

# ○ 'WE DON'T HAVE A CRYSTAL BALL ...'

## NEONATOLOGISTS' VIEWS ON PROGNOSIS, MAGNETIC RESONANCE IMAGING AND TREATMENT WITHDRAWAL FOR INFANTS WITH BIRTH ASPHYXIA

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Birth asphyxia is the most common single cause of death in term newborn infants. The majority of deaths in developed countries follow decisions to withdraw intensive care. Recent technological advances, particularly the use of magnetic resonance imaging (MRI) of the brain, may affect the process of prognostication and decision-making. There is little existing evidence about how prognosis is determined in newborn infants and how this relates to treatment withdrawal decisions.

An exploratory qualitative study was performed using in-depth semi-structured interviews with a sample of ten neonatologists from tertiary intensive care units in the UK. Participants were purposively selected to ensure a range of experience and type of unit. They were asked about the process of prognostication for infants with birth asphyxia and decisions about treatment withdrawal. Interviews were transcribed and thematically analysed.

MRI played a significant role in decision-making about life-sustaining treatment for a number of clinicians. Clinicians did not identify particular ethical concerns related to MRI, though wider discussion revealed issues relating to uncertainty around predictions, the timing of prognostication and decision-making, and difficulty in predicting quality of life.

## 1. INTRODUCTION

Birth is one of the most dangerous points in human life (Save the Children 2006). Half of the four million global neonatal deaths occur on the first day after birth (Save the Children 2006). About 900,000 of these deaths are due to compromised blood and oxygen supply around the time of labour and delivery (Lawn et al. 2005a; Lawn et al.

2005b). In developed countries mortality rates are much lower, but approximately 10 per cent of newborn infants require some help with establishing breathing after birth (American Heart Association 2005), and almost 1 per cent of newborns need more extensive resuscitation after birth (Thornberg et al. 1995; American Heart Association 2005). Some of these infants subsequently manifest abnormal neurological symptoms and signs (encephalopathy) in the newborn period. In countries like Sweden, France, and Australia, 2–4 infants out of every 1000 live births have moderate or severe encephalopathy (Thornberg et al. 1995; Badawi et al. 1998; Pierrat et al. 2005). Almost half of these infants either die in the neonatal unit or survive with significant impairment (Jacobs et al. 2007; Volpe 2008, 441; Azzopardi et al. 2009).

In the face of poor prognosis parents and doctors sometimes come to a decision to allow a newborn infant to die. Birth asphyxia (more properly referred to as Hypoxic Ischaemic Encephalopathy or HIE) is a common reason for withdrawal of life-sustaining treatment in newborn intensive care. It is the commonest single cause of death in term newborn infants (The Consultative Council 2008; Verhagen et al. 2009), and the majority of such deaths follow decisions to limit or withdraw treatment (Wall and Partridge 1997; Pierrat et al. 2005; Verhagen et al. 2009). These decisions are often in practice particularly difficult and controversial (McHaffie and Fowlie 1996, 98).

In recent decades there have been significant advances in prognostication for infants with HIE (Robertson and Wyatt 2004). Magnetic Resonance Imaging (MRI) of the brain provides detailed assessment of the pattern and severity of brain injury (Rutherford et al. 1998; Thayyil et al. 2010). It differs from previous prognostic tests in being able to provide specific predictions of the nature and extent of future impairments (Cowan 2000; Rutherford et al. 2006). It has been recommended that all infants with HIE have MRI performed in the newborn period (Ment et al. 2002). But how have such technological developments affected decision-making in newborn intensive care. Do they raise any particular ethical issues for doctors or parents?

There are a small number of previous empirical studies of decision-making in newborn intensive care (Anspach 1993; McHaffie and Fowlie 1996; McHaffie and Fowlie 2001; Brinchmann et al. 2002; Orfali 2004; Orfali and Gordon 2004; van Zuuren and van Manen 2006). None of these have focused specifically on HIE, and none have addressed the impact of new technologies on treatment decisions. My own experience working in newborn intensive care is that MRI is used frequently in infants with HIE in centres where the technology is available. The results of imaging strongly influence parents and doctors in treatment decisions, perhaps more than any other single factor.

