HOW MUCH WEIGHT SHOULD WE GIVE TO PARENTAL INTERESTS IN DECISIONS ABOUT LIFE SUPPORT FOR NEWBORN INFANTS?

Dominic Wilkinson
The Ethox Centre, Department of Public Health and Primary Health Care, The University of Oxford
Oxford Uehiro Centre for Practical Ethics, The University of Oxford
Dominic Wilkinson is supported by an Oxford Nuffield Medical Fellowship, Eric Burnard Fellowship, and Royal Australasian College of Physicians Astra-Zeneca Medical Fellowship. The funders had no involvement in this work.
Correspondence to Dominic Wilkinson: dominic.wilkinson@ethox.ox.ac.uk

Life-sustaining treatment is sometimes withdrawn or withheld from critically ill newborn infants with poor prognosis. Guidelines relating to such decisions place emphasis on the best interests of the infant. However, in practice, parental views and parental interests are often taken into consideration.

In this paper I draw on the example of newborn infants with severe muscle weakness (for example spinal muscular atrophy). I provide two arguments that parental interests should be given some weight in decisions about treatment, and that they should be given somewhat more weight in decisions about newborns than for older children. Firstly, the interests of the infant and of parents intersect, and are hard to separate. Parents' views about treatment may be relevant to an assessment of the infant's interests, and they may also affect those interests. Secondly, the interests of the infant in her future are relatively reduced by her developmental immaturity. In some situations parents' welfare interests outweigh those of the infant. However, I argue that this would not justify treatment limitation except in the setting of severe impairment.

INTRODUCTION

For newborn infants who are critically ill and predicted to have severe impairment if they survive, parents and doctors sometimes decide to withdraw or withhold further life-sustaining treatment. The majority of deaths of newborn infants in intensive care follow decisions to limit potentially life-sustaining treatment (Singh et al. 2004; Wilkinson et al. 2006; Verhagen et al. 2009). The justification of such decisions is that treatment is no longer in the best interests of the patient. This is in accordance with professional

guidelines that stipulate that the best interests of the child should be the primary or paramount consideration (British Medical Association ethics department 2004; Royal College of Paediatrics and Child Health 2004; General Medical Council 2006; Nuffield Council on Bioethics 2006; American Academy of Pediatrics Committee on Fetus and Newborn 2007). However, in practice, as in the case of RB below (Box 1), the views and interests of parents are often taken into account. Clinicians making such decisions place significant weight on the interests of parents (Hardart & Truog 2003a), and will not usually withdraw treatment if parents are opposed to this (Wilkinson 2010b).

Box 1. The case of RB (Baby RB 2009)

In late 2009 the UK Family court heard the sad case of RB. RB was a 13 month-old infant with an extremely rare neuromuscular disorder (congenital myasthenic syndrome) rendering him quadriplegic and permanently dependent on a ventilator to breathe. He was not believed to have any cognitive impairment, but was unable to move, communicate or even interact with those around him. Experimental treatments had failed to improve his condition. RB had been a patient in the intensive care unit since birth. Long-term survival would be possible with a surgical tracheostomy and home ventilation treatment. However, RB's mother and doctors had come to the conclusion that it would not be in his interests to have this treatment; that, in fact, it would be best for him if his breathing support were to be withdrawn and he were allowed to die. The case came to court because RB's parents disagreed. His father believed that RB should have a tracheostomy performed and that life support should continue. After several days of the court hearing RB's father withdrew his objection to the medical treatment plan; RB was subsequently taken off the ventilator and died in his parents' arms.

Source: Day 2009

Treatment for infants like RB with such severe muscle weakness that they require breathing machine support from birth or soon after birth is controversial (Hardart & Truog 2003b; Ryan et al. 2007; Inwald 2008). In recent years there has been increasing experience with long-term invasive and non-invasive ventilation for infants with a similar condition, spinal muscular atrophy type 1, particularly in Japan (Sakakihara et al. 2000; Bush et al. 2005). Whereas previously all such infants would have died, there are now a number of infants who survive into childhood and there is increasing willingness to contemplate providing long-term support (Hardart et al. 2002; Hardart & Truog 2003b; Geevasinga & Ryan 2007). UK courts have considered several similar cases in the past

decade or so where there has been conflict between parents and medical staff about continuing treatment (Table 13.1).

Such cases raise a number of questions, including whether or not life is worth living for an infant who is dependent on breathing machines, unable to move, or communicate, and unlikely ever to improve (Ryan et al. 2007). It also raises questions about the resource implications of providing long-term respiratory support for infants with such profound impairment and whether this should enter into decisions (Ryan et al. 2007). In this paper I wish to set those issues aside to focus on another related question. For cases like the one described above, what weight should be given to the interests or views of parents? Had RB's parents agreed to withdrawal of life support it is highly unlikely that the case would have come before the court, and likely that treatment would have been withdrawn considerably earlier. On the other hand, if RB's parents had both sought tracheostomy it is conceivable that doctors would have acceded to their request. In a similar case several years ago, the High Court of England and Wales decided in favour of parents who requested continuation of mechanical ventilation (An NHS Trust v MB 2006). If our focus is on the best interests of the child why should parents' views matter? Secondly, should we give any *more* weight to the views or interests of parents for decisions about infants or newborn infants compared to older children? A survey of intensive care physicians in the United States suggests that those who treated newborn infants were more likely to incorporate family interests into their decision-making model than paediatric intensivists, and considerably more likely than adult intensivists (Hardart & Truog 2003a).

I will argue in this paper that weight *should* be given to the interests of parents. In the first half of the paper I suggest that parents' desires about treatment and the interests of the child overlap and interact in ways that make them difficult if not impossible to separate. Parents' views and desires may be relevant to the question of what is in the best interests of the child. In the second half, I assess the genuine conflicts. I consider in detail the strength of the interests at stake for parents and child. I argue that a newborn's interest in her future is less than that of an older child, and as a consequence parental interests may be given relatively more weight for decisions about newborn infants than for older children. In some cases of conflict, parents' welfare interests may outweigh those of the child, though I suggest that this would only justify treatment withdrawal in cases of severe predicted impairment.

Case	Medical condition	Age	Setting	Parents views (supported/ opposed doctors)	Ultimate decision
Re C (medical treatment) [1998] 1 FLR 384	Spinal Muscular Atrophy type 1	16 months	Doctors sought authority to withdraw ventilation and not reinstitute if required; parents wanted infant to be reventilated if required	Opposed	Ventilation withdrawn
An NHS Trust v MB [2006] 2 F.L.R. 319	Spinal muscular atrophy type 1, normal intellect	18 months	Doctors sought authority to withdraw treatment	Opposed	Treatment continued
Baby RB [2009]	Congenital myasthenic syndrome (completely paralysed, ventilator dependent), normal cognition	13 months	Doctors wanted to withdraw.	Mother wanted to withdraw treatment. Father wanted treatment to continue	Father withdrew opposition to ventilator withdrawal. No judgement – though decision by mother and doctors endorsed by judge. Treatment withdrawn.

