

Emerging roles for law and human rights in ethical conflicts surrounding neuro critical care

This paper argues that recourse to judicial resolution for protracted ethical disputes concerning end-of-life decision making may become a more necessary and common part of clinical practice in neuro critical care. It discusses the relevance of this in the context of legal and ethical standards in this area becoming significantly influenced by a political agenda with an absolutist rather than qualitative view of the value of life. It discusses the emerging importance of international human rights in this context.

The *Schiavo* dispute in the United States has recently heightened interest in the role of the judiciary and legislature in withdrawal and withholding of treatment decision-making in neuro critical care. It also raised questions about whether “substituted judgment” or “best interests” should be the determinant test for making end-of-life decisions in neuro critical care. In the United States, courts have been prepared to accept as decisive clear and convincing evidence of what the incompetent patient would have wanted.¹ In the United Kingdom, courts have looked to the more objective standard of determining what is in the patient’s best interests.² There, critical care clinicians more routinely seek judicial resolution of protracted ethical disputes with relatives about when to cease active treatment of patients.³

The Australian legal system has till recently had few precedents in these types of cases. In *Auckland Area Health Board v Attorney General (Re L)* [1993] 1 NZLR 235 Thomas J held that withdrawal of treatment could take place when it was no longer in the best interest of the patient as determined by “prevailing medical standards.” He encouraged referral to a clinical ethics committee in contentious cases.

In a series of cases, the Queensland Guardianship and Administrative Tribunal (GAAT) found a 39 year old man with severe brain and spinal injuries, competent to request the removal of artificial ventilation (*Re PVM* [2000] QGAAT 1), agreed to a no-CPR order, but refused to consent to the withdrawal of antibiotics on the application of the wife of a 73yo male with an acquired brain injury (*Re RWG* [2000] QGAAT 2) and

granted permission to withdraw artificial feeding from an 80 year old woman in persistent vegetative state on the basis that it was not in her best interests (*Re MC* [2003] QGAAT 13). In these cases “best interests” was defined as involving an assessment of the patient’s reasonable prospects of return to what would be considered a meaningful quality of life. The role of the patients prior statements in helping define “meaningful quality of life” is one of the most problematic areas in this process.

In *Northridge v Central Sydney Area Health Service* (2000) 50 NSWLR 549 relatives of a patient who’d suffered brain damage after a drug overdose contested the decision of clinicians at the Royal Prince Alfred Hospital to withdraw artificial nutrition and hydration, as well as antibiotics, after five days in intensive care. A no-CPR order was entered on his chart, even though his GCS rating had risen to 9, and he was responding to voice. On the relatives application to the NSW Supreme Court, orders were made by a single judge to continue treatment and the court to be involved in future decisions about his treatment. Justice O’Keefe stated:

“There is undoubted jurisdiction in the Supreme Court of New South Wales to act to protect the right of an unconscious person to receive ordinary reasonable and appropriate (as opposed to extraordinary, excessively burdensome, intrusive or futile) medical treatment, sustenance and support.”

The judgment is a poor authority, however, as it contains no reference to prior judicial decisions in any jurisdiction and makes conceptual errors concerning the definition of futile treatment. It was also based on affidavit evidence rather than direct testimony from the health professionals involved.

In *Re BWV* [2003] VSC 173 – the Supreme Court of Victoria ordered a guardian to be appointed to refuse artificial feeding for a 68 year-old woman with advanced Pick’s disease. The Supreme Court found that artificial feeding was medical treatment, not the reasonable provision of food and water, and so could be refused under the *Medical Treatment Act* 1988 (Vic).

In the recent case of *Messiha (by his tutor) v South East Health* [2004] NSWSC 1061 however, a judge adopting the “best interests” of the patient test, common in United Kingdom jurisprudence authorised the withdrawal of futile treatment from a 71 year old COPD patient suffering hypoxic brain damage after an out of hospital asystolic cardiac arrest, over the objection of relatives. His Glasgow Coma Score ranged between 5 and 3 persistently and his EEG showed complete absence of cortical activity. The patient was off sedation and metabolically stable, being mechanically ventilated via an endotracheal tube and fed via a nasogastric tube. The patient had not met the criteria for brain death and

though in a deep coma, was not yet in a persistent vegetative state. The patient's relatives believed, however, that the patient had spontaneously opened his eyes to voice and demanded everything possible be done. They arranged for an eminent independent neurologist to examine the patient on 27 October. The neurologist agreed with the clinician's assessment of Mr Messiha's condition, and with her proposal to withdraw active treatment.

It is at this point that many clinicians would consult a clinical ethics committee (and the wide range of professional and community views there represented) to reassure relatives that processes were transparent and in the patient's best interests. Its effectiveness would depend on how familiar its senior members had previously become with the requirements of such situations and on its capacity to convene rapidly and offer appropriate expertise. For this to happen effectively a senior clinician should chair such committees. The St George Hospital has no clinical ethics committee.