In the first part of this paper I report an exploratory qualitative study, interviewing a small sample of neonatologists about their experience and views of prognostication in infants with HIE. I will describe the principle themes arising from those interviews. In the second part of the paper I will relate these themes to previous empirical research in newborn intensive care, and highlight potential questions for further analysis.

## 2. METHODS

In-depth qualitative interviews were conducted with ten consultant neonatologists over a six month-period in 2008. The research used a pragmatic approach (Ritchie and Lewis 2003) aiming to elicit a diversity of perspectives without necessarily achieving theoretical saturation.

Six tertiary neonatal units were identified (i.e., units providing intensive care including assisted ventilation), of which three had specific research experience in HIE (two of these had a research interest in neuroimaging). Three of the units were based in London, the other units were based in metropolitan centres in the south of England. Participants were purposively selected to include both male and female consultants with a range of clinical and research experience. Informed consent was obtained.

A topic guide was developed to cover relevant issues for interviews (Box 5.1). Interviews were semi-structured, with a series of open-ended questions, and participants were encouraged to elaborate on their answers. At the conclusion of the interview participants were asked to comment on a case example (of an infant with severe HIE and an early MRI) (Micallef 2001). The aim of the case was to bring together some of the different threads of discussion and relate them to a specific example. In the discussion below the case is not discussed separately – rather the themes emerging from that part of the interviews are discussed along with other discussion of those themes.

### Box 5.1 Summarised topic guide for interviews

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1. Background and professional practice
2. Prognosis for infants with HIE
3. MRI for infants with HIE
4. Decisions to withdraw or withhold life-sustaining treatment in HIE
5. Role of parents in treatment-limitation decisions
6. Case vignette

Interviews were recorded and transcribed verbatim. Transcripts were reviewed, and coded on the basis of emergent themes (Ritchie and Lewis 2003). Analysis was iterative, returning to transcripts to ensure that coding reflected the content of interviews, and that relevant responses were identified and appropriately classified. The study was approved by an NHS Human Research Ethics Committee (Approval 08/S0709/10). I will outline below the dominant themes that emerged from the interviews.

### **3. RESULTS**

Four male and six female neonatologists were interviewed, ranging in age from 37 to 61, and in consultant experience from 1 to 20 years. Four had long-standing research interests in prognostic tests in HIE.

Interviewees described several different purposes for prognostication. Very soon after birth prognostication might be needed to determine whether infants were eligible for potential neuro-protective therapies. Then, within the first days of life prognosis may be important for determining whether or not intensive care is withdrawn or continued. If treatment is continued prognostication was felt to be important to provide a guide for parents as to the future for their child. One neonatologist described an assumption that it is better for parents to know if infants are going to be impaired. She also referred to the possibility that early intervention with physical or other therapies may improve outcome for infants predicted to be impaired.

In practice, prognostication in HIE was described as a question of putting together information from different sources including the perinatal history, condition at birth, response to resuscitation and subsequent clinical behaviour, with results of investigations including infants' biochemistry, EEG, cranial ultrasound and MRI. A number of neonatologists referred to this as akin to piecing together a 'jigsaw puzzle', and noted that if some pieces of the puzzle did not fit with others it would lead to uncertainty, and motivate clinicians to consider alternative diagnoses. Clinicians varied in the emphasis they placed on investigations. Some, particularly those from centres without research interests in HIE, relied heavily on history and clinical examination. (They noted, however, that their use of investigations such as imaging had increased over the last few years and anticipated that this may change further). Neonatologists from specialist centres placed more emphasis on the results of EEG and MRI. One limitation of clinical and (to some degree) electrophysiological tools was the influence of anticonvulsants and sedatives. If infants had received large or repeated doses of sedatives (particularly benzodiazepines)

the clinical and EEG assessment may be overly pessimistic. One consultant noted that the neurological examination was potentially subjective.

