions supported by the brainstem and hypothalamus. However unlike the case of the relentlessly progressive dementias where there is no hope for recovery, some patients recover wakefulness and a measure of awareness of others months or even years following severe brain injuries. Such cases are rare but reason to pause sometimes before we consider any form of assisted death.

The criteria these days for 'brain death' are very strict. The reasons for brain death must make sense on the basis of the clinical, imaging studies such as MRI and physiological (EEG monitoring and Evoked potential studies) evidence, there are no other factors in play such as drugs, intoxications, septicemia or non-convulsive seizures from which the patient

might recover, sufficient time has been allowed for any significant recovery to take place and finally the brainstem must be shown to be incapable triggering respiration on its own in the face of rising CO₂ levels in the blood despite adequate oxygenation. Only when the foregoing criteria have been met, may a patient may be considered to be 'brain dead' and possibly an organ donor for kidneys, the heart and sometimes the lungs.

Moral and ethical problems arise not with those meeting the criteria for brain death but for those TBI patients who for example might be comatose or otherwise severely behaviorally affected but in whom there remains some potential for recovery. There are after all, those rare patients who waken and even partially recover, months or even a few years from a 'vegetative state' or 'minimally conscious state'. The vegetative state is characterized by periodic opening of the eyes, but without any sense self-awareness or awareness of others, and may be sustained by the upper brainstem and the thalamus with little if any activity in bulk of the brain's neocortex. On the other hand, patients in a minimally conscious state show some evidence of awareness of others and speech both of which depend on the integrity of the brain's neocortex. And it is the survival of the latter cortex on which quality of life and all that we associate with being 'human' depends.

In recent years some patients – invariably young – living in what appeared to be a persistent vegetative state lasting many months and even years based on clinical criteria alone, turned out to show some evidence of higher-cortical function and hence 'awareness' based on sophisticated imaging such as fMRI studies and physiological tests. These findings have raised questions about whether clinical observations alone suffice for determining whether what it means to be human, exists in some patients, otherwise thought to be insensate. It's easy to see why these issues provoke so much medical, legal, philosophical, religious and ethical controversy when it comes to making practical decisions about the quality and meaning of life. Is all life sacred? Is supporting life by any means possible correct? What does it mean to be alive? It's a dilemma we've created for ourselves through the growing capacity of modern medicine to prolong life, at some level and in some cases almost indefinitely – not something the ancient prophets had in mind and something too few

physicians gave much thought to when they created their life sustaining tools.

These and other questions about what it means to be human and whether and under what circumstances we should continue to support life or end life on our own terms are worth serious consideration well before events overwhelm us, our families and others charged with our care.

Questions Week 3

What's your experience been with Emergency rooms and Intensive Care Units for your parents or friends?

Are you worried about what might happen to you near the end with respect to ERs and ICUs?

Is all life sacred for you? What does that mean for supportive care for you or those you know and love?

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