

Deficiencies and Missed Opportunities to Formulate Clinical Guidelines in Australia for Withholding or Withdrawing Life-Sustaining Treatment in Severely Disabled and Impaired Infants

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Abstract This paper examines the few, but important legal and coronial cases concerning withdrawing or withholding life-sustaining treatment from severely disabled or critically impaired infants in Australia. Although sparse in number, the judgments should influence common clinical practices based on assessment of “best interests” but these have not yet been adopted. In particular, although courts have discounted assessment of “quality of life” as a legitimate component of determination of “best interests,” this remains a prominent component of clinical guidelines. In addition, this paper highlights the lack of uniform clinical guidelines available to medical professionals and parents in Australia when making end-of-life decisions for severely ill infants. Thus, it is argued here that there is a need for an overarching prescriptive uniform framework or set of guidelines in end-of-life decision-making for impaired infants. This would encourage greater transparency, consistency, and some degree of objectivity in an area that often appears subjective.

Keywords End-of-life care · Withdrawal or withholding of life-sustaining treatment · End-of-life treatment for infants · “Best interests” · Clinical guidelines · Medical ethics

Introduction

The main purpose of this paper is to highlight the deficiencies in clinical guidelines in relation to decisions to withdraw or withhold life-sustaining treatment from critically ill infants in Australia. This paper argues that given the considerable amount of subjectivity that informs end-of-life decision-making for sick infants, national uniform guidelines would provide, at minimum, some consistency and transparency. This paper does not detail every aspect of a workable set of uniform guidelines¹; rather, it focuses on the shortcomings of the current guidelines in order to inform the development of uniform guidelines in the future. There are four main parts of this paper. The first section analyses the few, but important Australian cases that have required legal or coronial intervention to decide whether life-sustaining treatment should be withdrawn or withheld from impaired infants in their “best interests.” This is followed by a critique of the current Australasian clinical guidelines available to medical practitioners when deciding whether to withdraw or withhold life-sustaining treatment from

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¹ This task needs to be completed incrementally and systematically. The first task is to highlight the current shortcomings, which necessitate a move to overarching standards.

infants. Section three discusses the New South Wales and Australian Capital Territory consensus workshop and the subsequent 2005 consensus statement that appears to have been an unrealised opportunity to construct a nationwide framework in Australia. The fourth section of this paper turns to the ethical need for and merits of uniform national clinical guidelines that would bring greater transparency and consistency in decision-making in an area that is fraught with subjectivity and legal and ethical challenges. The final section of the paper offers concluding remarks.

While decisions regarding adult end-of-life care and withdrawal or withholding of treatments are often debated and subject to legal conditions, there seems to be a reluctance to formalise a decision-making process for infants on the brink of death. Of all groups, critically-ill infants (neonates) are perhaps the population that warrants a formal process. Infants are voiceless and unable to exercise their own free will on any issue concerning their welfare. Whilst adult patients lacking mental capacity may be able to exercise some autonomy by declaring their wishes via advanced directives (Maclean 2008), infants are entirely dependent on the will of others, principally on doctors, parents, and the courts.

This dependency places infants in an extremely fragile position, subject to decisions for treatment based on a variety of factors, such as gestational age, quality of life, and futility of treatment as evaluated by doctors and parents. Academics and decision-makers alike acknowledge the difficulty in reconciling such factors that are further complicated by social, cultural, religious, and ethical issues. Together, these obscure decision-making and may depend on elements of subjectivity and moral judgement (Barr 2007; Orfali 2004).

Decisions to withdraw or withhold life-sustaining treatment from critically impaired infants are complex, involving multifaceted considerations and competing interests and principles. It is indisputably an area of clinical practice that is fraught with inconsistency, conflicting opinions, and often the subjective beliefs of the treating medical practitioner (Rebagliato et al. 2000). As medical technology has advanced over the latter decades of the 20th century, the instances in which young lives can be saved or extended have increased. However, sometimes even after aggressive treatment, impaired infants may survive with poor health and a poor quality of life due to unresolved severe and debilitating disability (Costeloe et al. 2000, 2012). The impact of surviving with severe disability can be profound,

affecting the individual, families, and wider communities. Accordingly, the medical and legal professions are thrust into situations that existing regulatory concepts struggle to govern.

In addition, the information age has engendered public awareness of the development of medical science and technology; consequently, parents of critically impaired infants are often encouraged by the use of the Internet and social networking support groups to request life-sustaining treatment to save their child from death (Thoren et al. 2013). Parent–doctor disagreements concerning withdrawal or withholding of life-sustaining treatment for severely ill infants are generally resolved in the hospital setting. However, there are instances where their “differences” become “disputes” that cannot be resolved internally and require legal intervention.