### **3.1 UNCERTAINTY IN PROGNOSIS**

The neonatologists who were interviewed described a number of difficulties with prognostication. One difficulty related to unrealistic parental expectations. Parents wanted to know specifically what was going to happen to their infant, whereas clinicians were in reality attempting to determine the range of possible outcomes for an infant.

‘I don’t have a crystal ball.’ M50<sup>1</sup>

‘I don’t think we can paint a black and white picture.’ F40

All of the participants talked about uncertainty in predictions. They identified a range of contributing factors to this uncertainty including limitations of the science, variability between families in their ability to cope, the impact of the family and environment on an infant’s developmental outcome, and differences between patients. One noted that this was particularly a problem for infants:

‘Unlike the adult brain, when you see quite devastating stroke for example you know that A = B outcome. I don’t think that you ... can always say A = B for outcome [in babies] because there are many different things happening.’ F50

A couple of neonatologists drew particularly on experiences where predictions of poor outcome had ultimately been proven wrong – leading them to be conscious of their own limitations.

‘I met a boy last week who had a massive [brain injury] and we withdrew on him. We had long, long discussions with the parents ... but this little boy was walking around our paediatric ward at 5 years of age ... he is at school, albeit with additional support, but is a lovely young man ... Actually we sent him to a hospice to die; he didn’t die. He was 5 years old and had quite a good quality of life. That to me highlights how actually difficult it is for us to prognosticate.’ M50

‘I have had the situation more than once of somebody coming to visit and some child coming bounding down the corridor and they say to

me “you know you told me that child should be taken off the ventilator”.’ F60

On the other hand, neonatologists also expressed a belief that a high degree of certainty was possible in some cases; some participants explicitly linked this to treatment withdrawal decisions. Some described graphically the outcome for such infants.

‘One child that I remember, ... was completely hypotonic, was blind, who couldn’t communicate, who literally just lay there, which was heart breaking I mean ... from my own perspective that is not a quality of life I would wish on anybody.’ F40

Some participants indicated that uncertainty would prevent withdrawal of life support.

‘We have a responsibility to have no reasonable doubt that the degree of disability is going to be so great that being able to participate in family life, communicate and share in the things that are valuable in life is not going to be possible ... if we really have doubt we will err on the side of life support.’ M60

On the other hand, other clinicians drew on uncertainty about prognosis and particularly quality of life (see section 3.5 below) as providing reasons to support parents who requested continuation of life-sustaining treatment.

### **3.2 PROBLEMS OR DELAYS IN ARRANGING MRI; DIFFICULTY IN OBTAINING RELIABLE INTERPRETATION**

All the neonatologists mentioned using late MRI (performed after infants had recovered from acute severe illness) to help provide prognostic information to parents. One cited advantage of MRI was its ability to predict the type as well as the severity of impairment. However, clinicians varied in their use of MRI within the first few days of life. For some this reflected limitations of the local MRI facilities and the difficulty in performing MRIs for ventilated infants. For example, in one unit this was likely to require transfer of the infant to another hospital. Others expressed a lack of confidence in MRI findings during the acute period, preferring to wait until the second week of life before performing scans. On the other hand a couple of clinicians from specialist centres placed a lot of emphasis on MRI in prognosis, and would be reluctant to make treatment decisions without that information.

'I come from an imaging background so I do find brain MRIs very helpful ... it is something that personally I would rely on quite heavily ... I would be reluctant to prognosticate very strongly without imaging to be honest.' F40

One clinician specifically noted that early scans would be sought in order to aid treatment withdrawal decisions, although at that stage they are more difficult to interpret. A couple of clinicians mentioned that therapeutic hypothermia, a new treatment for infants with HIE, may influence the timing of MRI since it may make it difficult to image within the first 3 days, and may influence the interpretation of imaging. One problem, raised by several respondents, was the need to obtain specialised interpretation of images. Although local radiologists may be able to provide reports on neonatal MRIs, clinicians noted that their interpretation of MRIs can lack prognostic utility, or may be less reliable than the interpretation provided by specialists in neonatal imaging. Several of the centres arranged for their MRI images to be reported by a specialist in newborn MRI in London.

