Managing complex ethical problems on the neonatal unit

Some neonatal patients, either due to the rarity of their condition or a combination of co-morbidity, can be very difficult to manage. When there are many or conflicting opinions, it can add to the difficulty of decision-making. The key ethical point is to determine what treatment choices lead to the best overall benefit ('best interests') to the infant. This article demonstrates a structured approach to managing complex problems on the neonatal unit. It also includes an example of an ethical framework, which can be used to help resolve difficult ethical problems.

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Key points

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1. A single spokesperson should represent the views of the MDT to work carefully with the family.
2. Ethical frameworks can improve the quality of decision-making and help develop teamwork.
3. It is important to identify what the infant's best interests are.
4. Difficult cases can be referred to a clinical ethics committee. External second opinions may be sought before pursuing mediation or legal review.

Although ethical dilemmas occur across all specialties, they are especially common in modern neonatal practice. Much has been said about the ethics of delivery room resuscitation, however most neonatal deaths now occur after intensive care is reoriented or following limitation or non-escalation of treatment orders. Due to a combination of factors including technological advances, improved service delivery and greater parental involvement, it seems that ethical dilemmas are even more challenging to resolve. There are a number of documents available to help professionals, including guidance for end-of-life care from the General Medical Council and protocols for better delivery of neonatal palliative care[1-4]. However, despite this, there are still a number of ethical problems that are more difficult to solve. Although judicial review has been sought in a number of headline cases, this is very much the last resort; such reviews are expensive and are extremely distressing for both professionals and parents. This article will look at some approaches to help the neonatal team cope with difficult ethical problems and for this, it is useful to consider some example case studies.

Case study examples

Amy

At birth, Amy has features consistent with Patau syndrome (trisomy 13) including a large cleft lip and palate and bilateral microphthalmia. Her cranial ultrasound shows an absent corpus callosum and her cardiac scan shows a large non-restrictive ventricular septal defect (VSD). She has a tracheoesophageal fistula – if she does not have surgery she will never be able to feed. One member of the team wonders whether surgery would be in her best interests but her parents are too distressed to make any decisions.

Thomas

Thomas was born at 23 weeks' gestation weighing 513g at birth. He has been ventilated for five months and has had four courses of postnatal steroids. He has had a patent ductus arteriosus (PDA) ligation, laser treatment for retinopathy of prematurity (ROP) and is growing well on high calorie milk given via continuous nasojejunal feeds. There was only a brief response to the last course of steroids and for the last two weeks he has had low oxygen saturations despite high pressure ventilation in 100% oxygen. His mother does not want to give up on him and refuses to discuss palliative care but his father is beginning to express that he does not want his son to continue to suffer. A number of nurses are concerned that he has very little interaction and responsiveness and think it is 'cruel' to carry on providing active intensive care.

Zach

Zach was born at 26 weeks' gestation. He had an absent left arm from mid-humerus, absent left leg from the lower femur and was missing all toes on the right foot – consistent with amniotic band syndrome. A cranial ultrasound showed an extensive haemorrhagic parenchymal infarction that could lead to hemiplegia. He develops fulminant gram negative sepsis and requires full cardiorespiratory support including high frequency oscillatory ventilation and inotropes. Subsequently, he develops acute renal failure including hyperkalaemia that is unresponsive to treatments. The regional renal unit is unable to admit him because of his size and condition but have forwarded a peritoneal dialysis protocol and equipment. One of the consultants is prepared to start peritoneal dialysis but another thinks the treatment is 'futile'.

Step 1: Define and review the problem

In each neonatal unit the collective experience of all members of staff often exceeds several hundreds of years and it might be that once the problem is aired then the solution is very obvious. Often the problem is easier to resolve if the parents are fully informed of all the relative risks and benefits and are directly involved in the decision-making process. Some units have regular team meetings where difficult cases can be discussed. Alternatively arrangements can be made for a one-off meeting. As many neonatal units have consultants who work on a shift pattern, it is quite likely that a number of consultants will be directly involved in each case. It is advisable to designate a single clinician to act as spokesperson and be aware that parents' views and treatment choices are influenced by how information is presented[5].