The desire or need for legal recourse is understandable, given that the consequence of decisions to withdraw or withhold life-sustaining treatment is so absolute. Further, making end-of-life decisions for infants is highly emotionally distressing, particularly since infants cannot express their own treatment desires and thus cannot make informed decisions that may potentially affect their future quality of life. Decisions to continue or discontinue treatment are overwhelmingly made by medical practitioners in a collaborative effort with parents. When parents and doctors do not agree on the best treatment option for an impaired infant, either party may seek intervention from the court to make a final decision regarding whether treatment can lawfully be discontinued.

Over the past three decades a number of cases have been brought before courts in the United Kingdom to resolve withdrawal or withholding of life-sustaining treatment decisions. Primarily, English courts have been required to resolve disputes on the withdrawal or withholding of treatment based on the principles of what is in the “best interests” of the child, whether further treatment would be futile or would result in poor quality of life. In doing so, the courts have weighed up the “burdens and benefits” of continued or futile treatment (*Portsmouth Hospital NHS Trust v Wyatt* [2004] EWCA 2247 (Fam)).

The number of cases that have come before Australian courts, however, is sparse and comprise only four to date, with only two requiring any legal intervention. The next section of this paper provides an analysis of these

four cases in Australia, before turning to explore clinical guidelines in Australasia.

Australian Cases Concerning Critically Impaired Infants

Re F: F v F (1986) (Unreported, Supreme Court of Victoria, Justice Vincent, 2 July 1986) was decided almost 30 years ago in Australia. The case concerned a newborn suffering from spina bifida. In this condition, a defect in the development of the lower vertebral column allows protrusion of spinal nerves into a sac (myelomeningocele) over the lower back with consequent severe motor disability and incontinence. The baby was under guardianship and surgical correction of the defect was not planned. However, the baby's father sought an application from the court alleging the baby was being deprived of food in order to starve it to death. The court made an order that while the case was considered in greater detail the baby be fed as normal. Interestingly in this case, unlike its English counterparts, neither hospital staff nor the treating medical team attended the court hearing.

In the absence of medical evidence concerning the baby's prognosis and only the allegations of the father that the infant was being "starved," Justice Vincent simply made a decision that would not have resonating consequences for any other cases that came before him or other judges in the future. Arguably, the judge in this case was cautious not to make a decision that could have resounding consequences for any future cases. The judge dismissed assessment of "quality of life" as a concept in questions of withholding treatment. His Honour stated:

[N]o parent, no doctor, no court, has any power to determine that the life of any child, however disabled that child may be, will be deliberately taken away from it. ... [The law] does not permit decisions to be made concerning the quality of life, nor does it enable any assessment to be made as to the value of any human being (at [9]).

His Honour ordered the medical team to "take necessary and reasonable steps" and to "pursue good medical practice" (at [20]).

Some years later, a coronial enquiry into the death of Baby M (*Baby M* (Victorian State Coroner's Office,

Record of Investigation into Death, Case No 3149/89, 29 October 1991) VIC) considered the matter of the withdrawal/withholding of life-sustaining treatment. Born in Melbourne on July 14, 1989, Baby M also suffered from severe spina bifida but in addition had obstructed circulation of fluid within the brain (hydrocephalus), herniation of the brain stem into the upper spinal canal (Arnold-Chiari malformation), vocal cord paresis, and severe deformities of the lower limbs. She was relatively unresponsive, had little spontaneous movement, and had difficulty sucking, swallowing, and breathing. If surviving, the doctors advised that she would be unable to walk, doubly incontinent, have no sexual function, would require an artificial airway (tracheostomy), and would require multiple operations on her spine and lower limbs. Baby M's parents were religious, following the Catholic faith, and sought regular guidance from their spiritual advisers. After agreement among the medical team, her parents, and the religious advisers, Baby M was provided with sedation, allowing her die 12 days after the decision to withhold treatment and surgery.

However, after receiving information from Baby M's great aunt, the "Right to Life" organisation informed the police, alleging that both her parents and doctors decided to allow Baby M to die after deciding her quality of life was so poor that it was not deemed worthy of preservation (Kuhse 1992).

This case was not brought before the courts but a coronial inquest was held. The issue at the centre of the inquest concerned Baby M's quality of life, which doctors argued would be very poor if the infant survived. The coroner, Wendy Wilmoth, concluded that withdrawal or withholding of life-sustaining treatment decisions should be made by the medical team in conjunction with the parents.

In contrast to the judicial decision in *Re F: F v F* (1986), the central issue considered by the doctors and the coroner in *Baby M* surrounded the infant's quality of life. In this case, the coroner presumably took on the role of an impartial adjudicator but issued the following ambivalent statement:

This gives recognition to the role of quality of life considerations, and recognises the lack of absolutes in life, whilst still upholding the principle ... that no parent or court can judge the quality of a person's life to be so low as not to be deserving of continuance (at [242]).