'It is not uncommon that there is either a minor or a major degree of difference in the reports that we get by different people.' F50

'[Other radiologists] are not fantastic in terms of the new born and ... basically they interpret everything as asphyxial change when you know perfectly well they are not ... we have had one or two quite unfortunate misinterpretations.' F60

Participants were asked whether they had encountered ethical issues or concerns related to MRI, and few clinicians admitted to having concerns of this nature (many appeared perplexed when this question was asked). After reflecting on the question a couple of clinicians mentioned the potential use of MRI results by parents in subsequent litigation (relating to perinatal injury), however, this was not judged to be a particular issue for neonatologists. Participants mentioned other practical concerns with MRI including the potential risk to infants from the high power magnet, as well as instability relating to transport to the scanner. Most indicated that they didn't think there were any particular ethical issues arising from MRI.

Doctors described differences between parents in their responses to MR imaging. Some parents apparently find the images helpful while others were said not to want to look at their infant's brain. A couple of participants described it as particularly helpful to show pictures to parents where infants had sustained very severe brain damage but

the parents appeared to be in denial. On the other hand one neonatologist described some parents who placed too great emphasis or attention on MRI.

'I think parents can potentially get hung up on MR appearances rather than the whole clinical picture of information from their baby.' F50

### **3.3 THE WINDOW OF OPPORTUNITY**

In discussing the timing of prognostic testing and decision-making a number of the neonatologists referred to a window of opportunity for withdrawal of treatment.

'There is "a window of opportunity" to withdraw with dignity for the child and for the family and if you don't withdraw during that window of opportunity, the child then may start to respond, may then start to breathe, may come off the ventilator and may survive and is profoundly handicapped.' M50

Clinicians who referred to the window, noted that it potentially applied in the first 2 to 4 days of life. Some clinicians suggested that this lent a degree of urgency to discussions with parents.

'The longer one delays that decision to withdraw intensive care, the greater the possibility that the child might actually then survive.' M60

But these clinicians also noted that this presented a problem for parents and doctors.

'That is quite difficult to say to parents, really, that you have got a short time frame perhaps in which to make a very difficult decision.' F60

The problem, noted by several, was that there was also a desire not to rush parents or push them into a particular decision; some parents needed time to come to terms with the severity of their infants' brain injury and a decision to withdraw treatment. It was also noted that earlier prognostication could be more difficult or uncertain. Several clinicians described infants where decisions had been delayed leading to the infants surviving with severe impairment.

On the other hand, two clinicians who referred to the window of opportunity expressed a degree of ambivalence about it. They suggested that it was not a factor that influenced their own practice.



'I am not sure I quite buy into that personally ... The fact that the baby might survive doesn't mean to say that you have made the wrong decision.' F40

### 3.4 DIFFICULTY IN DEFINING OR DETERMINING BEST INTERESTS

When discussing treatment withdrawal any ethical concepts that were raised by clinicians were explored in more detail. Often participants used medical terms or descriptors such as the phrases 'severe disability' or 'severe brain damage', qualifying this in terms of particular types of physical impairment (severe spastic or athetoid forms of cerebral palsy) or cognitive impairment (severe intellectual impairment). Some explicitly mentioned the *best interests* of the infant.

'And if we actually concluded ... [that] this baby is going to be very, very severely disabled, unable to sit up, very likely to have severe learning problems, (there could be a little bit of leeway on that, because not everybody ... with severe quadriplegia has got severe cognitive problems) and we are still ventilating, ... this is the point where we think that actually it is not in the baby's best interest.' M60

However, several expressed difficulty or discomfort in articulating what the best interests of the infant meant in practice.