One of the key elements of ethical decision-making is to define exactly what the problem is. In the case of Thomas, is the ethical problem one of making the right clinical decision or getting his parents to agree to a planned course of action? In the case of Zach, is the problem about pushing the boundaries of medical treatment or about managing conflicting opinions between individual consultants?

It can also be helpful in everyday management to use clear and unambiguous ethics language. Although it can be tempting to use general terms such as: "I think it is unethical to operate on Amy", it may be of more benefit to say: "I think complicated chest surgery is not in Amy's best interests as her lifespan is likely to be very limited". It is also important to realise the interpretation of ethical problems is also not always objective and even the concept of 'futility' means different things to different people – especially to parents who feel they can never give up hope.

Step 2: Arrange a multidisciplinary clinical review meeting

If the standard process for clinical problem solving on rounds fails to resolve the issue, it may be helpful to arrange a formal multidisciplinary review. By arranging a broader discussion of the problem, it firstly identifies that the problem itself is more difficult to resolve and secondly allows more people to be involved in the decision-making process. Particularly when there has been conflict of opinion, such a meeting allows all views to be aired and can help improve team working. Important features of such a meeting are detailed in **TABLE 1**. When there is uncertainty or confusion over conflicting opinions, it may be more appropriate to arrange a meeting without the parents.

UK practice has changed considerably over the last few decades, moving away from a paternalistic approach and placing a much greater emphasis on co-operation and parental involvement in end-of-life decision-making. Both staff and parents feel that improved dialogue helps to share the burden of decision in these difficult cases[6]. When treatment becomes increasingly unsuccessful it is even more important to help parents understand they have to make new choices[7]. Exceptional cases can haunt staff long after the case has ended and consequently there may be a need to provide a support mechanism for staff, eg a departmental counsellor.

- Ensure all relevant members of the multidisciplinary team (MDT) are present, or represented.
- Plan in advance – attendees should not have any other urgent duties or responsibilities.
- Choose an appropriate venue, especially if parents or their representatives are attending.
- Where appropriate and with permission from the parents, invite other family members, spiritual advisers, advocates, etc.
- Set aside adequate time – two hours may be necessary.
- Ensure all attendees are aware of the uncomfortable/distressing nature of the meeting.
- Delegate one team member as chairperson and another to take notes.
- The chairperson should present the clinical details and bring copies of investigations, etc.
- Use of an ethical framework may help structure the meeting, particularly in detailed cases.
- Ensure everybody has a chance to talk and recognise that some people find it difficult to talk openly in such circumstances.

TABLE 1 Important features of a multidisciplinary review.

Step 3: Use an ethical framework

There are various moral and ethical approaches to clinical care and conflict often arises when one particular ethical approach is used to contradict another. For example, a deontological approach (duty-based) would argue that clinicians have a duty to treat Amy and to respect the sanctity of her life. However, a consequentialist would argue that as she is likely to have a reduced life expectancy, all surgery (including for her cleft palate and VSD) would more likely cause her harm and be of little overall benefit – thus her quality of life is more important than her quantity. Moral philosophers may argue and counter-argue different ethical theories without ever reaching a firm conclusion. The clinician has to come up with a solution – like it or not!

One of the ethical frameworks more commonly used in adult practice is described as the Four Quadrant Approach[8]. A significant aspect of ethical discussion in adults, stems from ascertaining their capacity for decision-making and determining what their views were before their health deteriorated. Obviously for neonatal patients, the decision-making capacity and the right to self-determination are delegated (in most cases) to the parents. Several examples of neonatal ethical frameworks have been used in other European centres and have helped in the decision-making process and improved the quality of team working[9,10]; however they have limited applicability to practice within the UK.