Despite this statement, the coroner found that the “decisions made by doctors and parents ... were legally, ethically and morally sound, have been tested and found entirely reasonable and appropriate (at [242]).

It was not until 2011 that the Australian courts were asked again to consider the withdrawal/withholding of treatment for critically-ill infants. Similarly to *Baby M*, the parents and medical team in *Baby D (No 2)* [2011] Fam CA 176 were in agreement that withdrawal/withholding treatment was in the “best interests” of the infant and simply required approval from the court. The fact that such adjudication was necessary bears testament to the absence of clear guidelines on the subject.

Baby D was a twin, born at 27 weeks in Melbourne. Although neither twin was born suffering physical or intellectual abnormalities, baby D required prolonged endotracheal intubation and mechanical ventilation for the treatment of apnoea of prematurity. However, after Baby D had gained the ability to breathe adequately, it proved impossible to remove the artificial tube that had been used to provide mechanical ventilation. The tube had caused inflammation and swelling in the trachea to the extent of resulting in severe narrowing that did not respond to treatment with steroid drugs. Whenever the tube was removed (i.e., extubation), obstruction in the trachea mandated its reinsertion. On one attempt to remove the tube, great difficulty was experienced on its reinsertion such that Baby D suffered a 35-minute episode of hypoxaemia (lack of oxygen) that manifested later as severe brain damage. Surprisingly her brain stem, which generates spontaneous automatic breathing and other basic functions, was undamaged. She responded to touch and feel; however, she also felt pain and distress. Although the tube remained in place to ensure her airway was open, she breathed independently and did not require mechanical ventilation.

After five months in this state, both her doctors and parents began to consider removal of the tube. However, they were uncertain as to the best course of action should Baby D suffer similar distress as had been experienced previously.

With this uncertainty, the doctors turned to the hospital ethics committee to consider whether palliative care, in the form of pain relief and sedation, would be more appropriate if Baby D suffered respiratory distress on removal of the tube in the future. The committee believed that the question required legal resolution and as such directed Baby D’s parents to seek advice from the courts.

One of the central issues the courts were required to consider in this case surrounded parental authority to remove the tube and, consequently, whether such removal and palliative care were in her best interest (Stewart 2011).

Justice Young reached the conclusion that the decision to remove the tube fell within the remit of parental responsibility under section 4 and section 64B(2)(i) of the federal *Family Law Act 1975* that state that any person fulfilling a parenting role has the responsibility to make decisions on any aspect of care, welfare, or development of the child. Consequently, the parents of Baby D could lawfully make the ultimate decision to consent to the extubation. Baby D had since died.

This legal decision is important, ultimately allowing parents to make end-of-life treatment decisions for their sick infants without requiring court intervention.

Justice Young accepted the opinions of the medical experts but declined to make any assessment of the nature of “best interests,” which has been the subject of criticism (Williams, Chesterman, and Grano 2012). The doctors involved had deposed that their recommendation to withdraw and withhold treatment on baby D had been based on elements of the three classical components of “best interests” Justice Young stated:

The consensus amongst all of the very experienced and qualified medical practitioners ... is that any future life for Baby D must, with certainty, be seen to be one that is, at the least, very burdensome and futile with no expectation of any enjoyment of life and without sight and any meaningful brain capacity (at [149]).

However, laying the parental responsibility aspect aside, the decision in *Baby D* in 2011 was not groundbreaking—it had not posed any particularly challenging ethical or legal dilemma for the court. It simply affirmed that where parents and doctors are in agreement about the withdrawal or withholding of life-sustaining treatment the courts are reluctant to intervene.

The case attracted considerable attention among the public, who seemed surprised that parents were able to make such decisions on behalf of their children. It also garnered criticism from members of the Office of the Public Advocate with regards to such decisions being made without judicial exploration of “best interests” of the child and claiming that such decisions are often made by

parents and clinicians without external oversight (Williams, Chesterman, and Grano 2012).

In a 2012 landmark case, for the first time in Australia the courts were asked to consider whether parents could demand life-sustaining treatment for their infant when the medical team considered it to be futile or not in the child's "best interests." The case involved Baby Mohammed (*TS & DS v Sydney Children's Hospital Network ("Mohammed's case")*) [2012] NSWSC 1609). The parents demanded mechanical ventilation for their 9-month-old infant who had suffered a severe lack of oxygen in addition to having the inherited conditions of Mosaic Down syndrome and pyruvate dehydrogenase deficiency, a metabolic condition due to a mitochondrial defect of enzyme function that causes severe neurodevelopmental lesions. He had already had an operation to ligate a cardiac defect patent ductus arteriosus, which unrepaired would have led eventually to heart failure.