The family challenged the clinician's decision to withdraw treatment judicially. Justice Howie, on hearing the application to restrain withdrawal of treatment, stated that the guiding principle under the *parens patriae* jurisdiction is the best interests of the patient and that medical opinion about that issue would be of great weight:

"It seems to me that it would be an unusual case where the Court would act against what is unanimously held by medical experts as an appropriate treatment regime for the patient in order to preserve the life of a terminally ill patient in a deep coma where there is no real prospect of recovery to any significant degree."

Subsequent to the judicial decision, requests by the family for a last electrocardiogram and to bring their own ventilator into the patient's palliative care room were refused. Outside court, the patient's son said "[I was told they] had to cancel two operations because of my dad. I heard [a staff member] say ... 'What you're doing to your father is cruel'. They play with you, they try to play with your mind psychologically and put you under a lot of stress in order to switch that life support off".⁴ This type of public expression of distress can be extremely upsetting for the clinicians involved and other staff at the relevant hospital. The publicity aspect may have been one of the most significant reasons why judicial declarations have previously been rarely sought in this area. Yet it may be that such judicial decisions are emerging as a means of resolving these issues with considerable advantages to clinicians. One important lesson was that the NSW Coroner's office recommended that where clinicians suspect that

relatives may be challenging a patient's death as unlawful, the death certificate should not be completed. This activates the jurisdiction of the coroner who will request an autopsy.

The Schiavo Case

On February 25, 1990, Terri Schiavo suffered hypoxic-ischaemic encephalopathy after a cardiac arrest caused by a hypokalaemia, precipitated by bulimia. Since that date she lived in nursing homes, and finally the Hospice of Florida Sun Coast, requiring constant care with defaecation, nutrition and hydration. She had severe contractures of her hands, elbows, knees and feet. Repeated subsequent neurological examinations revealed at best some persistence of sleep-wake cycles, reflex responses to light and noise and gag and swallowing reflexes. She made moaning sounds randomly, but displayed no signs of emotion, willful activity or cognition. CT-Scans revealed her frontal cortex had been substantially replaced by cerebro-spinal fluid. Her electroencephalograph ("EEG") produced a flat trace. This left her in what was clinically diagnosed by her attending physicians and other expert witnesses as a persistent vegetative state.⁵

Her husband, Michael, was appointed her legal guardian under a Florida statute. In 1993, he was awarded one million dollars in a malpractice lawsuit against physicians who failed to diagnose and appropriately treat his wife's eating disorder. In 1998, Mr. Schiavo filed a petition with the court to discontinue his wife's feeding tube, a request that her parents, Mr. and Mrs. Schindler, devout Catholics, opposed. These parties became involved in more than 25 court rulings and interventions over ten years, as a result of which Mrs Schiavo's PEG feeding tube was twice removed and reinserted. Contentious issues concerned whether Terri made an informal advance directive and who had the ultimate authority to withdraw futile treatment from her.

In 2001 a guardianship court found that Theresa Schiavo was in a persistent vegetative state and, despite her having left no written advance directive, there was "clear and convincing evidence" that, if capable, she would elect to cease life-prolonging procedures.⁶ On October 15, 2003 the Second District Court of Florida, after a close review of all the evidence, issued its fourth opinion on the matter. It confirmed the order of the guardianship court and agreed that Mrs Schiavo's nutrition and hydration tube could be removed. The court held:

"In the end, this case is not about the aspirations that loving parents have for their children. It is about Theresa Schiavo's right to make her own decision, independent of her parents and independent of her husband."⁷

An executive order (Public Law 03-418) was now passed as the behest of the President's brother Florida Governor Jeb Bush. This stayed the order of a Florida Second District Court that Mrs Schiavo's nutrition and hydration tube be removed.

- A. Effective immediately, continued withholding of nutrition and hydration from Theresa Schiavo is hereby stayed.
- B. Effective immediately, all medical facilities and personnel providing medical care for Theresa Schiavo, and all those acting in concert or participation with them, are hereby directed to immediately provide nutrition and hydration to Theresa Schiavo by means of a gastrostomy tube, or by any other method determined appropriate in the reasonable judgment of a licensed physician.
- C. While this order is effective, no person shall interfere with the stay entered pursuant to this order.
- D. This order shall be binding on all persons having notice of its provisions.
- E. This order shall be effective until such time as the Governor revokes it.
- F. The Florida Department of Law Enforcement shall serve a copy of this Executive Order upon the medical facility currently providing care for Theresa Schiavo."

The Florida Supreme Court and Florida Circuit Court found this legislation unconstitutional, principally on the ground that it allowed the Florida Governor to nullify the orders of the judicial branch of government, making individual rights insecure and permitting rule by "whim, favoritism and unbridled discretion."⁸

Late in March 2005 her doctor Dr Stanton Tripodis, following the permit of a Florida Supreme Court judge, again removed the feeding tube that had been keeping Schiavo alive for 15 years. This was despite the extraordinary, last-minute efforts of Republican congressional leaders to extend her life by issuing a subpoena for her to give testimony before them. Catholic organisations, including the Vatican, supported the Schindlers.