Table 13.1 UK legal cases relating to treatment withdrawal in infants with severe muscle weakness

OTHER DECISIONS

Before considering the different ways in which parental interests might be relevant, it is worth noting that for other decisions about children parental views are given considerable weight. Parents are given discretion for a wide range of decisions, including those relating to housing, education and basic health care. In most countries there is a legal presumption that parents have a right to make decisions on behalf of their children (Dare 2009). Parental decisions are respected, even if they do not promote the best interests of the child, unless they appear to risk a substantial harm to the child (Diekema 2004). This presumption may have some basis in historical ideas of the child as the property of their parents (Fost 1981; Kipnis & Williamson 1984; Downie & Randall 1997). Contemporary writers have defended it on the basis of the value of parenting and the importance of preserving intimate family relationships (Schoeman 1985; Downie & Randall 1997).

For example, it would often unquestionably be in the best interests of the child if parents were to purchase private education or private health insurance for the child. But parents are permitted to take into account the impact on themselves and on other family members of such decisions and to elect not to provide these significant benefits. More controversially, parents are usually permitted to make medical decisions that potentially impose some risk on their children, for example electing not to have routine childhood immunisations (Dawson 2005).

However, when it comes to decisions about life-sustaining treatment there is less weight given to the views and interests of parents (Paris & Schreiber 1996). As noted already, existing guidelines suggest that for children and incompetent adults, the interests of parents and family members should not be considered at all.

DEFINITIONS/ASSUMPTIONS

Firstly it will useful to be clear about what I mean by interests.

> **Interest:** P has an interest in X if they stand to gain or lose by the nature or condition of X (Feinberg 1984: 33–4).

Put even more simply, we have an interest in something when we can be benefited or harmed by it. What counts as an interest is intimately related to theories of axiology or prudential value (DeGrazia 1995; Veatch 1995). There are various axiological theories, and these are often divided into those that place emphasis on the presence/absence of pleasure and pain (mental-state theories), on preference or desire satisfaction (preference-based theories), or on the presence or absence of objectively valuable components of

flourishing (objective list theories) (Parfit 1984: 493–502; Griffin 1986: 7–74; DeGrazia 1995). Detailed discussion of these theories is beyond the scope of this paper, nevertheless, much of the following discussion will be relevant whichever view is held (though potentially in different ways).

Secondly, we might distinguish two types of parental interest at stake in treatment decisions.

> **Expressed Desires (Interests$_{ED}$)** – parents' views and wishes about treatment for the infant.
>
> **Welfare Interests (Interests$_{W}$)** – the effect of decisions on how well parents' lives go, for example the effect on their happiness, personal relationships, finances, career, recreational and life plans.

These could diverge, since parents' expressed desires about treatment for an infant may not reflect what would be best for themselves (ie in their own welfare interests). They will also converge, since on most theories of prudential value an individual benefits by having their desires fulfilled. The important practical question is how much weight to give to parents' Interests$_{ED}$, since it is rarely possible to separate out their welfare interests. However, if there is reason to give parents Interests$_{W}$ weight in decisions, that would support giving weight to their Interests$_{ED}$.

Thirdly, in this paper I refer largely to parents. The other group potentially influenced by the child's survival are existing siblings in the care of the parents. For simplicity I will not discuss siblings separately, but the principles are likely to be similar.

Finally, I will refer to the concept of a *life worth living*. I use this to refer to a life that contains or will contain overall more intrinsically good experiences (benefits) than intrinsically bad ones (burdens) (Broome 2004: 66–8). I also discuss the potential interest of the child in withdrawal of life support. This raises the question of whether it is coherent to think that an individual can be benefited or harmed by death, since if they die they will cease to exist. I assume in what follows that an individual *can* be benefited or harmed by their death.

APPARENT CONFLICT: THE ARGUMENT FROM OVERLAPPING INTERESTS

Why should parents' interests be given weight in decisions? One reason is that there are a number of ways in which the interests of infants and of parents (particularly their In-

terests$_{ED}$) intertwine (Duff 1981; Diekema & Fost 2010). Conflict may be more apparent than real.

DETERMINATIVE

Firstly, the interests$_{ED}$ of parents may, in some cases, influence or *determine* whether or not the infant has an interest in continuing life. Parents' interests$_{ED}$ may reflect both their capacity to care sufficiently and their desire to do so. For example, some parents of very severely impaired infants and children devote enormous amounts of time, energy and financial resources into the care of those children. They are able to enrich the lives of such children and help them experience benefits despite enormous challenges. Though it might be usually the case that for a child with such severe impairment life-sustaining treatment would not be in their best interests, the strength of these particular parents' interest in the child surviving may make the difference for the child between a life that is worth living, and one that is not.

Conversely, some parents with limited financial and personal resources, perhaps with other existing children, may be unable to devote sufficient attention to a child with severe impairment. They do not neglect the child, but nor are they able to care for them optimally. The benefits of life for that child may be outweighed by burdens, though in other environments they would have had a life worth living.

EVALUATIVE

Secondly, there is the possibility that the values of parents will influence how we *evaluate* the interests of an infant. I referred above to different theories of prudential value, and the lack of consensus about which theory should be adopted. Given such disagreement it is difficult to know how to weigh up different values or preferences. We cannot be guided by the infant's own values, but nor is there a value neutral perspective that can yield an answer. One option would be to adopt the parents' values (or at least to give them greater weight in deliberation). We might do this because it respects the point of view of parents and avoids privileging the perspective of the doctor. But we might also do so because the values that the child will or would adopt (if they survive) are likely to be influenced by those of their parents (Glass et al. 1986). They will not *necessarily* share the values of their parents, but this is at least somewhat more likely than not. Consider, for example, an infant like RB with very severe predicted physical impairment but no cognitive impairment. If his parents had a strong attitude of optimism, and a determination to overcome physical adversity we might anticipate that this will influence their care for him, and the balance of benefits and burdens in his life. But it also seems plausible

that this may make it more likely that he will have a similar outlook on life. It would potentially influence his future judgement about whether life is tolerable.

INTERDEPENDENT

Third, in many families at least, there is a sense in which the interests of child and parent are interdependent. The parent has an Interest_W in promoting the child's interests, and the child has an interest in promoting those of their parents. An infant may, therefore, have an interest in a decision that is consistent with their parents' wishes. There are two ways of justifying this. We might point to the future desires of the child. It is reasonable to think that a child will have, or would have (if capable of forming it) a desire that their loved ones are happy. Alternatively, if a rational preference or objective value theory is adopted, the child could have such an interest now even if they are never capable of actually desiring it.