As a consequence of his inherited enzymatic metabolic condition and a subsequent episode of hypoxaemia, Mohammed exhibited unresponsiveness, seizures, blindness, deafness, and cardiac failure, requiring continuous positive airway pressure by non-invasive means. In response to the demands of the parents, doctors were disinclined to provide mechanical ventilation to Mohammed on the basis that his prognosis was poor, that his conditions of brain damage and enzymatic defect were incurable, and that palliative care and pain relief were in Mohammed's "best interests." In agreeing with the doctors, the court ruled that mechanical ventilation would cause pain and discomfort, would provide only temporary benefit, and would not cure or alleviate his underlying conditions. These notions affirm that treatment regarded as burdens rather than benefits and treatment that is futile are not in a child's "best interests." Rather, his best interests were to receive pain relief and palliative care.

In his judgment, Justice Garling briefly referred to judgments made by English courts in cases concerning withdrawal/withholding of treatment in infants, stating that the "nature of the problem with which this court is confronted is not new" (at [82]). The judge was careful to consider Mohammed's parents' views that their son was "a fighter" (at [73]), and his Honour went on to say, "I entirely accept the genuineness and sincerity of the submissions of Mohammed's parents. I accept that it is

their view that Mohammed's best interests are that he be placed on a ventilator" (at [74]).

However, taking a conservative stance, Justice Garling further stated:

Mohammed's life is to be measured in the short term. He should not be subjected to pain and discomfort for the remainder of his life by being placed on mechanical ventilation from which he will not be weaned. It is for these reasons that I agree with the expert opinions of Mohammed's doctors that it would be better for him to be treated by pain relief and palliative care than by the invasive procedure of mechanical ventilation. That is what is in his best interests. This conclusion is sufficient to warrant a rejection of the parents' application (at [90–91]).

Interestingly, although noting that further treatment would not be in the infant's best interests, his Honour did not consider issues of "quality of life" at any great length. Justice Garling found that the standard *Macquarie Dictionary* meaning of "quality of life"—that enjoyment that can be obtained from living based on having sufficient physical and mental health to be able to participate in a meaningful way—was inapplicable in the case before him. Applying a (somewhat) literal interpretation of the term quality of life as defined by the dictionary, his Honour found:

[A]s it seems to me, when applying that term to a 9 month old baby who does not yet talk or communicate verbally, and does not physically respond to anything other than painful stimuli, and cannot see or hear, identifying the integers which comprise an assessment of the baby's "quality of life" is impossible. Any such assessment necessarily reflects the individual values of the assessor (at [69], *emphasis original*).

Justice Garling thus rejected assessment of "quality of life" as an index of "best interests." He found that assessing the infant's "quality of life" was open to the subjective interpretation of such life by each person assessing his life, stating, "I have not made any such assessment and I have disregarded as irrelevant, any expression of opinion by any of the doctors as to what Mohammed's quality of life is or will be" (at [70]). However, as noted above, seemingly his Honour did not apply the same level of caution and potential

subjectivity to the application of the term “best interests”—on the basis of medical opinion that being placed on a ventilator was not in his best interests. Justice Garling, relying heavily on medical opinion, added:

[I]t is not the role of the court to interfere in such a professional relationship and to compel action by an unwilling participant which would have the consequence of placing that individual in the position, in good conscience, of choosing between compliance with a court order and compliance with their professional obligations (at [93]).

Further, Justice Garling’s reluctance to make a decision contrary to medical advice is perhaps concerning, as he said that “regardless of my opinion, I would not have been prepared as a matter of discretion to order them [the medical practitioners] to do something with which they did not agree” (at [94]) and “the court’s responsibility is to assess what is in Mohammed’s best interests and not to allow its judgment to be swayed by sympathy, and the attractive ease of requiring the medical practitioners to provide mechanical ventilation for Mohammed” (at [96]).

Justice Garling also stated:

If the court is satisfied that the opinion of the doctors have [sic] been reached after careful consideration having regard to the correct and relevant matters and are opinions reached in the proper exercise of their professional judgement as to what is in the best interests of their patient, then I very much doubt that a court would ever make an order of the kind sought here (at [93]).

Thus, this case affirms that doctors can make decisions regarding the withholding of life-sustaining treatment if it is considered futile and/or burdensome and thus not in a child’s “best interests,” but they should not rely upon their assessment of “quality of life” as an index of “best interests.”