At a midnight sitting in March 2005, the US Congress now voted to order a federal court to review the case. A bizarre aspect was medically qualified politicians claiming, after viewing a videotape of the patient appearing to turn toward her mother's voice and smile, moaning and seeming to follow the progress of a brightly coloured Mickey Mouse balloon, that treatment was not technically "futile."

The legislation gave Mrs Schiavo's parents standing to challenge the withdrawal and withholding of treatment in the District Court for the Middle District of Florida. On Monday 21 March 2005, US President Bush issued the following public statement:

"Today, I signed into law a bill that will allow Federal courts to hear a claim by or on behalf of Terri Schiavo for violation of her rights relating to the withholding or withdrawal of food, fluids, or medical treatment necessary to sustain her life. In cases like this one, where there are serious questions and substantial doubts, our society, our laws, and our courts should have a presumption in favor of life. This presumption is especially critical for those like Terri Schiavo who live at the mercy of others. I appreciate the bipartisan action by the Members of Congress to pass this bill. I will continue to stand on the side of those defending life for all Americans, including those with disabilities."

The resultant Act of Congress granted the US District Court for the Middle District of Florida, and ultimately the US Supreme Court, unique jurisdiction over any claim made by the parents of 41 year old Theresa Marie ("Terri") Schiavo, concerning any violation of their daughter's rights "relating to withholding or withdrawal of food, fluids or medical treatment necessary to sustain her life." Both the Florida District Court and the US Supreme Court, however, declined to intervene.⁹ The patient died and a subsequent autopsy revealed she was blind and had severe, irreversible brain damage.

***Schiavo* and Emerging Roles for Law and Human Rights in Neuro Critical Care**

The *Schiavo Case* represented an unprecedented legislative involvement in individual end-of-life clinical decision making. Clinicians around the world are entitled to ask what was so unique about this case as to require individually-tailored pieces of legislation from both the Florida legislature and US Congress. The resource allocation consequences of making such intervention routine would be considerable. Criticisms that the legislative action in this instance is the result of a broader agenda on the human right to life and the political role of its religious proponents must be taken seriously. The courts involved in the *Schiavo Dispute*, in the face of considerable political pressure, confirmed that end-of-life decision making in the US involves an assessment of the substituted judgment of the patient, what the patient would have wished.¹⁰

Perhaps one hitherto under-emphasised reason for this conceptual position may be that in the US the entire doctor patient relationship is regarded as fiduciary in nature.¹¹ This creates, in effect, an equitable legal

obligation on a treating doctor to champion the interest of his or her particular patient against all others. In Australia, on the other hand, the doctor-patient relationship is merely regarded as having fiduciary aspects (that is, equitable legal duties of utmost loyalty against sexual or financial abuse).¹²

The more objective “best interests” test, has dominated the limited Australian jurisprudence in the contentious area of defining “futile” treatment.¹³ One important issue in this respect, discussed by Justice Howie in the *Messiha Case* was whether resource restriction (pressure for beds) should ever be mentioned to relatives in discussions of end of life treatment. Clinical experience shows that to do so risks relatives considering that the relevant doctors involved are not truly attempting to evaluate what is in the patient’s best interests. Yet, macro-level rationing of government health expenditure inevitably filters down to intensivists for whom it often reluctantly becomes a matter of trading lives in pressured clinical deliberations.¹⁴ It would be a logical next step in the current political debate for right to life organizations to encourage their members en masse to complete advance directives requiring everything be done. The consequences of such a step for medical professionalism and social justice distribution of scarce healthcare resources, are significant.

Disagreements also still arise as to what level of probability of a treatment producing return to a meaningful quality of life clinicians should choose before one says a treatment is not in the patient’s best interests. Making these types of judgments is regarded by most clinicians as a professional skill. Ethically clinicians are mandated to make a close assessment of the unique features of each patient’s “Best interests.” The *NHMRC Guidelines on Providing Information to Patients*, for example, require competent clinicians to seek to understand the patient’s “temperament, attitude and level of understanding,” as well as “circumstances, personality, expectations, fears, beliefs, values and cultural background”.¹⁵

Many would thus consider that developments such as that in the United Kingdom *Mental Capacity Bill 2004* merely codify what is already good clinical practise. Clause 4 of that Bill gives specific guidance as to what should be considered in any evaluation of what is in an incompetent patient’s “best interests.” Factors include likelihood that the patient will undergo a return to capacity and encouragement to do so, the patient’s past and present wishes and feelings, the beliefs and values that would be likely to alter the patient’s decision if she or he had capacity, the other factors this particular patient would consider and the views of nominated guardians or carers. The Bill provides that if a clinician who attempts to comply with the above decision making

process believes their determination is in the patient’s “best interests” then no liability attaches.

Some changes to advance directive legislation that might improve the process of “best interest” determinations for clinicians include: hospital admission staff being required to encourage patient completion of such a direction, a form encouraging specification not only of what treatments should be withheld, but what level of functioning the patient considered provided a minimum acceptable level of quality of life. Informal oral and written advance directive should be available for clinician and judicial consideration, provided they reach the level of “clear and convincing” evidence.