'That is very difficult to judge ... I think it is dictated by the parents, it is dictated by the clinical circumstances and there is no hard and fast rule about how to approach [it].' M50

Another neonatologist also referred to the importance of the family in determining the best interests of the infant.

'You can say that the best interest of the child is for them as an individual, irrespective of anybody else's views or wishes. They are an individual, they have legal rights, we should be doing what is right for them. But personally I put the child within the context of their family and what that particular family feels is right for them.' F40

That respondent also related best interests to a judgement that life was '*unbearable*', however, she was the only clinician to refer to this concept. None of the interviewees referred to the related concept of 'intolerability', nor did any of them refer to a weighing

of the benefits and burdens of treatment. Two neonatologists referred to a life of severe impairment as being '*worse than death*' or being 'better off dead'. The first of these referred to '*futility*' rather than best interests. The second observed that only a small number of individuals with severe impairment have lives as bad as this.

### **3.5 DIFFICULTY IN JUDGING QUALITY OF LIFE OF THE CHILD**

Clinicians also expressed some discomfort with judgements about quality of life. A number of clinicians referred to examples of individuals with severe disabilities who nevertheless had what they felt to be acceptable quality of life. Several mentioned that families differed in both in their judgments about quality of life and in their ability to cope with a disabled infant. At the same time the participants also felt that some infants with severe disabilities had very difficult lives.

'For some children who are severely brain damaged it is what appears to be a miserable existence of being totally dependent for all their bodily functions. [However] ... I have certainly seen some children who are quite severely physically handicapped be happy children and be able to engage in all sorts of stimuli and enjoy life.' F50

'I mean of course I know that ... some children [who are] wheelchair bound and all sorts of other things ... say 'thank god somebody didn't take me off the ventilator' ... but I still think that ... if I think that there is likelihood that somebody is not going to be able to be independent, I think that it is important that the parents understand that.' F60

The potential for 'independence' was referred to by several of the clinicians in discussion of the severity of impairment that might lead to treatment withdrawal. On further probing some referred to total dependence or very high levels of dependency as being significant.

A couple of the neonatologists referred specifically to the significance of intellectual impairment for decision-making. Severe cognitive impairment, particularly if combined with physical impairment was seen to prevent participation in valuable activities, was worse than physical impairment alone, and was harder for parents to cope with.

'[It is] quite well recognised that one can have severe motor disability and have considerable mental abilities and have a life. That isn't to minimise the huge problems from having quadriplegia and the suffering that is involved ... but if you do have microcephaly as well then that

really does rule out participation in normal human communication and activities and family life and education and everything with a greater degree of certainty than being quadriplegic.’ M60

However, one respondent articulated a view that a life with very severe physical impairment but preserved intellect may be extremely difficult and may potentially also justify treatment withdrawal.

Some of the neonatologists with specialised experience of MRI referred to particular patterns of MR imaging that would support treatment withdrawal.

‘Our MRI definition for such an outcome might be clear severe basal ganglia abnormalities and almost always in conjunction with cortical abnormalities as well so that usually translates into major physical handicaps together with major mental, cognitive deficiency. And I think we are unanimous in our view that that prognosis is terrible.’ M60

‘The imaging patterns that I would move towards suggesting withdrawal of care [include] ... very global grey and white matter infarction so very, very severe injury to all areas including the cortex, ... [or] the very severe white matter and partial basal ganglia problems ... I think those two fall into the area of something I would feel might be able to offer withdrawal of care ... I would feel less happy about withdrawal of care in an isolated focal basal ganglia lesion [or] ... severe white matter infarction.’ F50

A couple of interviewees referred to survival with very severe impairment as the worst outcome. One referred to the potential for error in prognosis but suggested that it was a worse error to keep a child alive with such a life. Another described his feeling of responsibility for taking on the burden of decision-making given a very high chance of severe impairment but a small chance of a non-severe outcome. Several expressed concern for the impact of a very severely impaired child on families.