Imagine, for example, that in the case of RB the burdens of life just outweigh the benefits, but his parents had a strong desire (and interest) in his continued life. RB's interest in his parents' wellbeing (however that is conceived) might tip the balance for him in favour of continued life. It is difficult to know how strong the interdependent interests of a child are, and whether they could outweigh the harm of ongoing existence. But in another context, we could imagine a patient with a sufficiently severe and debilitating illness that they are led to contemplate ending their life (they judge their life to be not worth living). Yet they determine not to commit suicide for the sake of a partner or other family member who would be devastated if they died.

EPISTEMIC

Finally, there is a sense in which parents are in an epistemically privileged position to *assess* the interests of the child (Diekema 2004). This perhaps makes most sense for older children, where parents are usually going to be in the best position to know the child's preferences, desires, dislikes and ability to tolerate physical suffering. But it could have some relevance to infants. In the case of MB (Table 13.1) the judge placed significant emphasis on the evidence of parents about the experience of the paralysed infant, and the degree that MB was aware of, and able to appreciate, his environment (An NHS Trust v MB 2006: para 16). The parents had spent large periods of time at his bedside and had done so since birth. As a result they were perhaps in a better position than medical or nursing staff who would have cared for multiple different patients over the same period. There is also the possibility that parents are better able to anticipate the future environment for the child and their own ability to care for him or her. On the

other hand, the parents' lens may be distorted by their need to maintain hope (Day 2009), or by their consideration of their own wellbeing and interests (Dare 2009), and consequently their assessment may be inaccurate.

The above four factors make it hard to separate the interests_{ED} of parents and the interests of the infant. In practice, when there is conflict, even if it *appears* that the interests of parents and the interests of the infant are opposed, it is almost always claimed by parents that they are representing the interests of the child. Thus, for example, parents who wish to continue treatment against the advice of doctors usually claim that it is in their child's interest to continue to live (see, for example, IM below). Parents who wish to discontinue treatment despite the belief of doctors that it should be provided usually claim that such treatment is not in their child's interest eg (Kopelman & Kopelman 2007). The second and fourth reasons listed above provide some reason to give extra credence to the assessment or value judgement that parents have made. The first and third factors may serve to bring the infant's interests closer to the parents' and resolve the conflict.

The relevance of these intersecting interests for the question posed at the start of the paper is that it is reasonable to give some weight to parental interests_{ED} in part because they may *influence* the interests of the infant. They are relevant to an assessment of whether, for the sake of the infant, treatment should continue. There are also some reasons why the argument from overlapping interests is stronger for infants than for older children. The determinative and evaluative components of this argument may be more relevant to infants because their own values are yet to develop, and because they are likely to have a longer period of dependency on the care of parents. On the other hand, the interdependent/epistemic reasons for overlapping interests do not appear any stronger in infants than older children.

Some authors have argued against parental discretion in decisions about children and newborns. They point out that parents may *not* be in the best position to assess the child's future interests (Fost 1981; Dare 2009). They may be mistaken about the effect of impairment on the child's life and on their own ability to care for the child (Fost 1981). Their own conflicting interests (to be discussed shortly) mean that they cannot be impartial judges of the child's best interest (Fost 1981; Fost 1986). These reservations are valuable, and should be taken into account. Sometimes parental interests will not overlap with the child's in the ways that I have described. But these arguments do not mean that parental views can *never* or should never influence our assessment of the interests of the child. At least in some situations, as argued above, I believe that they can and should.

The force of the argument from overlapping interests relates largely to cases where infants have lives that are close to the level of a life worth living. It would not justify

giving weight to parental views where an infant clearly had a life worth living or where it was clearly contrary to the infant's best interests to continue treatment.

TRUE CONFLICTS: THE ARGUMENT FROM THE WEIGHT OF INTERESTS

Although the interests of the infant and those of the parents are difficult to separate they are in principle separable, and there may be situations where they can be clearly distinguished.

It is worth noting that although these interests may conflict they will often coincide. The most common situation in intensive care is that of an infant whose life will be worth living, and whose parents have a strong interest in the infant's survival. In such cases, obviously, there is no conflict and no difficulty (A, Table 13.2). Nor is there any problem when both the interests of the infant and the interests of parents lie in withdrawal of life support (D). These interests may also come apart, however. This can arise either when the infant has an interest in continued life, but the parents have an interest in withdrawal of the infant's life support (B) (case PM, Box 2), or when the opposite is true (C) (Case IM, Box 2). I focus below on type B conflicts, though the principles should be similar for type C conflicts.

A – Life/life agreement Infant – interest in continuing life Parents – interest in infant continuing to live	**B – Life/Death conflict** Infant – interest in continuing life Parents – interest in life support withdrawal
C – Death/Life conflict Infant – interest in life support withdrawal Parents – interest in infant continuing to live	**D – Death/Death agreement** Infant – interest in life support withdrawal Parents – interest in life support withdrawal

Table 13.2 The relationship between interests of parents and the interests of the infant

Box 2. Type B and C conflicts

Case of PM (Type B conflict): PM had severe birth asphyxia. Her parents were informed that if she survived she was likely to be severely intellectually and physically disabled, blind and deaf. PM's parents and doctors together reached a decision to withdraw mechanical ventilation. However, PM continued to breathe off the ventilator, and subsequently doctors raised with

parents the possibility of withdrawing artificial feeding. Her parents consented to this, but shortly afterwards the hospital ethics committee ruled that feeding and other necessary treatments should be continued.

At 16 months of age PM's parents brought a lawsuit against the hospital claiming that the ethics committee unlawfully interfered with their decision, and seeking support for PM's ongoing medical care. (Canadian television 2010; Canadian television company 2010; The Current 2010)

Case of IM (Type C conflict): IM also had severe birth asphyxia. The case reached media attention after his parents sought a court injunction to prevent doctors from withdrawing mechanical ventilation. At that point he was 3 months old, and had required mechanical ventilation since birth. He was believed to have sustained very severe brain injury. The doctors believed that he had no chance of recovering 'meaningful function'. His parents were determined that his life, even if impaired, was worth fighting for.

The courts granted the parents a chance to obtain a second medical opinion. His parents subsequently agreed to withdrawal of life support after this doctor confirmed IM's prognosis. (Bailey & Amann 2010; Castagna 2010; Priest 2010).

In both of the above cases there is a potential conflict between the Interests_{ED} of parents and the interests of the child. In the case of PM it appeared that the hospital ethics committee believed that she had an interest in continued treatment, though her parents desired that life-sustaining treatment be withheld. In the case of IM, the doctors believed that continued intensive care was contrary to his best interests, while his parents wanted treatment to continue. I do not claim that the doctors/ethics committees in the above cases were necessarily right in their judgement about the infant's interests. For the reasons given above it may be difficult to separate out the interests of parents and of the infant. Perhaps the parents are correct in their assessment of the infants' interests. But I will temporarily set that aside to consider whether, if there *is* a genuine conflict between interests, weight should be given to those of parents. If the interests of IM and PM clash with those of their parents which should we favour? To answer this question we need to have some idea of the nature and relative strength of the interests at stake.