Another emerging development clinicians should be aware of could be the creation of a legal fiduciary duty to promptly disclose to a patient or his or her guardian the occurrence of a adverse event. Such a duty flows naturally from the vulnerability of the patient and is important given that tort law reform has restricted the time limits for patients to bring actions for compensation.¹⁶

Importance of International Human Rights In Neurocritical Care

The Florida Supreme Court in the *Schiavo Case* considered whether or not withdrawing and withholding treatment in that instance might breach legislation prohibiting discrimination against disabled persons. Such arguments could become more important in other jurisdictions not only because of similar legislation but due to moves towards a United Nations *Disability Convention*. The court held it did not, as the guardian who was making the decision was not exercising State power and the hospice’s decision to do so arose only from its need to comply with a court order. The Florida Supreme Court considered the constitutional prohibition (via the 8th and 14th amendments) on cruel and unusual punishment, but held it only applied after a lawful conviction. They evaluated the 14th amendment right to life (no deprivation without due process of law) but held it created no obligation on the State to protect citizens from private actors.¹⁷

Judges and clinicians in other jurisdictions, however, are paying greater attention to international human rights in this context. There are a variety of reasons for this. First, almost every country in the world has ratified the *International Covenant on Civil and Political Rights* (“ICCPR”). This contains a right to life (article 6) and a prohibition on cruel, inhuman or degrading treatment (article 7) which are much broader in scope than the rights enunciated in the US constitution.¹⁸ Patient advocacy groups, arguably, are increasingly appealing to the ICCPR rather than to medical ethics, which they see as too oriented to professional interests.¹⁹

Second, much influential UK jurisprudence has been increasingly influenced by human rights concepts since the *Human Rights Act 1998* (UK) required the judiciary to take into account norms flowing from the *European Convention on Human Rights* which are similar in this area to those in the ICCPR.

Third, Australian judges are beginning to pay more attention to international human rights, using them to fill in lacunae under the so-called Bangalore Principles, or, if they sit in the Australian Capital Territory, because of the *Human Rights Act 2004* (ACT). The ACT *Human Rights Act* is essentially declaratory in form rather than being a statement of enforceable rights in the model of the US Constitution. In this it resembles the United Kingdom Human Rights legislation and that of New Zealand. The crucial section is section 30 (1). This provides that “in working out the meaning of a Territory law, an interpretation that is consistent with human rights is as far as possible to be preferred. Section 30 (2) provides that this is subject preference be given to that interpretation which best achieves the purpose of a law. ACT judges faced with a legislative ambiguity or obscurity (for example, in advance directives legislation) or otherwise seeking to discover the meaning of such a law or avoid its absurd or unreasonable application, will thus be involved in a process of balancing statutory purpose against consistency with human rights.

The right to life is one international human right set to loom large in end-of-life decision making. Article 2 of the *European Convention on Human Rights* (“ECHR”) provides

“Everyone’s right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.”

The case-law of the European Court of Human Rights accords pre-eminence to Article 2 as one of the most fundamental provisions of the Convention.²⁰ The European Court of Human Rights has held that Article 2 enjoins the State not only to refrain from the intentional and unlawful taking of life, but also to take appropriate steps to safeguard the lives of those within its jurisdiction.²¹ US judicial authorities appear not to have gone so far with the right to life in the US Constitution.²²

This obligation may also imply in certain well-defined circumstances a positive obligation on the authorities to take preventive operational measures to protect an individual whose life is at risk from the criminal acts of another individual.²³ In *Dianne Pretty’s* case, the Court was not persuaded that “the right to life” guaranteed in Article 2 can be interpreted as involving a negative aspect. They held it was unconcerned with issues to do with the quality of living or what a person

chooses to do with his or her life. Article 2 could not, without a distortion of language, be interpreted as conferring the diametrically opposite right, namely a right to die; nor can it create a right to self-determination in the sense of conferring on an individual the entitlement to choose death rather than life.²⁴ Both UK courts and that at Strasbourg have confirmed that the withdrawal of artificial nutrition and hydration from a patient in a persistent vegetative state does not constitute a breach of the international human right to life as its positive obligation only arises where such treatment is in the patients best interests.²⁵

Article 3 of the *European Convention on Human Rights*, reads similarly to article 7 of the ICCPR. It provides:

“No one shall be subjected to torture or to inhuman or degrading treatment or punishment.”