### **3.6 INFANTS WITH POOR PROGNOSIS MAY NOT DIE AFTER WITHDRAWAL OF TREATMENT**

All of the respondents expressed the view that withdrawal of mechanical ventilation was appropriate in some cases of HIE even if long-term survival were possible with continued treatment. However, several clinicians mentioned that they would warn parents when

removing them from assisted ventilation that they could not predict how long the infant would survive, or that, in fact, the infant may not die. Several also stressed that while sedation may be provided after extubation, the aim of such sedation was not to prevent the infant from breathing.

'We are not sedating the children to an extent that they don't survive, we are sedating them if needed to keep them comfortable and seizure free.' F60

One referred to an infant who had continued to breathe after mechanical ventilation was withdrawn, and whose parents had requested that the infant should not be provided with artificial feeding. The neonatologist had agreed to the parents' request despite initial misgivings. Two other clinicians mentioned the option of withholding artificial feeding as something that they were aware took place in some units, but that they did not personally support. Several doctors raised the possibility of adoption if parents felt unable to support a severely impaired, surviving infant.

### **3.7 SHOULD PARENTS HAVE THE FINAL SAY IN DECISIONS?**

When discussing such decisions with parents, clinicians presented them with options, or suggested that treatment withdrawal may be an alternative for parents to consider. It was felt to be important to give parents choices and to respect their autonomy. Clinicians also suggested that parents differ, and what may be right for one family may not be for another.

'Some parents will want their child to live at all costs, every family is different ... I am just sharing my opinion with the parents.' F50

However, several senior consultants expressed concern about placing the burden of decisions entirely on parents. Two described presenting a recommendation of withdrawal of treatment to parents.

'Parents are tremendously important but I would hope that ... one avoids ... their feeling that it is *they* that are having to make the decision. I think one tries to steer them with a strong recommendation as to what we should do and to get their blessing.' F60

Another described taking the burden of decisions onto his own shoulders at least in some cases, with parents invited to tacitly agree to a plan of treatment withdrawal. Two

clinicians described a staged process of negotiation with families, addressing first the question of withholding resuscitation in the event of the infant collapsing, moving on to discuss withholding of other treatments, before finally discussing explicit withdrawal of intensive care.

Respondents were unanimous that treatment would not be withdrawn if parents wanted to continue treatment.

'We never withdraw life support against the parents' wishes.' M60

Clinicians described attempting to avoid confrontation with parents, and expressed support (and sometimes admiration) for parents who did not want to withdraw life support. One clinician suggested that it would be unthinkable to go to the court in such a case because of the adverse publicity that it would attract.

'But even if one felt that one was in an absolutely, ghastly, ghastly situation the last thing on earth I could hack ... [would be] being over the front of the [local newspaper] about taking a [religious] family to Court.' F60

Another clinician suggested that he would seek legal advice if parents insisted on prolonging mechanical ventilation in such a case, however, he had not had to in the past. On the other hand, participants suggested that in their experience it was rare for parents to request withdrawal of treatment while doctors were uncertain of outcome. They described some examples of this type of disagreement with premature infants. But for infants with HIE it was suggested that this was less relevant, since less severely affected infants are likely to be breathing independently of the ventilator. Most suggested that treatment would not be withdrawn unless doctors were certain that infants would be severely disabled.

## 4. DISCUSSION

New prognostic technologies were important for decision-making for a number of the clinicians interviewed. MRI has been used in newborn infants with HIE for over twenty years (McArdle et al. 1987). In 2002 a guideline from the American Academy of Pediatrics recommended that all encephalopathic term infants have MRI performed between days 2 and 8 (Ment et al. 2002). There is little published data on how often this guideline is followed, but in one recently published survey of 95 Australian or New Zealand neonatologists 78 per cent would use MRI in the management of an infant with HIE

(Filan et al. 2007). If considering withdrawal of life support 62 per cent reported that they would attempt to organise an MRI prior to that decision.