THE INTERESTS OF PARENTS

Parents' lives are not necessarily worse if an infant survives with severe impairment. Some parents eloquently describe the ways in which their personal life, and those of other members of their family are enriched by the experience of caring for an impaired child. Parents may have a very strong desire that the child survive. In my experience, this is often particularly the case for parents who have had considerable difficulties conceiving, or who are unable or unlikely to be able to have further children.

On the other hand, other parents describe substantial negative consequences of the illness or impairment of their child. There are well-documented potential costs for families. Having a child with a serious illness or impairment increases the incidence of parents divorcing or living apart, (by 10–20 percentage points) (Corman & Kaestner 1992; Reichman et al. 2004), and is associated with higher rates of psychological and physical ill health (Thyen et al. 1999; Raina et al. 2005; Murphy et al. 2007; Harrison 2008; Reichman et al. 2008). Primary caregivers are at significant risk of clinical depression and abnormally low subjective quality of life (Cummins 2001; Olsson & Hwang 2001). Care needs of children with severe impairments do not diminish with age, and mothers are frequently unable to work outside the home with negative effects on family income (Thyen et al. 1999; Curran et al. 2001). The financial demands of caring for a child with impairment are estimated to be more than three times the cost of bringing up a non-impaired child (Curran et al. 2001).

The relationship between the desires of parents and their Interests_W may be complex. For example, parents' lives may predictably go worse overall if they have to care for a surviving child, and yet parents may have a very strong desire that the child does survive. It may often be the case that parents have interests both in the survival of the infant *and* in withdrawal of life-sustaining treatment. It is not clear how such competing interests should be weighed against each other.

It is, therefore, somewhat difficult to generalise about the strength of the interest that parents have in withdrawal of life support. But two points appear reasonably plausible. Some parents will have a strong interest_W in intensive care not being continued for their newborn infant. Secondly, the strength of this interest is likely to be proportional to the severity of the child's impairment. This is because the greater the severity of impairment, the greater the demand that a child's care is likely to place on caregivers. Higher caregiving demands, in turn, are associated with lower physical and psychological wellbeing in caregivers and greater financial cost to families (Leonard et al. 1992; Raina et al. 2005).

THE INTERESTS OF THE INFANT

For type C conflicts, the infant has an interest in not experiencing physical or mental suffering that outweigh the benefits that he or she will experience in future life. The strength of this interest will vary. We could imagine cases where future burdens just outweigh benefits, and there is a relatively small net interest in life support being withdrawn. Equally there will be cases where future suffering vastly outweighs the benefits for the infant, and they have a strong interest at stake.

In my description of type B conflicts I have specified that the infant has an interest in continued life. But what is the nature and the strength of *this* interest? It is generally thought that an individual's interest in continuing to live is one of the strongest interests that they hold. At least for adults and children it is usually believed that the lesser interests of others cannot outweigh their interest in continued life (Janvier et al. 2007). If the interest of the newborn in their future life were of *this* nature it would seem to preclude any weighing of parents' interests against those of the infant. I will consider (and reject) two opposing suggestions.

NO INTEREST?

Peter Singer has controversially argued that infants have *no* interest in continued existence (Singer 1993: 97–8). Singer's argument is based on three claims. Firstly, he holds a preference-satisfaction view of the good; it is necessary for individuals to have a desire for something for it to be in their interest (ibid.: 13, 94). Secondly, he claims that infants lack self-consciousness, and consequently lack an interest in continued existence (ibid.: 169). Thirdly, he makes a claim about personal identity: that infants are not identical with the adult they subsequently develop into (ibid.: 97–8).

Taking this last claim first, Singer writes 'I am not the infant from whom I developed' (Singer 1993: 97), and 'When I think of myself as the person I now am, I realise that I did not come into existence until some time after my birth' (Kuhse & Singer 1985: 133). The implication is that the toddler or young child who develops self-consciousness is a different individual from that toddler at a slightly younger age. This claim is highly counterintuitive, but it also risks non-coherence (McMahan 2002: 349; Kaposy 2007: 309–12). As pointed out by Jeff McMahan, self-consciousness is typically thought to require higher order awareness of ongoing conscious experience. But if identity only begins when that individual develops the higher order awareness, then the lower order conscious experience that they are starting to appreciate must belong to a different individual (McMahan 2002: 350). There are also reasons to think that there is *some* psychological continuity between the newborn and later fully self-conscious individual. Although few children or adults have any memory of early infancy (Hayne 2004), there are psychological ripples of unremembered events. For example, six-month old infants who had been circumcised in the newborn period had a stronger pain response to routine vaccination at 6 months of age; this was attenuated by providing local anaesthesia for the procedure (Taddio et al. 1995). Two year-old children have been demonstrated to retain non-verbal memories from events or training at 6 months of age (Hartshorn 2003; Bornstein et al. 2004).

There are also reasons to cast doubt upon Singer's second claim, that infants lack self-consciousness. Newborn infants distinguish tape-recordings of their own cry from that of other infants (Martin & Clark 1982); in one study they stopped crying on hearing their own voice, while they continued to cry on hearing a recording of another infant. In other studies infants, as early as an hour after birth, have been shown to imitate adult facial gestures (Meltzoff & Moore 1977; Meltzoff & Moore 1983). Imitating behaviour appears to be non-reflexive, involves memory, and improves over time (Meltzoff & Moore 1994). These experiments, and others, suggest that infants have a degree of proprioceptive (ie non-visual) awareness of their own face (Gallagher 1996). They appear to have a form of primitive, non-conceptual self-consciousness (Bermudez 2001; Lagercrantz & Changeux 2009).

Still, even if newborn infants have some degree of self-consciousness, they do not appear to possess a desire or preference for continued life. If Singer's first claim were true they would still potentially lack an interest in living; they would not be harmed by their death, nor would they benefit from life-saving treatment in the newborn period. There is, however, a coherent and plausible sense in which a newborn who has a life worth living *is* benefited by having their life saved in infancy. If we compare two scenarios, A1, where a newborn dies shortly after birth, and A2, where they live to adulthood (and have a life worth living), there is clearly greater wellbeing in A2 than in A1. If the newborn shares identity with their older self, they would benefit from experiencing the wellbeing in A2; correspondingly, the infant has an interest in not dying in the newborn period (McMahan 2002: 352).

The above arguments provide reasons to reject Singer's claim; infants do have an interest in continuing to live as long as that future life would contain more intrinsically positive than negative experiences (ie they would have a life worth living) (Kaposy 2007). But how strong is that interest? The most widely held view is that newborn infants have a strong and overriding interest in continued life, equivalent to that of older children and adults (Kaposy 2007).