This creates an absolute obligation, no exceptions or derogations have been permitted by the European Court of Human Rights. It may be described in general terms as imposing a primarily negative obligation on States to refrain from inflicting serious harm on persons within their jurisdiction and to take measures designed to ensure that individuals within their jurisdiction are not subjected to torture or inhuman and degrading treatment or punishment, including such treatment administered by private individuals.²⁶ Where treatment humiliates or debases an individual, showing a lack of respect for, or diminishing, his or her human dignity, or arouses feelings of fear, anguish or inferiority capable of breaking an individual’s moral and physical resistance, it may be characterised as degrading and also fall within the prohibition of Article 3.²⁷

In *Dianne Pretty’s* Case the European Court of Human Rights held that it is by Article 8 of the ECHR (“Everyone has the right to respect for his private and family life”) that “notions of the quality of life take on significance. In an era of growing medical sophistication combined with longer life expectancies, many people are concerned that they should not be forced to linger on in old age or in states of advanced physical or mental decrepitude which conflict with strongly held ideas of self and personal identity.”²⁸ The Court found, in agreement with the House of Lords and the majority of the Canadian Supreme Court in *Rodriguez v. the Attorney General of Canada* ([1994] 2 Law Reports of Canada 136), that States are entitled to regulate through the operation of the general criminal law activities which are detrimental to the life and safety of other individuals.

In *Burke’s* Case it was held that “If Article 3 [of the ECHR] embraces...the right to die with dignity and the right to be protected from treatment, or from lack of treatment, which will result in one dying in avoidably distressing circumstances, then the personal autonomy

protected by article 8 means that in principle it is for the competent patient, and not his doctor, to decide what treatment *should* or *should not* be given in order to achieve what the *patient* believes conduces to his [or her] dignity and in order to avoid what the *patient* would find distressing".²⁹ In effect this decision is stating that the international human rights prohibiting degrading treatment (article 3 ECHR) and protecting private life (article 8 ECHR), in certain limited circumstances, create a capacity in incompetent patients (who leave clear advance directives to that effect) to require everything to be done, that treatment never be withdrawn or withheld from them at any point.

The International Right to Health (article 12 of the *International Covenant on Economic, Social and Cultural Rights*) of which Australia is a signatory, requiring a regular report on compliance to the relevant United Nations committee, may be relevant in these circumstances in terms of ensuring that health care systems continue to provide a minimum level of universal access to healthcare services (particularly those of an emergency nature). At its justiciable core, the international right to health was previously generally regarded as involving a state's obligation to fulfil public health duties providing the preconditions for health, such as provision of food, water, sanitation, shelter and protection of the environment, but also access to health care.³⁰ Progressive realisation of such a right requires effective use of available resources.³¹ The minimum content of this core, which cannot be set aside on grounds of progressive realisation, may be conceptualised as a responsibility to reduce serious threats to the health of individuals, or the state's population, according to international standards.³² It is uncertain whether the human right to health has horizontal application within the doctor-patient relationship.³³

The international right to health includes a component assuring universal access to affordable, essential medicines. This could be challenged by provisions in Annex 2C of the Australia-United States Free Trade Agreement. These facilitate multinational pharmaceutical companies lobbying the Pharmaceutical Benefits Advisory Committee to break comparator classes and offer price premiums (on top of increasingly "evergreened" patent royalties) for innovation without, as is required by Annex 2C, having to also justify that in terms of benefits to overall public health. The result could be to reduce the fiscal price control mechanism provided by scientific cost-effectiveness pricing. The flow-on effect could be higher medicines expenditures for ICU's and hospitals.³⁴

Conclusion

The *Schiavo Case* emphasises the important protective role that applying for a judicial declaration

may have for clinicians involved with relatives in a dispute over end-of-life decision making about a patient. In *Burke's Case* an English judge went further and held that in certain circumstances judicial authorization was now required as a matter of law before medical treatment could be withdrawn. These circumstances, each with salutary lessons for clinicians, are:

1. where there is any doubt or disagreement as to the capacity (competence) of the patient
2. where there is a lack of unanimity amongst the medical professionals as to either (i) if the patient's condition or prognosis or (ii) the patient's best interests or (iii) the likely outcome of ANH being either withheld or withdrawn or (iv) otherwise as to whether or not ANH should be withheld or withdrawn
3. where there is evidence that the patient when competent would have wanted ANH to continue in the relevant circumstances
4. where there is evidence that the patient (even if a child or incompetent) resists or disputes the proposed withdrawal of ANH; or
5. where persons having a reasonable claim to have their own views or evidence taken into account (such as parents, close relatives, partners, close friends, long-term carers) assert that withdrawal of ANH is contrary to the patient's wishes or not in the patient's best interests.³⁵

Finally, in a political climate where end-of-life-decisions may become a public spectacle, the capacity of clinicians to argue their case in terms of international human rights may hold distinct advantages, not the less so than because this may increasingly be the normative system their disputers will appeal to. The prospect of increasing numbers of advance directives requiring everything be done, regardless of clinical judgment or resource implications is a real one. It may create one of the most significant emerging problems for law and human rights in ethical conflicts surrounding neuro critical care.

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When do we stop?

Incremental improvements in the outcomes of patients treated for intra-cerebral catastrophes¹⁻³ have encouraged Australasian intensivists to take a more liberal approach to the intensive care admission of high-risk patients and the initial application of often heroic surgical, medical and radiologic therapies. Traditionally this has been followed early by the withdrawal of those therapies from many patients whose subsequent progress is seen to be poor.