One interesting finding was that on direct questioning in this study clinicians generally did not identify specific concerns or ethical issues related to MRI. This may reflect cognisance that there are few issues that are unique to MRI (as opposed to other prognostic tests). Alternatively, it may be that this reflected a particular (limited) conception of what 'ethical problems' refers to. Neonatologists described a number of practical problems arising from MRI, including difficulty in obtaining reliable interpretation of images and delays in obtaining tests. Wider discussion of the process of prognostication and decision-making, including the use of MRI, revealed a number of areas where clinicians found it very difficult to know what was the right course of action, and what they ought to do.

One major question arising from MRI is which patterns of injury, and which predictions of impairment warrant discussion of treatment withdrawal with parents. Some respondents in this study referred to the 'best interests' of the infant, though a number found it very difficult to articulate how to determine this, or which patterns of impairment would make treatment withdrawal in the best interests of the infant. Hazel McHaffie, in her study of decision making in Scottish neonatal units in the early 1990s, found that almost 80 per cent of doctors and nurses in Scottish neonatal units believed that there should be an option of limiting treatment in the face of severe impairment (McHaffie and Fowle 1996, p. 94). Quality of life and the wishes of family (along with futility) were the most frequently cited criteria for determining when treatment should be withdrawn (McHaffie and Fowle 1996, p. 101). But many of those that she interviewed described difficulty or discomfort in deciding what constitutes good quality of life and in articulating the severity of impairment that would warrant consideration of withdrawal of treatment (McHaffie and Fowle 1996, 95, 97–8). In McHaffie's study, as in this one, many respondents distinguished between physical and cognitive impairments, almost all judging physical impairment preferable. This raises the question of the relationship between cognitive impairment and the interests of the infant (Wilkinson 2006).

The other broad theme described by clinicians was that of uncertainty. Uncertainty pervades prognostication for newborns, and the responses above suggest that it provides a major challenge for those involved in making such decisions – both parents and medical professionals. Uncertainty makes it difficult to know what future lies in store for infants, and hard to communicate with parents who expect definitive answers. One question emerging from the interviews is how to respond to the potential window of opportunity for treatment withdrawal. The difficulty in expeditiously arranging MRI noted by several neonatologists risks exacerbating the problem. One approach that might

help clinicians and parents resolve the conflicting values at stake would be to use decision theory (Wilkinson 2009b). Some clinicians expressed ambivalence about the window of opportunity. There is a separate normative question about whether it is appropriate for clinicians to take into account the chance of an infant dying in decisions about treatment withdrawal.

Previous studies support the finding in these interviews that doctors rely heavily on objective data from investigations in evaluating prognosis and establishing medical certainty (Anspach 1993, 60–63; Orfali 2004). On the other hand there is also evidence from those studies of the potential subjectivity of prognosis. In a study of neonatal units in France and the United States, Kristina Orfali found that neonatologists systematically differed in their evaluation of prognosis in identical cases (Orfali 2004). In the French units data that appear to reduce or erase uncertainty were valued and emphasised in justifying a decision to withdraw treatment. On the other hand, in the American unit clinical evidence that potentially contradicted the radiological evidence of brain injury was taken to preclude certainty and warrant continued treatment (Orfali 2004). Orfali argued that beliefs about whether or not treatment should be continued (including the value of survival with disability and the impact of disability on families and on society) influenced physicians' assessment of the likelihood of adverse outcomes for the infant (Orfali 2004, 2018–9). The other issue relating to the different beliefs about prognosis in the American and French units is that such beliefs are potentially self-reinforcing through their effect on outcome (Wilkinson 2009a).