STRONG AND OVERRIDING INTEREST?

Most people, I suspect, have instinctively strong protective feelings towards newborn infants. Enormous efforts are made to save the lives of infants who are critically ill after birth. Parents and family members are usually devastated by the death of a newborn. It is believed to be a tragedy when this occurs – both for the parents and for the infant.

Death is a harm to such infants because it deprives them of future wellbeing. But given that a newborn is typically deprived of significantly more years of wellbeing than

a child or an adult, this loss appears *greater* for a newborn than for the child or adult who dies. This conflicts, however, with other widely held intuitions.

The *Transplant Choice* may illustrate the point:

> A 6 year-old child with a severe cardiomyopathy is awaiting a heart transplant. She has had multiple admissions to hospital, and is becoming more unwell each time. It is feared that if she has to wait much longer she will either become ineligible to receive a transplant (because she will be too unwell), or will die. At the same hospital, a newborn infant is born with a rare congenital form of the same illness. He is critically ill and is put on a heart bypass machine. If he does not receive an urgent heart transplant he too will die.
>
> A heart becomes available that would suit either the older child or the infant. With transplantation the child and infant would have equal chances of surviving to early adulthood at least. Who should receive the transplant organ? (Whoever does not receive the heart is likely to die.)

The usual response to the *Transplant choice* is to refuse to choose between the children. But if forced to make a choice like this, the majority of respondents choose the 6 year-old (Ross 2007). In a more systematic survey, when doctors and non-doctors were asked to make hypothetical resuscitation decisions for a series of children and adults of varying ages, greater priority was consistently given to resuscitating an older child than to resuscitate a newborn, even when the older child's prognosis was poorer (Janvier et al. 2008a; Janvier et al. 2008b).

Even if such intuitions are widespread, it does not follow from this that newborns *should* be treated differently than other children. Our intuitions may be unjustified or unreliable. The authors of that survey suggested that there is a bias against newborns, and premature infants in particular, and that such attitudes might have anthropological and evolutionary roots in the high neonatal mortality rates present throughout most of human history (Janvier et al. 2007; Janvier et al. 2008a). Others have suggested that the difference lies in the older child's lived experience, and the potentially greater grief for her parents (Ross 2007).

A REDUCED INTEREST

However, one plausible way of explaining this intuition is that death is a greater harm for the 6 year-old than for the newborn. Death is bad for us because it deprives us of future wellbeing. The better and longer our life would have been, the greater the harm it is to us to die. But death is also bad for us because it cuts short our desires, plans and hopes for that future and severs the relationships that we have developed with those around us. The more of these that we have developed, the greater our psychological connection with that future and the greater the harm it is for us to die. In *The Ethics of Killing*, Jeff McMahan has argued that the combination of these two elements helps to explain many of our intuitions about death (McMahan 2002). Thus, it is worse for a 20 year-old to die than a 40 year-old (because the 20 year-old would be deprived of more life). But it is also worse for a 6 year-old to die than a newborn or a foetus, because of the older child's greater awareness of herself, and psychological links with her future. The interest of a newborn in his future is less than that of an older child, while greater than that of a foetus.

The above argument does not establish just how strong the interest of a newborn is in their future. The difference between newborns and children might be sufficiently small that it only makes a difference in exceptional treatment dilemmas like the one described above. Alternatively, it might mean that treatment decisions for newborns are completely different from those in older children. I do not propose to settle that question here (though the next section provides a separate argument against the latter possibility). It raises difficult questions about the relationship between different elements of interests, and the weighing of different types of interests, questions that are beyond the scope of this paper. Nevertheless, the argument above provides support for the idea that decisions in newborns are not identical to decisions in older children.

The other point to note is that infants will vary in the strength of their interest depending on the amount of wellbeing in their future life. While it is difficult to know when the burdens outweigh benefits in an infant's life, it is clear that impairment can affect the interests of the infant (Wilkinson 2006). Severe physical impairment is likely to increase the intrinsically negative features of future life for the infant. Severe cognitive impairment reduces the benefits of life (Wilkinson 2006). Both may thus reduce the strength of the newborn's interest in their future. Infants who are predicted to have such impairments have a relatively weak interest in their future life.

To sum up this section, I have argued that a newborn has an interest in their future, but that it is not as strong as it would be if they were older. For infants with predicted severe

impairment, their interest in continuing life support is relatively weak, while parental interests in not keeping the infant alive may be strong. For both type B and type C conflicts, where an infant's future life is predicted to be close to the level of a life worth living, the presence of a strong conflicting parental interest may outweigh a weak interest on the part of the infant. This is more likely to be the case for infants compared to older children, though in principle it could also occur for older children.

OBJECTIONS

There are two potential objections to this conclusion.

UNLIMITED TREATMENT WITHDRAWAL

The first objection is that allowing parents' interests$_W$ to be taken into account in such decisions would amount to parents being given free rein in decisions about life-sustaining treatment. It would potentially lead to withdrawal of life-sustaining treatment from infants with only mild degrees of impairment, or on the basis of relatively trivial reasons.

There are several reasons, however, why this would not follow. The first is simply that the overwhelming majority of parents have a strong desire that their infants live – even if they will be impaired. In my experience, and in the experience of other neonatologists (Wilkinson 2010b), it is very rare for parents to want to withdraw life-sustaining treatment in situations when doctors believe that survival without severe impairment is probable. It is not likely that allowing parental interests to be considered would lead to withdrawal of treatment from a large number of mildly impaired infants. But secondly, and more significantly, the relative balance of interests is potentially quite different for an infant with mild or moderate impairment. As noted above, the strength of parents' potential interest$_W$ in withdrawal of treatment is likely to be proportional to the severity of impairment. The impact on parents' lives is likely to be much less for an infant with mild or moderate impairment than for a more severely affected infant. What is more, for infants with mild or moderate impairments the strength of their own interest in future life may not be substantially less than unimpaired infants.

The other reason that the above arguments would not lead to withdrawal of life-sustaining treatment from mildly impaired infants is that for such infants there is the alternative of adoption or foster care. For infants who will have a life worth living, adoption would respect the interests of parents to a similar degree as allowing the infant to die. (It would not be identical, since parents may feel guilty about giving the child up for adoption or worry about their ongoing care). But adoption would also be consistent

with the infant's interest in future wellbeing. In terms of the interests at stake it would be better to adopt the infant than to allow them to die.

On the other hand, adoption would not as easily resolve the conflict in interests for infants with predicted severe impairment. Permanent adoptive parents or foster placements are significantly harder to find for children with severe impairment than for unimpaired or less impaired children (Bain 1998; Local Government Association 2001). The impact on adoptive families is also likely to be just as great as that noted above for birth families. Children who are unable to be placed and end up in institutional care, or those who have a succession of temporary foster placements may experience additional emotional trauma. There is a risk that as a consequence such children are harmed by ongoing life. Finally, the supportive care of such children is very expensive.