This selective approach is in keeping with a British clinical tradition and contrasts to extremes of practice in other societies where either these therapies may not be offered at all to high-risk groups⁴ or may be offered liberally and only withdrawn by "family surrogate decision-makers" if there is "clear and convincing evidence", based on previous verbal or written statements, that such actions were consistent with the patient's known wishes.⁵

The importance of words

Unfortunately, one of the inevitable effects of an individualised “attempted rescue” approach to the patients with catastrophic illness is that at some stage heroic or intensive therapies are seen to no longer be appropriate and the conversation is then about “withdrawal of therapy” – a form of words which creates resonances of deprivation, abandonment and hopelessness. Many other authors have lamented this phenomenon and urged us to construct a different conversation – e.g. about “alternative treatment”⁶ or “comfort care”⁷ or even “allowing natural death”.⁸ I agree with such generic advice and suggest that emphasising that “intensive caring” continues during any alternative treatment plan is a vital part of altering family and staff perceptions about the process. The visible expression of this “intensive caring” on behalf of the medical staff should surely include – *inter alia* – keeping the patient in the ICU, including the patient on all rounds, ensuring that all forms of patient suffering are addressed and relieved, ensuring that the family have access to the patient and continuing to communicate with the family members as they require.⁹

Nurses have been better at recognising and enhancing the ways in which their intensive caring is expressed¹⁰ – including for example attention to the emotional and spiritual needs of both the patient and the family as well as maintaining the physical comfort and dignity of the dying patient.

What is decided and who decides

Traditionally in Australasia we have focussed on “what is the right decision for the patient” and have (probably correctly) assumed that a medically-led but consensual model of shared decision-making,^{6,11-13} has widespread support in our two countries. In sharp contrast, in other societies (prototypically the US), there has been a much stronger focus on “who has the legal right to decide” and on the use of the courts for resolution of disputes.

Australian and New Zealand clinical practice in this area may begin to diverge as Australia has become more aligned with the United States,¹⁴ Australian courts have increasingly addressed end-of-life disputes,¹⁵ and Australian intensivists may now feel more exposed either to threat of legal processes,^{16,17} or perhaps adverse media reporting. Similarly, the limited Australasian intensive care literature has, often tacitly, implied that a “reasonable” expectation of likely prognosis is an acceptable standard upon which decisions can be made in these inherently uncertain situations. By contrast, the (near) absolute concepts of “futility” or “certainty” continue to feature highly in US writings.

I contend that strenuous attempts to prevent Australian and New Zealand courts becoming the locus

of decision-making regarding withdrawal of intensive therapies continue to be both justified and worthwhile. I endorse a prophylactic approach to these potentially problematic situations which relies heavily on the leadership, communication and political skills of intensivists and illustrate how such an approach can continue to be highly successful in practice.

A re-iterated Australasian approach

I contend that for the purpose of formulating a reasonable approach to the provision of intensive therapies and for communication with families, it is enough to broadly risk-stratify patients at the time of admission. For example low risk patients (e.g. sedative drug overdose, liver transplant, elective vascular surgery), can be expected to usually have a short, uncomplicated ICU stay and low (< 5%) mortality and medium risk patients (e.g. major extracranial trauma, sepsis without shock) to have longer ICU stay with some complications and intermediate mortality (5 - 15%). However high risk patients (e.g. post-cardiac arrest hypoxic-ischaemic encephalopathy, subarachnoid haemorrhage, severe traumatic brain injury) have a less predictable ICU course with both high mortality (15 - 50%) and a significant risk of permanent disability.

We ensure that the families of high-risk patients (so defined) are told by an intensivist within 24 hours of ICU admission that death is a real possibility. This is usually in a formal family meeting at around 1100 hours on the morning after ICU admission, if such a meeting has not already occurred. The meeting is held in one of our two separate large family meeting rooms which are inside the ICU but remote from the waiting rooms. The meeting is led by the intensivist (the “bearer of bad news”) and attended by the bedside ICU nurse (the “family support person”) and the family (as self-defined, often involving more than 20 people). We do not use euphemisms or medical terminology.⁷ Rather, we use plain simple everyday speech including referring to death directly – e.g. “This is a very serious situation. We are doing everything we can to help but I’m afraid that it is possible that he/she may die during this illness”. We also tell the family that we will ensure that the patient does not suffer at any stage and express our confidence in the expertise of our ICU nurses to both provide the intensive therapies needed and to ensure that the patients comfort is assured. As a 1:1 ICU-nurse to critically ill patient ratio continues to be the standard in Australian and New Zealand ICUs,¹⁸ this opinion can be confidently expressed.

In the light of the inherent uncertainty about an individual high-risk patient’s outcome, treatment is usually aggressive at the beginning of the ICU stay and the patient’s subsequent course is observed. Most patients improve quickly and substantially and leave the

ICU alive in a few days. However, some patients progressively deteriorate despite all intensive therapies, a few become brain dead, while some develop multiple organ failure or display signs of very severe persistent brain dysfunction.