It is too early to seriously consider whether the two cases that have been heard in Australian courts within the recent three-year period herald a new trend in Australia. Thus far, only a very sparse number of cases have come before the courts for resolution where doctors and parents disagree on treatment decisions. Such court cases are outcomes that most would prefer to avoid. There are no clear answers to the circumstances in which infants should be permitted to die.

Other Australian academics also have acknowledged that the issue of withdrawing and withholding treatment in newborns “remains unclear, due to the lack of cases reaching the courts in Australia, and resulting in the absence of any judicial discussion or authority on such matters” (Boneh et al. 2008, 145).

Analysis of case law has demonstrated that many important, often competing, interests are at stake such as best interests and including quality of life and parental wishes, with no clear reference point against which these should be evaluated.

However, even with the very few cases considered above, it is apparent that the opinion of treating physicians is given considerable deference by the courts. In addition, hospital medical teams in Australia do not have a widely-accepted uniform set of guidelines to assist them in making withdrawal or withholding of life-sustaining treatment decisions. Taken together, this allows for end-of-life decision-making for critically ill infants to be arbitrary and subjective in nature.

It is noted that decisions to withdraw or withhold life-sustaining treatment cannot be made rigidly and a degree of flexibility is necessary, dependant on each infant’s medical prognosis and other competing variables. However, this paper argues that the development of a uniform set of guidelines will allow for a normative basis from which Australian hospitals can commence the end-of-life decision-making process and eliminate some of the subjectivity that surrounds this area. This would provide consistency and transparency for those closely involved in the decision-making process, particularly parents of sick infants (discussed later in this paper).

Australasian Clinical Guidelines

There are no freely available extensive clinical guidelines that have been published by any national Australian or New Zealand body that exclusively consider withdrawal or withholding of treatment of infants. The closest document is the Royal Australasian College of Physicians (RACP) guidelines, which is modelled on the guidelines of the British Royal College of Paediatrics and Child Health (RCPCH). In its document, the RACP focuses and places emphasis on the role of the family and the shared role of both parents and doctors in the decision-making process, stating:

Collaborative decision-making is the safest and most robust model, incorporating and balancing the observation, knowledge and insights of both the family/whanau and the members of the treating team. This model allows a variety of responses and can adapt to most circumstances. It also provides an inherent system of “checks and balances” against extremes in decision-making, while providing support and validation for the conclusions of the key decision-makers (RACP 2008, 11).

The RACP document further states that the role of the health team is to care for the family/whanau, while facilitating the process of decision-making around the child’s care and maintaining a relationship of trust and respect. ... Health professionals have a duty to argue their views concerning management choices but there is also an obligation to respect group decisions and the decisions of the family/whanau, regardless of personal beliefs (RACP 2008, 8).

The emphasis on “collaborative decision-making” with families briefly mentions the best interests principle:

Clinicians and guardians, usually parents, have a duty to make all key decisions in the best interest of the child. The treating team must always see itself as the advocate for the interests of the child and be prepared to manage differences with the parents from this perspective (RACP 2008, 6).

Given that the central notion in these guidelines regarding decisions to withdraw or withhold life-sustaining treatment is based on what is best for the infant, it is surprising that the principle of “best interests” is not defined or discussed. Further, the guidelines highlight the possibility of conflict between medical practitioners and parents when making treatment decisions, and the potential for such disagreements to require legal intervention. In light of this, the guidelines fail to consider instances in which continuation or discontinuation of life-sustaining treatment would be in the best interests of an infant, although the document describes three situations whereby the appropriateness of continuing treatment is questionable, when:

- death is imminent
- treatment would be ineffective making life intolerable because of pain and suffering

- life would be shortened regardless of treatment and non-treatment would allow for increased comfort (RACP 2008, 9).

The RACP guidelines do correctly state that there are “no legal or morally relevant differences between withholding or withdrawal of treatment” (2008, 9).

While the phrases when “death is imminent” and “treatment would be ineffective” suggest futile treatment and “making life intolerable” suggests imposition of burdens rather than benefits, the terminology lacks clarity and is inadequate.

The document briefly considers neonatal treatment decision-making under a section titled “Specific Issues: Neonatal Period.” Although not entirely specific to those born at the edge of viability, the document mentions: “In the circumstances of infants with an extremely small chance of survival it may be appropriate not to offer treatment, such as with infants at 22 or 23 weeks gestation, particularly if in poor condition” (RACP 2008, 21). It further states:

There is no legal obligation to offer treatment which is not medically indicated or which is futile, although taking this step in the absence of agreement should be considered only after all avenues have been exhausted (RACP 2008, 21).