UNACCEPTABLE IMPLICATIONS FOR TERMINATION OF PREGNANCY DECISIONS

A parallel (though quite different) objection to the arguments above is that they would potentially have serious implications for pre-natal decision-making. If a newborn infant has a relatively strong interest in their future because of the wellbeing that they have at stake if they die, then correspondingly so would a foetus. It is difficult to know how much wellbeing a foetus experiences in utero, but they would potentially have somewhat *greater* future wellbeing than a term newborn. I argued that a term newborn infant has a primitive degree of self-conscious and some psychological connections with their future. But so too might a near-term foetus in utero. If parents' interests are to be given only limited weight in newborn decision-making, then perhaps this should also apply to decisions about termination of pregnancy. This might have major implications for the morality of abortion.

There are three responses to this objection, however. Firstly, there are relevant differences between the foetus and newborn that would potentially warrant different treatment. There is an explosive phase of synaptic development in late gestation and especially in the period immediately following birth as the newborn responds to their environment (Bourgeois 2001). The infant rapidly adapts to her changing environment and starts to develop reciprocal relationships with those around her. Furthermore, some have argued that the primitive self-consciousness evident in newborns cannot be present in utero because of the lack of interaction that is required to manifest phenomena such as the imitative features described above (Bermudez 1996). Consequently there may be a significant difference in moral status between the near-term foetus and the ex-utero newborn, even though they are neurophysiologically similar. Although Bermudez's argument about near-term foetuses may be challenged (Gallagher 1996), there is no doubt that there are

substantial differences in neurodevelopment between *early* foetuses and newborn infants. Prior to 20 weeks gestation there are no cortical synapses in the foetus and no apparent capacity for consciousness (McMahan 2002: 267). This would justify the significant difference in treatment between first trimester foetuses and newborn infants that is present in most societies.

Secondly, there are differences in the interests at stake when the foetus is in utero, compared to the ex-utero newborn. As famously argued by Judith Jarvis Thomson, even if the foetus has an interest in their future (or a right to life) as strong as that of an adult, there may be reasons to permit a mother to have an abortion (Thomson 1971). It is beyond the scope of this paper to outline Thomson's argument in detail or the many responses to it. Nevertheless, the adoption alternative discussed in the previous section makes the situation for a newborn significantly different. We might require parents who do not wish to care for an infant with moderate or mild impairment to give the child up for adoption. This would not problematically conflict with the rights of parents in the way that prohibiting abortion would.

Thirdly, the above arguments imply that parental interests may be taken into account in the face of severe predicted impairment, a situation not radically different from the framework currently applied to late-term foetuses, at least in some jurisdictions. In the United Kingdom, for example, abortion is permitted in the later stages of pregnancy only if there is substantial risk of serious handicap, or if there is a grave risk to the life or health of the mother (Nuffield Council on Bioethics 2006: 55). The above arguments might have implications for abortion in jurisdictions that are more restrictive about third trimester abortion.

CONCLUSIONS

In this paper I have argued that some weight should be given to the interests of parents in treatment decisions for children and newborn infants (especially the latter). One reason for doing so is that in such cases the $\text{Interests}_{\text{ED}}$ of parents and the interests of the child overlap in ways that make it hard to separate them. Although it may appear that their interests are conflicting they may in fact coincide. We should give some weight in our deliberation to the parents' *assessment* of what would be best for the child. What is more, parents' views may *influence* the interests of the child, and cause the two to converge. The argument from overlapping interests would also apply to older children, but is somewhat stronger for infants.

The second reason to give some weight to the interests of parents in decisions for newborns is because a newborn's interest in their future wellbeing is relatively reduced by their developmental immaturity. This means that, compared to older children, it is more easily outweighed by other considerations. It is difficult to know how to balance different competing interests. I have argued, however, that it is most likely that the interests$_W$ of parents would outweigh those of the infant where a newborn is predicted to have severe impairment. The infant has a relatively weak interest in future wellbeing because of their immaturity and because of the reduced wellbeing in their future. In contrast the impact on parents and siblings may be substantial. They potentially have a strong welfare interest in treatment not continuing.

These arguments help explain why, for infants with severe disabilities such as spinal muscular atrophy, or congenital myasthenic syndrome or following severe birth asphyxia it is appropriate for clinicians to seek parents' views about treatment, and to include the interests of parents and siblings in decisions about life-sustaining treatment. Depending on parental views and interests it may be appropriate either to continue treatment or to withdraw treatment and to allow the infant to die (Wilkinson 2010a). It also explains why it is particularly difficult when parents are divided about what should be done.

This is not a radical suggestion. It is similar to a proposal that a 'family-based welfare approach' rather than a pure 'best interests test' should be adopted for decisions in paediatric intensive care (Inwald 2008), and to the model of decision-making that is adopted by the majority of paediatric and neonatal intensive care physicians (Hardart & Truog 2003a). The importance of the above analysis is that it tries to clarify how and why parental interests are relevant, and justifies subtle differences in decision making for infants and newborns compared to older children.

Although parental interests should be given some weight the possibility of adoption provides a limit to the freedom of parents to opt for withdrawal of treatment in the face of lesser degrees of impairment. It means that treatment limitation for newborn infants with mild or moderate impairment would not be permitted.

Taking parents' interests into account does not mean that they are given precedence, nor that they will always be decisive. Where their decisions would pose a 'significant risk of substantial harm' (Diekema 2004), they may be overruled by physicians, ethics committees or by the courts. It means, however, that as in almost all other areas of life, parents are acknowledged to have a key role in important decisions about their young children.

REFERENCES

An NHS Trust v MB 2006 2 F.L.R. 319.

Baby RB EWHC (Fam) 2009. Comments by Mr Justice McFarlane. Accessed 9 February 2010 Available at: www.bailii.org/cgi-bin/markup.cgi?doc=/ew/cases/EWHC/Fam/2009/3269.html.

American Academy of Pediatrics Committee on Fetus and Newborn 2007. Noninitiation or withdrawal of intensive care for high-risk newborns. *Pediatrics* 119: 401–3.

Bailey, T., Amann, M. 2010. Defining best interests. *Edmonton Journal*. Edmonton, Ca. Accessed 1 February 2010. Available at: http://www.edmontonjournal.com/news/Defining+best+interests/2476916/story.html.

Bain, K. J 1998. Children with severe disabilities: Options for residential care. *Med J Aust* 169: 598–600.

Bermudez, J. L 1996. The moral significance of birth. *Ethics* 106: 378–403.

Bermudez, J. L. 2001. Nonconceptual self-consciousness and cognitive science. *Synthese* 129: 129–149.