The other subjective element in prognostication apparent from previous studies of medical decision-making is the way in which prognosis is communicated with parents. Physician and sociologist Nicholas Christakis has suggested that in certain settings (particularly in chronic illness) doctors exhibit 'ritualised optimism' in their prognostication, systematically overestimating the chances of survival for patients (Christakis 1999, 165–9). One reason for this is a desire not to remove all hope from patients (Christakis 1999, 49–50, 124, 126, 130). One important earlier study of newborn intensive care suggested that such ritualised optimism comes at the cost of overtreatment and harm to infants (Guillemin and Holmstrom 1986). On the other hand, in certain settings doctors are far more pessimistic, deliberately painting a bleak picture with parents. Such ritualised pessimism was characteristically used by doctors when discussing treatment limitation or withdrawal (Christakis 1999, 165–7; Orfali 2004, 2018). In her study of neonatal decision-making in two American hospitals in the 1980s Renee Anspach described a functional role for prognosis. Uncertainty was used to exclude parents from decisions about continuing treatment (Anspach 1993, ch4). But when doctors believed that treat-

ment should be withdrawn the way in which prognosis was discussed with parents obscured or denied uncertainty and was designed to coerce parents to agree to treatment limitation.

The neonatologists interviewed in this study emphasised the importance of parents in decisions about life-sustaining treatment. However, other studies suggest that in practice parental autonomy is constrained by a number of factors (McHaffie et al. 2001; Orfali 2004). Parents are reliant on medical staff for facts. They are only presented with the alternative of treatment withdrawal after doctors have made a prior judgement that this is 'medically appropriate', and may be presented with strong recommendations or advice (McHaffie et al. 2001). Paradoxically, in one study, units ostensibly placing a strong emphasis on parental autonomy seriously limited parental choice by failing to offer parents the option of withdrawal of intensive care (Orfali 2004).

Two of the more experienced consultants in this study suggested that, at least in some circumstances, it was appropriate for doctors to take responsibility for decisions or guide parents towards a decision to withdraw treatment. A pattern similar to this was described by Renee Anspach in her study of two American neonatal units from the 1980s; she referred to the decision-making process as one of 'producing assent' to medical decisions (Anspach 1993, 4). In Anspach's study doctors used a variety of techniques to persuade or coerce parents to agree with a decision to withdraw treatment, and consequently conflict with parents was rare (Anspach 1993, 93–5). In a more recent study of decision-making in the US, parents were apparently given a much greater role in decisions; treatment was continued if parents disagreed with doctors, as was described in this study (Orfali 2004; Orfali and Gordon 2004). Medical and nursing staff in Scotland in the 1990s mostly favoured a joint approach to decision-making (McHaffie and Fowlie 2001). On the other hand, in continental Europe, particularly in France, parental involvement in decisions may be very limited. In French neonatal and paediatric intensive care units treatment withdrawal decisions are generally made by doctors alone (Orfali 2004; Carnevale and Bibeau 2007).

The aim of this study was to explore the way in which prognostic tests (particularly MRI) are used in neonatal intensive care, and the ethical and practical issues arising from this for clinicians. The study was designed to help identify relevant questions for further analysis, and as such did not seek to achieve theoretical saturation. However, at least across this group the issues apparent to neonatologists were remarkably similar, and there was not a great deal of new material in the last interviews. Further empirical research with nursing staff, other specialists, or with parents might well elicit other issues.



Advances in prognostication for infants with birth asphyxia such as the use of magnetic resonance imaging raise a number of ethical issues for clinicians. The majority of these issues are not new, but technological progress may bring them to the fore, or may give them new urgency. Neonatologists in this study described practical problems raised by technology, including the impact of testing on the timing of decisions about treatment withdrawal. More specific predictions of future impairment also raise difficult questions about how such impairments affect the interests of infants, and about the threshold for permissible treatment withdrawal. How should prognostic uncertainty affect treatment limitation decisions? There are important questions about the role of parents in decisions. Which predictions of impairment would make it appropriate for parents to be given the choice about treatment continuation or withdrawal? Empirical research such as that described above is helpful in identifying the right questions to ask, but determining the right answers is likely to be much harder.

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## ENDNOTES

- <sup>1</sup> In this section quotes from consultants are followed by their sex and approximate age (rounded to the nearest decade). Words that have been omitted are indicated by '...' Additional words that have been added to clarify meaning (obtained from the context) are indicated by square brackets.

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