The guidelines fail to explain the meaning of futility and fail to define the nature of “other avenues.” Overall, they are too basic and provide little concrete clinical guidance. Moreover, the emphasis on parental involvement, although worthy, does not negate the need for more prescriptive guidelines to assist doctors with end-of-life treatment decisions. On the contrary, this paper contends that uniform national guidelines would encourage further parental involvement with greater trust, consistency, and transparency in end-of-life decisions by the medical institution charged with an infant’s care.

Consensus Statement Based on the New South Wales and Australian Capital Territory Consensus Workshop in 2005

Arguably, the nearest that Australia came to developing uniform guidelines for critically ill infants was almost a decade ago with the “consensus statement.” Although

objectives of the statement provided a good starting point for discussions for uniform guidelines, national engagement and collaboration were required for it to have realised its potential, conceivably resulting in national uniform guidelines.

The workshop was attended by nominated representatives from each of the 10 neonatal intensive care units across New South Wales (NSW) and the Australian Capital Territory (ACT) and included the disciplines of obstetrics, midwifery, neonatology, neonatal nursing, and allied health professionals. In addition, individuals from parental groups, medical and nursing colleges, and rural and regional practices were invited to participate in the generation of a consensus statement (Lui et al. 2006).

The group acknowledged the large number of international guidelines on end-of-life treatment decisions for premature infants and the associated “grey zones” of uncertainty whereby end-of-life decisions are the most fragile (Lui et al. 2006, 498). Further, and most importantly, the group noted the lack of satisfactory guidelines for Australia and considered the need for such guidelines, consequently leading to a consensus workshop with participants from NSW and the ACT. Its findings were published in *The Medical Journal of Australia* in 2006. The aims of the workshop were twofold:

1. To produce consensus statements to supply clinicians and parents in dealing with the challenging scenarios encountered at the borderlines of viability; and
2. To agree on accurate, meaningful and consistent information across NSW and the ACT for clinicians, parents and prospective parents of extremely premature infants (Lui et al. 2006, 495).

After studying the outcomes at two to three years of age of 897 premature infants born between 22 weeks and 25 weeks and six days of gestation in NSW and the ACT, the group concluded that the viability of an infant born at or less than 23 weeks of gestation was minimal and the risk of morbidity so high that resuscitation was not appropriate, while for an infant born at or greater than 26 weeks of gestation resuscitation should be routine. However, for an infant born between 23 and 26 weeks there was a “grey zone” or discretion for which clinical treatment could be variable according to the clinicians and parents. Provision of treatment or

withholding of treatment would be appropriate at the following gestational periods:

- At 23 weeks, active treatment may be discussed, but would be discouraged in NSW/ACT neonatal intensive care units.
- In an otherwise normal infant born between 23⁰ and 25⁶ weeks’ gestation, there is an increasing obligation to treat. However, it is acceptable medical practice not to initiate intensive care if parents so wish, following appropriate counselling.
- At 24^{0–6} weeks, antenatal transfer to a tertiary centre for fetal reasons is indicated. The option of non-initiation of intensive care/resuscitation should be offered.
- At 25^{0–6} weeks, active treatment is usually offered, but the option of non-initiation of intensive care/resuscitation—particularly in the presence of adverse fetal factors such as twin-to-twin transfusion, intrauterine growth restriction or chorioamnionitis—should also be discussed.
- In an otherwise normal infant born at 26 weeks and above, the obligation to treat is very high, and treatment should generally be initiated unless there are exceptional circumstances (Lui et al. 2006, 498).

The consensus statement also asserted that where the family of a pre-term infant opt for non-intervention at 23 to 25 weeks of gestation the following should be available:

- All hospitals should have guidelines for communication with parents in situations in which the family has opted for nonintervention.
- Counselling should be done by, or at least in consultation with, senior clinical staff.
- If the birth occurs in a non-tertiary centre, access to senior staff in a tertiary centre for consultation should be available and should take place prior to delivery.
- Clinical staff should be well versed in preparing parents for palliative care of their infant. ...
- Appropriate support for the grieving process should be made available ... and [there should be] discussion of post-death arrangements (Lui et al. 2006, 498).

As promising as the intention of the workshop and consensus statement initially appears, it has been subject

to clinical and ethical critique. For example, while Darlow (2006) generally supported the statement, he criticised it for claiming that consensus agreement of at least 90 percent of the participants had been reached. The number of agreeing participants was only 72 percent on the matter of withholding treatment upon parental request for an infant 25^{+0–6} days weeks of gestation. In addition, the composition of the multidisciplinary group was mainly health professionals with no ethical, legal, or religious representation.

Another commentator, French (2007), questioned how much and whose opinions should be afforded the greatest weight in treatment decision-making—medical professionals or parents:

[I]f parents dealing with an otherwise uncomplicated labour at 23 weeks gestation request initiation of intensive care, having had discussions and being duly informed of the possible outcomes, would these families be offered full support for their infant even if it were not the recommendation of the attending neonatologist or obstetrician? (French 2007, 493).