Patients who rapidly deteriorate despite treatment in ICU do not usually produce problematic decision-making as it is soon clear to everyone that the patient is dying despite all available efforts. These patients very rarely receive CPR and may have therapies limited or withdrawn shortly before death, when it is clear that the course of the illness is rapid and inexorable. Typical circumstances include cardiogenic shock after myocardial infarction, septic shock associated with meningococcal disease or rapidly progressive intracranial hypertension after an intracranial catastrophe.

However, there are two groups of patients where decision-making about limitation or withdrawal of intensive therapies is more problematic viz. those in whom persistent multiple organ failure develops and those who are the focus of this paper: patients with very severe brain damage who do not become brain dead.

Severe brain damage

None of those with severe brain damage (and perhaps only 5% of those with multiple organ failure) are competent to be involved in their own decision-making.¹⁹ Consequently, decisions about the appropriateness, intensity and duration of intensive therapies must almost always be made by others. Despite inherent prognostic uncertainties, intensivists and patients' families together often decide on the basis of clinical information, ethical principles and personal values to withhold or withdraw intensive therapies from such patients.²⁰ Most often (but not always) withdrawal of intensive therapies is followed by the death of the patient in the ICU.¹⁹

Decision-making can potentially be difficult in these circumstances for many reasons. These include inherent imprecision in the prediction of the likely outcome of the individual patient, possible differences in opinion between various members of the healthcare team or between the healthcare team and the family or between the previously-expressed wishes of the patient and the wishes of the family. Sometimes there are institutional, religious or perhaps legal constraints. At least in New Zealand these factors continue to be relatively easily managed. We and our patients' families are tolerant of imprecision in our prediction of outcome and there are strong collegial links between members of the healthcare team. Most families seem realistic and reasonable in their expectations, understanding the limits of medicine and accepting that we cannot perform miracles. If the patient has previously expressed a wish not to survive with significant disability most families

concur with this view. We are not encumbered by institutional or legal constraints. However, some of these issues are more problematic in other countries with different laws and customs.

What do we know about outcome, prognosis and decision-making?

Positive predictive values for poor outcome of 70 - 100%, typically ~95%, occur with various findings associated with severe CNS damage. For example – in traumatic brain injury these include : GCS3,²¹ bilaterally absent pupillary responses,²¹ age > 60,²¹ hypotension (SBP < 90 mm Hg) with hypoxia,²¹ some CT features²¹ and bilaterally absent somatosensory evoked potentials (SEPs)²² and in hypoxic-ischaemic encephalopathy: persistent abnormal flexion,²³ or worse,²⁴ status myoclonus,²⁵ burst suppression on EEG,²⁴ fixed pupils,²⁴ or absent short latency SEPs.²⁴ In other catastrophic cerebral situations (e.g. stroke, encephalitis, acute demyelination) the equivalent adverse prognostic features are less well characterised statistically but are beginning to be systematically described.²⁶ Persistent coma especially when associated with signs of progressive or structural brainstem dysfunction features strongly.

Even moderate CNS-mediated disability often results in loss of cognitive, emotional, social and psychological well-being, unemployability and social isolation.^{27,28} Severe CNS-mediated disability in addition involves dependence upon others to a very large degree for activities of daily living.

Decision-making under conditions of uncertainty considers both the probability of a good outcome and the risk of a bad outcome.²⁹ Both providing decision-makers with more information and also presenting that information in a manner which emphasises “possible loss” rather than “possible gain” are ways of communication which promote more risk-averse decision-making.³⁰ Both health professionals and the lay public hold similar views on severe CNS disability, usually considering it worse than death.^{31,32}

Recommended clinical practice

Our own practice^{33,34} is to assess CNS function clinically (both initially and later when the patient is free of sedation and other potentially confounding factors) and to consider this information together with other relevant information (e.g. CT scan, SEPs, electroencephalogram, intracranial pressure and magnetic resonance imaging).

During this time we meet often (usually daily) with the family and update them on developments, answer their questions and support them during this very difficult time.³⁴ We (including the ICU nurses) are alert to cultural differences and to specific scenarios e.g.

strongly held religious beliefs, “internal family conflict or disarray”, “prodigal son coming from far away”, and “family guilt over previous events” and we address these issues in parallel with our clinical care for and ongoing assessment of the patient. The establishment of robust trust and evident mutual understanding between the family and the ICU team is an explicit goal of these meetings. The achievement of these goals is specifically discussed during the systematic bedside review of all aspects of patient care that takes place on each ward round.

We (the intensivists and other involved specialists) formulate a consensus opinion on prognosis. This may necessitate several days of treatment, investigation and observation but rarely requires longer than a week.