Boonin, D. 2002. *In Defense of Abortion*. Cambridge: Cambridge University Press.

Bornstein, M; Arterberry, M; Mash, C. 2004. Long term memory for an emotional interpersonal interaction occurring at 5 months of age. *Infancy* 6: 407–16.

Bourgeois, J.P. 2001 Synaptogenesis in the neocortex of the newborn: The ultimate frontier for individuation? In *Handbook of Developmental Cognitive Neuroscience*, edited by C. Nelson and M. Luciana. Cambridge, MA.: MIT Press.

Brinchmann, B. S 1999. When the home becomes a prison: Living with a severely disabled child. *Nursing Ethics* 6: 137–43.

British Medical Association ethics department 2004. *Medical Ethics Today: The BMA's Handbook of Ethics And Law*. London: BMJ Books.

Broome, J. 2004. *Weighing Lives*. Oxford: Oxford University Press.

Bush, A; Fraser, J; Jardine, E; Paton, J; Simonds, A; Wallis, C 2005. Respiratory management of the infant with type 1 spinal muscular atrophy. *Arch Dis Child* 90: 709–11.

Canadian television 2010. Couple sues Montreal Children's Hospital. CTV Montreal. Montreal, Ca. Accessed 1 February 2010. Available at: http://montreal.ctv.ca/servlet/an/local/CTVNews/20090313/mtl_montreal_childrens_suit090313/20090313?hub=MontrealHome.

Canadian television company 2010. 'Couple sues hospital for keeping sick baby alive.' CTV accessed 27 January 2010. Available at: http://www.ctv.ca/servlet/ArticleNews/story/CTVNews/20090313/montreal_lawsuit_090313/20090313.

Castagna, C. 2010. Baby Isaiah dies in parents arms. *Toronto Sun*. Toronto. Accessed 15 March 2010. Available at: http://www.torontosun.com/news/canada/2010/03/11/13198176.html.

Corman, H; Kaestner, R 1992. The effects of child health on marital status and family structure. *Demography* 29: 389–408.

Cummins, R 2001. The subjective well-being of people caring for a family member with a severe disability at home: A review. *J Intellect Dev Dis* 26: 83–100.

Curran, A. L; Sharples, P. M; White, C; Knapp, M 2001. Time costs of caring for children with severe disabilities compared with caring for children without disabilities. *Dev Med Child Neurol* 43: 529–33.

Dare, T 2009. Parental rights and medical decisions. *Paediatric Anaesthesia* 19: 947–52.

Dawson, A 2005. The determination of the best interests in relation to childhood immunisation. *Bioethics* 19: 72–89.

Day, E. 2009. Baby RB: Heartbreak in Court 50 as life of a one-year-old hangs in the balance. *The Guardian*. Accessed 11 November 2009. Available from: http://www.guardian.co.uk/society/2009/nov/08/baby-rb-court-case.

DeGrazia, D 1995. Value theory and the best interests standard. *Bioethics* 9: 50–61.

Diekema, D. S 2004. Parental refusals of medical treatment: The harm principle as threshold for state intervention. *Theor Med Bioeth* 25: 243–64.

Diekema, D. S; Fost, N 2010. Ashley revisited: a response to the critics. *Am J Bioeth* 10: 30–44.

Downie, R. S; , R. S; Randall, F 1997. Parenting and the best interests of minors. *J Med Philos* 22: 219–31.

Duff, R. S 1981. Counseling families and deciding care of severely defective children: A way of coping with 'Medical Vietnam'. *Pediatrics* 67: 315–320.

Feinberg, J. 1984. *The Moral Limits of The Criminal Law: Harm to Others*. Oxford: Oxford University Press.

Fost, N 1981 Counseling families who have a child with a severe congenital anomaly. *Pediatrics* 67: 321–324.

Fost, N 1986. Treatment of seriously ill and handicapped newborns. *Critical Care Clinics* 2: 145–159.

Gallagher, S 1996. The moral significance of primitive self-consciousness: A response to Bermudez. *Ethics* 107: 129–140.

Geevasinga, N; Ryan, M. M 2007. Physician attitudes towards ventilatory support for spinal muscular atrophy type 1 in Australasia. *J Paediatr Child Health* 43: 790–794.

General Medical Council 2006. Withholding and withdrawing life-prolonging treatments: good practice in decision-making. London, GMC. Available at: www.gmc-uk.org/guidance/ethical_guidance/witholding_lifeprolonging_guidance.asp.

Glass, J; Bengtson, V; Dunham, C 1986. Attitude similarity in three-generation families: Socialization, status inheritance or reciprocal influence? *American Sociological Review* 51: 685–698.

Griffin, J. 1986. *Well-Being: Its Meaning, Measurement and Moral Importance*. Oxford: Clarendon.

Hardart, M. K.; Burns, J. P.; Truog, R. D. 2002. Respiratory support in spinal muscular atrophy type I: A survey of physician practices and attitudes. *Pediatrics* 110: e24.

Hardart, G. E; Truog, R. D 2003a. Attitudes and preferences of intensivists regarding the role of family interests in medical decision making for incompetent patients. *Crit Care Med* 31: 1895–1900.

Hardart, M. K; Truog, R. D 2003b. Spinal muscular atrophy – type I. *Arch Dis Child* 88: 848–850.

Harrison, H 2008. The offer they can't refuse: Parents and perinatal treatment decisions. *Semin Fetal Neonatal Med* 13: 329–334.

Hartshorn, K 2003. Reinstatement maintains a memory in human infants for 1(1/2) years. *Developmental Psychobiology* 42: 269–282.

Hayne, H 2004. Infant memory development: Implications for childhood amnesia. *Dev Rev* 24: 33–73.

Hollander, J. 2008. *When the Bough Breaks: A Mother's Tale*. London: John Murray.

International Planned Parenthood Federation 2008 Abortion Legislation in Europe (Updated January 2009). Brussels, IPPF European Network. Accessed 18 October 2010. Available at: http://www.ippfen.org/en/Resources/Publications/Abortion+Legislation+in+Europe.htm.

Inwald, D 2008. The best interests test at the end of life on PICU: A plea for a family centred approach. *Arch Dis Child* 93: 248–250.

Janvier, A; Bauer, K. L; Lantos, J. D 2007. Are newborns morally different from older children? *Theor Med Bioeth* 28: 413–425.

Janvier, A; Leblanc, I; Barrington, K. J 2008a. Nobody likes premies: The relative value of patients' lives. *J Perinatol* 28: 821–826.

Janvier, A; Leblanc, I; Barrington, K. J 2008b. The best-interest standard is not applied for neonatal resuscitation decisions. *Pediatrics* 121: 963–969.

Kaposy, C 2007. Can infants have interests in continued life? *Theor Med Bioeth* 28: 301–330.