These critical evaluations of the consensus statement have merit. Despite the workshop highlighting the need for “accurate, meaningful and consistent information,” the final statement is perfunctory in nature, and while the statement provides that families of pre-term infants should be given counselling or support, it is illuminating that the workshop omitted to include ethical, legal, or religious representatives. This is a clear flaw—particularly given that medical practitioners and parents are often guided or comforted by the counsel of these very groups—and likely unduly narrowed the breadth of considerations that were considered. A more holistic approach that included such representation would have given the consensus statement greater legitimacy and authority. Moreover, while the workshop was attended by (primarily clinical) representatives from NSW and the ACT, national engagement, including representatives from all other states and territories, was imperative for a true and informed “consensus statement.” Arguably, the workshop provided an ideal opportunity for the development of national uniform guidelines, but this was a missed opportunity.

The Need for Uniform Guidelines

Thus far, it has been noted that although only four cases concerning critically ill infants have required legal or coronial intervention in Australia, the courts have illustrated a deference to medical opinion. When considered in isolation, this regard for the opinion of treating physicians is understandable to a certain degree. Judges are not medically trained and cannot make medical prognoses. However, this deference potentially undermines a cardinal rule of legal virtues in the form transparency, consistency, and predictability in the operation and application of important human endeavours. Further, end-of-life decisions may be unduly dependant on the subjective attitudes, beliefs, and values of the treating practitioner or parents, especially where the treatment wishes of the patient are unclear (Wilkinson and Truog 2013).

At present, the RACP guidelines in Australia lack any “clout”—merely offering unclear definitions and no prescribed course of action. When such decisions are being made, with consequences that are so absolute, such a considerable amount of latitude is concerning. Overall, the one aspect of uniformity that exists among other Australian guidelines is their variability. Individual hospital guidelines or frameworks vary from institution to institution (even within the same state) and are not mandated or audited by a national body within the medical community. Further, such guidelines do not describe treatment options based on any objective criteria and could possibly be considered to be “motherhood” statements.²

In Australia, approaches to end-of-life decision-making for impaired infants appear to be specific to individual hospitals and look to be a “closed model” of care (Williams, Chesterman, and Grano 2012). Guidelines within hospitals on withdrawing or withholding life-sustaining treatment are often confidential and internal and are unavailable to the public. Moreover, such careful guarding of these policies provides little transparency for parents, who may be seeking information and understanding about the significant and sometimes irreversible decisions that are being made about their infant.

The documents that guide doctors on end-of-life decisions are arguably symptomatic of the high level of autonomy that hospitals have to set their own guidelines; however, the lack of uniformity among such

² Statements that are overwhelmingly considered to be good or worthy statements that most people would agree with.

clinical guidelines allows for an inappropriate level of medical discretion in end-of-life decision-making for sick infants. This variation creates further potential subjectivity in the decision-making process and runs the risk of parental confusion, ambiguity, and a lack of trust and confidence in medical management, whereby parents may consider that in a different hospital their infant might receive treatment more in line with their own views.

Although there is no clear solution to avoid parental loss of trust in the medical team, this paper argues that the development of uniform national clinical guidelines can mitigate many of the issues presented here. A uniform set of national guidelines would alleviate at least some of the subjectivity and allow a greater level of trust and confidence in medical teams through the assurance that all hospitals nationwide are utilising the same clinical guidelines as a starting point in the often complex task of deciding whether life-sustaining treatment should be withdrawn or withheld.

Although it cannot be denied that every individual case has its own unique characteristics, this should not be confused with a lack of need for a unified national framework. On the contrary, a unified framework would allow the intricacies of each case to be given a thorough examination against a common denominator. This is of key importance to moving forward to a better system of decision-making with greater transparency and consistency, particularly given that the majority of withdrawal/withholding of treatment decisions are made in the hospital setting with very few (so far) in Australia requiring legal intervention. While this paper acknowledges that the development of uniform clinical guidelines will not remove much of the medical uncertainty for critically imperilled infants, uniform guidelines would inject some degree of objectivity to end-of-life decisions.

Given that end-of-life decision-making is so emotionally and ethically charged and open to a great deal of subjectivity, a better model would be to create and utilise a unified body of guidelines that are applied nationally. Although it cannot be predicted whether Australia will see a flux of cases brought to courts for resolution, it is no doubt invaluable to consider more structured, consistent, and transparent guidelines that are mandated as hospital policies or procedures that could potentially prevent parent–doctor “disagreements” escaping the hospital corridors and becoming disputes that end in court.