We then meet with the family and explain again the sequence of events and the nature and extent of the brain damage which has occurred. We describe the likely functional consequences of brain damage in terms of everyday activities. For example we discuss the nature of personality change, the many domains of cognitive impairment, the likelihood of unemployment, specific likely focal neurological deficits if any and the level of interaction, speech, responsiveness and dependency. We ensure that these issues are understood, answer any questions and listen to spontaneously expressed opinions of family members or recounting of the patients previously-expressed wishes. We then usually proffer a firm medical consensus recommendation that intensive therapies be withdrawn and invite family discussion and agreement with that recommendation. We seek consensus with that opinion, but we do not “ask for permission” to withdraw therapies.^{34,35}

These decisions take place in a medical, social and cultural context. They are best taken in a consensual manner in which conflict between members of the team and between the team and the family is prevented and avoided. It is essential to allow the time necessary for information-gathering and for obtaining agreement amongst clinicians and with the family. However, when intensivists appreciate that this work is an important clinical responsibility and facilitate the necessary processes, including holding sensitive and repeated family meetings, the process does not take undue time, does not deprive other patients of treatment and is highly appreciated by families.

We recommend that families of all patients who die in ICU are interviewed some time after the death and asked about the communication process that informed them during the critical illness. In particular, they should be asked about the extent to which they understood the sequence of events that lead to the death and their opinion sought as to how the service that they and their relative received could be improved. We have provided such a service now for ten years and have

found that feeding this information back to the staff involved as part of a continuous quality improvement programme leads to improvement in communication and in self-reported family understanding.³⁶

Traumatic brain injury

By way of example, we admitted 627 patients with severe traumatic brain injury between 1996 and 2000, including 257 with AIS4 severity injury³⁷ and 370 with AIS5 level severity. Intensive therapies were withdrawn in 66 patients (median age 39, median hospital admission GCS 5) because of severe brain damage – including 4 of the 257 AIS4 patients and 62 of the 370 AIS5 patients. Sixty-five of the 66 patients died in hospital, 58 of them while in ICU (median 3 days) and 7 shortly after transfer to another ward. The sole survivor is very severely disabled. Six weeks after the death 43/44 contactable next-of-kin³⁸ of the 58 patients who died in ICU said they were well informed and 41/44 understood the fatal sequence of events.

Hypoxic-ischaemic encephalopathy

Similarly, we admitted 141 patients after resuscitation from primary cardiac arrest between 1998 and 2002. One patient with very severe hypoxic-ischaemic encephalopathy became brain dead 44 hours after admission and 12 others died with unsupportable circulatory failure 1 - 42, median 7 hours after admission. Intensive therapies were withdrawn because of severe hypoxic-ischaemic encephalopathy in 54 patients (age range 22 - 85, median 63 years), GCS on hospital arrival range 3 - 6, median 3). All 54 patients had signs of severe brain damage, including status myoclonus (25 patients), abnormal motor responses (absent 25, extensor 4, abnormal flexion 16), bilaterally absent somatosensory evoked potentials (7 patients), burst suppression on EEG (5 patients), or fixed pupils (1 patient). All 54 died in hospital – 52 of them while in ICU at a median of 34 hours after admission (range 5 - 163 hours), the other two died in hospital a few days later after transfer to another ward. Six weeks after the death³⁸ 40/52 contactable next of kin of 52 ICU deaths “considered themselves well informed by medical and nursing staff” and 38/52 “understood the fatal sequence of events”.

Subarachnoid haemorrhage

Finally, we admitted 244 patients with presumed (38) or confirmed (206) aneurysmal SAH between 2000 and 2004. Fifty-two patients became brain dead 8 - 145, median 26 hours after ICU admission and one died of cor pulmonale 23 hours after ICU admission following aneurysm rupture during craniotomy. Intensive therapies were withdrawn because of severe encephalopathy in a further 32 patients (age range 28 - 82, median 56

years), last GCS before ICU admission range 3 - 15, median 9). Thirty patients had signs of severe brain damage "highly predictive of futility",²⁶ including persistent coma [No eye-opening 30 patients – whose best motor response was: none (16), extension (2), abnormal flexion (5), withdrawal (4) or localising (3)], massive IVH with hydrocephalus (6) or delayed global brain oedema on CT (2). Other adverse features in these 32 patients included CT evidence of focal cerebral infarction (11), hemiplegia (8), unilateral (3) or bilateral (10) fixed dilated pupils, unilaterally (1) or bilaterally (2) absent SEPs and absent cranial nerve reflexes (7). The families of the two patients who retained eye-opening to stimulation requested withdrawal of intensive therapy as both patients had hemiplegia and had previously expressed strong objection to survival with disability. Thirty-one patients died while in ICU at a median of 61 hours after ICU admission (range 3 - 198 hours), the other patient improved and had a delayed aneurysm coiling. Four years later she was moderately disabled with vertigo, vomiting, myoclonus, impaired memory and concentration, depression and fatigue.

Six weeks after the death,³⁸ 25/27 contactable next of kin of 31 ICU deaths "considered themselves well informed by medical and nursing staff" and 26/27 "understood the fatal sequence of events".

Summary

When severe brain damage has occurred, early withdrawal of intensive therapies is clinically, ethically and legally justified. Early withdrawal in a structured intensivist-led consensual process does not delay death, is accepted by next-of-kin, minimises devastated survivors and husbands scarce and valuable intensive care resources.

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