Kipnis, K; Williamson, G. M 1984. Nontreatment decisions for severely compromised newborns. *Ethics* 95: 90–111.

Kopelman, L. M; Kopelman, A. E Using a new analysis of the best interests standard to address cultural disputes: Whose data, which values? *Theor Med Bioeth* 28: 373–391.

Kuhse, H.; Singer, P. 1985. *Should the Baby Live? The Problem of Handicapped Infants*. Oxford: Oxford University Press.

Lagercrantz, H; Changeux, J. P 2009. The emergence of human consciousness: From fetal to neonatal life. *Pediatric Research* 65: 255–260.

Leonard, B; Brust, J. D; Sapienza, J. J 1992. Financial and time costs to parents of severely disabled children. *Public Health Rep* 107: 302–312.

Local Government Association 2001. Memorandum submitted by the Local Government Association. Adoption and Children Bill. in Select Committee on Adoption and Children Bill Ed.). Accessed 1 February 2010. Available at: http://www.publications.parliament.uk/pa/cm200001/cmselect/cmadopt/431/1050108.htm.

Martin, G; Clark, R 1982. Distress crying in neonates: Species and peer specificity. *Dev Psychol* 18: 3–9.

McMahan, J 1988. Death and the value of life. *Ethics* 99: 32–61.

McMahan, J. 2002. *The Ethics of Killing: Problems at the Margins of Life*. New York: Oxford University Press.

Meltzoff, A. N; Moore, M. K 1977. Imitation of facial and manual gestures by human neonates. *Science* 198: 74–78.

Meltzoff, A. N; Moore, M. K 1983. Newborn infants imitate adult facial gestures. *Child Development* 54: 702–709.

Meltzoff, A. N; Moore, M. K. 1994. Imitation, memory and the representation of persons. *Infant Behav Dev* 17: 83–99.

Murphy, N. A; Christian, B; Caplin, D. A; Young, P. C 2007. The health of caregivers for children with disabilities: caregiver perspectives. *Child Care Health Dev* 33: 180–187.

Nuffield Council on Bioethics 2006. *Critical Care Decisions in Fetal and Neonatal Medicine: Ethical Issues*. London: Nuffield Council on Bioethics.

Olsson, M. B; Hwang, C. P 2001. Depression in mothers and fathers of children with intellectual disability. *J Intellect Disabil Res* 45: 535–543.

Parfit, D. 1984. *Reasons and Persons*. Oxford: Oxford University Press.

Paris, J. J; Schreiber, M. D 1996. Parental discretion in refusal of treatment for newborns. A real but limited right. *Clinics in Perinatology* 23: 573–581.

Priest, L. 2010. The two faces of a life or death dilemma. The Globe and Mail. Toronto, Canada. Accessed 2 January 2010. Available at: http://www.theglobeandmail.com/news/national/the-two-faces-of-a-life-or-death-dilemma/article1445507/.

Raina, P.; O'Donnell, M.; Rosenbaum, P.; Brehaut, J.; Walter, S. D.; Russell, D.; et al. 2005. The health and well-being of caregivers of children with cerebral palsy. *Pediatrics* 115: e626–636.

Reichman, N. E; Corman, H; Noonan, K 2004. Effects of child health on parents' relationship status. *Demography* 41: 569–584.

Reichman, N. E; Corman, H; Noonan, K 2008. Impact of child disability on the family. *Matern Child Health J* 12: 679–683.

Ross, L. F 2007. The moral status of the newborn and its implications for medical decision making. *Theor Med Bioeth* 28: 349–355.

Royal College of Paediatrics and Child Health. 2004. *Withholding and Withdrawing Life-Saving Treatment in Children: A Framework for Practice*. London: Royal College of Paediatrics and Child Health.

Ryan, M. M; Kilham, H; Jacobe, S; Tobin, B; Isaacs, D 2007. Spinal muscular atrophy type 1: Is long-term mechanical ventilation ethical? *J Paediatr Child Health* 43: 237–242.

Sakakihara, Y; Kubota, M; Kim, S; Oka, A 2000. Long-term ventilator support in patients with Werdnig-Hoffmann disease. *Pediatr Int* 42: 359–363.

Schoeman 1985. Parental discretion and children's rights: Background and implications for medical decision-making. *J Med Philos* 10: 45–61.

Singer, P. 1993. *Practical Ethics*. Cambridge: Cambridge University Press.

Singh, J; Lantos, J; Meadow, W 2004. End-of-life after birth: Death and dying in a neonatal intensive care unit. *Pediatrics* 114: 1620–1626.

Strong, C 1984. The neonatologist's duty to patient and parents. *Hastings Cent Rep* 14: 10–16.

Taddio, A; Goldbach, M; Ipp, M; Stevens, B; Koren, G 1995. Effect of neonatal circumcision on pain responses during vaccination in boys. *Lancet* 345, 291–292.

The Current 2010. Montreal couple suing hospital. *CBC*. Toronto, Canada. Accessed 1 February 2010. Available at: http://www.cbc.ca/thecurrent/2009/200903/20090318.html.

Thomson, J 1971. A defense of abortion. *Philos Public Aff* 1: 47–66.

Thyen, U; Kuhlthau, K; Perrin, J. M 1999. Employment, child care, and mental health of mothers caring for children assisted by technology. *Pediatrics* 103: 1235–1242.

Veatch, R. M 1995. Abandoning informed consent. *Hastings Cent Rep* 25: 5–12.

Verhagen, A.; Dorscheidt, J.; Engels, B.; Hubben, J.; Sauer, P. 2009. End-of-life decisions in Dutch neonatal intensive care units. *Arch Pediatr Adolesc Med* 163: 895–901.

Wilkinson, D 2006. Is it in the best interests of an intellectually disabled infant to die? *J Med Ethics* 32: -45-09.

Wilkinson, D. 2010a. A life worth giving: The threshold for permissible withdrawal of treatment from disabled newborn infants. *Am J Bioeth* (forthcoming).

Wilkinson, D 2010b. 'We don't have a crystal ball': neonatologists views on prognosis and decision-making in newborn infants with birth asphyxia. *Monash Bioethics Review* 29 (1): 5.1–5.19.

Wilkinson, D. J.; Fitzsimons, J. J.; Dargaville, P. A.; Campbell, N. T.; Loughnan, P. M.; McDougall, P. N.; et al. 2006. Death in the neonatal intensive care unit: Changing patterns of end of life care over two decades. *Arch Dis Child Fetal Neonatal Ed* 91: F268–71.

Wyn, N. 2007. *Blue Sky July*. Bridgend: Seren.

Cite this article as: Wilkinson, Dominic. 2010. 'How much weight should we give to parental interests in decisions about life support for newborn infants?' *Monash Bioethics Review* 29 (2): pp. 13.1 to 13.25. DOI: 10.2104/mber1013.