Conclusion

This paper posits that present guidelines for withholding and withdrawing life-sustaining treatment for infants in Australasia are inadequate. They are not supported by current common law and lack clarity and precision. There is an urgent need to (re)formulate national guidelines. This may not be as momentous a task as perhaps perceived. A good starting point would be to decipher and consider both the valuable data and information and the failings of the NSW/ACT consensus statement. By way of example, a working group should be created that involves other community leaders or entities, in particular those with expertise in the law, (bio)ethics, and religion. In addition, such a working group should include all states and territories in Australia, rather than just the ACT and NSW. It is not suggested that creating a comprehensive working group and developing uniform guidelines are by any means easy tasks; however, the NSW/ACT consensus statement can be utilised as a springboard for a more refined and definitive framework.

An overarching, uniform framework would inject clarity, consistency, and transparency in decisions to withdraw or withhold life-sustaining treatment. This is of considerable importance in creating a more open and honest dialogue between parents and doctors. Additionally, removing some of the subjectivity that informs end-of-life decisions will allow for greater parental trust and confidence in health care institutions and treating practitioners.

Moreover, when withdrawing or withholding life-sustaining treatment is the best option, uniform and clear standards will allow the finite period of time to be better spent on providing the appropriate care and perhaps alleviating parents from some emotional turmoil where treatment simply prolongs an infant’s inevitable death.

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References

- Barr, P. 2007. Relationships of neonatologists’ end-of-life decisions to their personal fear of death. *Archives of Disease in Childhood: Fetal and Neonatal Edition* 92(2): 104–107.

- Boneh, A., S. Allan, D. Mendelson, M. Spriggs, L.H. Gillam, and S.H. Komman. 2008. Clinical, ethical and legal considerations in the treatment of newborns with non-ketotic hyperglycaemia. *Molecular Genetics and Metabolism* 94(2): 143–147.
- Costeloe, K., E. Hennessy, A.T. Gibson, N. Marlow, and A.R. Wilkinson. 2000. The EPICure study: Outcomes to discharge from hospital for infants born at the threshold of viability. *Pediatrics* 106(4): 659–671.
- Costeloe, K.L., E.M. Hennessy, S. Haider, F. Stacey, N. Marlow, and E.S. Draper. 2012. Short term outcomes after extreme preterm birth in England: Comparison of two birth cohorts in 1995 and 2006 (the EPICure studies). *British Medical Journal* 345: e7976. doi:10.1136/bmj.e7976.
- Darlow, B.A. 2006. The limits of perinatal viability: Grappling with the “grey zone.” *The Medical Journal of Australia* 185(9): 477–479.
- French, N. 2007. Consensus statement on perinatal care. *Journal of Paediatrics and Child Health* 43(6): 492–493.
- Kuhse, H. 1992. Quality of life and the death of “Baby M”: A report from Australia. *Bioethics* 6(3): 233–250.
- Lui, K., B. Bajuk, K. Foster, et al. 2006. Perinatal care at the borderlines of viability: A consensus based on a NSW and ACT consensus workshop. *The Medical Journal of Australia* 185(9): 495–500.
- Maclean, A.R. 2008. Advance directives and the rocky waters of anticipatory decision-making. *Medical Law Review* 16(1): 1–22.
- Orfali, K. 2004. Parental role in medical decision-making: Fact or fiction? A comparative study of ethical dilemmas in French and American neonatal intensive care units. *Social Science and Medicine* 58(10): 2009–2022.
- Rebagliato, M., M. Cuttini, L. Broggin, et al. 2000. Neonatal end-of-life decision making: Physicians’ attitudes and relationship with self-reported practices in 10 European countries. *The Journal of American Medical Association* 284(19): 2451–2459.
- Royal Australasian College of Physicians [RACP]. 2008. *Decision-making at the end of life in infants, children and adolescents*. Sydney: Paediatrics and Child Health Division. <http://www.racp.edu.au/index.cfm?objectid=B5603385-D3A3-F3B4-7159013AE33D4697>.
- Thoren, E.M., B. Metzke, C. Bühner, and L. Garten. 2013. Online support for parents of preterm infants: A qualitative and content analysis of Facebook “preemie” groups. *Archives of Disease in Childhood: Fetal and Neonatal Edition* 98(6): F534–F538.
- Wilkinson, D.J.C., and R.D. Truog. 2013. The luck of the draw: Physician-related variability in end-of-life decision-making in intensive care. *Intensive Care Medicine* 39(6): 1128–1132.
- Williams, M., J. Chesterman, and P. Grano. 2012. Challenging Australia’s “closed” model of neonatal care: The need for reform following Re Baby D (No 2). *Journal of Law and Medicine* 19(4): 835–853.