For local use in Sheffield, a framework was devised (**TABLE 2**). This framework can be used to help resolve ethical dilemmas either on an individual basis or used as a focus within the setting of a MDT decision meeting. Some problems can be resolved relatively easily by a small number of

Section I: Background details	
Contextual details	**Time frame**
What were the relevant antenatal and fetal details – was there diagnostic certainty and what expectations of prognosis were given? What was the early clinical course? What information was given on effectiveness of treatments and clinical progress? What evidence is there that the baby is experiencing pain, suffering or distress? What measures are being taken to treat any pain, suffering or distress and how effective are they? What kind of interaction does the baby have with other people? Does the baby experience pleasure of any kind? Does the baby react to its surroundings? Does the baby exhibit any signs or efforts to survive?	When does the problem need to be resolved? Is there any possibility of delaying the discussion or decision? How long will the baby survive if life-sustaining treatment is continued? How long will the baby survive if life-sustaining treatment is withdrawn?
Stakeholder views	**Estimates on prognosis**
What do the parents think the most important clinical problems are? What do they understand about these problems? What support is being provided to the family? How are the parents coping with their child's condition? How do medical and nursing staff interpret the clinical problems? What current therapy and support is being provided? How easy is it to provide emergency care in terms of airway support, vascular access or other organ problems? Have other specialists been involved and what is their conclusion? What type of nursing care and specialist expertise is being provided? How does the baby behave during urgent procedures and care?	What diagnostic tests and information are available? What additional diagnostic tests could be considered? What is the range of opinion on prognosis and how is this uncertainty addressed? Is it likely that life-sustaining treatments will lead to the baby surviving independently? What plans are in place if current treatments do not work? What is the short-term prognosis? What is the long-term prognosis? How certain are these estimates of prognosis? Has the process of palliative care been appropriately considered as a treatment option?
Section II: Ethical issues	
Problem definition	**Dimensions of ethical problem**
What is the ethical problem – can the patient be cured, what burdens and challenges will the patient have to bear? Is the problem acute or chronic, permanent or reversible? What are the moral dimensions of this problem?	What are the goals of treatment? What is the probability of success? Do the benefits of current treatments outweigh the burdens? Do the benefits of alternative treatments outweigh the burdens? What are the ethical arguments for and against these? Are there any biases that might prejudice estimates of duration or quality of life? Is there any deprivation of moral rights to the patient? Are the relevant moral arguments valid?
Burdens and challenges to treatment	**Ethical decision-making**
What are the unwanted effects of current treatment? What degree of pain, suffering or discomfort will current treatments inflict on the baby? Will there be a need for repeated, painful and distressing medical interventions? What are the side-effects of future or alternative treatments? Are there any signs that the infant is suffering? What impact would the burdens have on the family? What are the prospects for a normal life? What physical or developmental impairments would the baby have if treatment succeeds?	What are the treatment choices? How much can the baby benefit from medical and nursing care and how can harm be avoided? What are the relevant arguments for and against these treatments? Which treatment choice leads to the best overall consequence for the patient? To what extent do the parents agree with these choices? If the parents do not agree with the conclusion, what further plan of action will be undertaken? Is there any evidence to suggest that parents lack capacity or legal validity for decision-making?

TABLE 2 A framework for ethical decision-making as used at Jessop Wing Neonatal Unit, Sheffield.

people, especially when there is no difference of opinion between staff and parents. However, for more complex issues it may be appropriate to broaden the discussion and include others, eg a dietitian, physiotherapist, psychologist, social worker, pastor or other religious representative. An assessment of an infant's responsiveness and developmental progress can be valuable as it helps to represent the identity of the baby and to reassure parents that their child's best interests are at the very core of the discussion.

Although most parents have very good relationships with the neonatal team, there are times when there are breakdowns in communication or misunderstandings of clinical problems. It is important to make clear that all those involved have a common understanding of the nature of the clinical problem. If parents are counselled in the middle of their pregnancy but do not deliver until later, they may still perceive that the clinical problems are unchanged. When they are updated and reassured after a few days of stability they may readjust their expectations, which may remain unrealistic in the face of additional information such as scan results.

Having defined the clinical problem it can be helpful to determine a time frame (Zach, for example, needs an urgent decision). In general, an urgent problem limits the number of people involved although it may still be possible to arrange an urgent second opinion or an ethics committee review. In general, the law protects clinicians when making urgent clinical decisions, providing they are doing so in the best interests of their patients. It is always helpful to ascertain the views of the parents and it may be useful to ask them to highlight these in order of importance. In Amy's case, her parents may simply need a little time to absorb the clinical information and a delay may help them reach a decision.

Even in the presence of diagnostic certainty, it can still be difficult to give a definite prognosis (as with Zach's intraventricular haemorrhage). If there are differences of opinion between staff about prognosis it is important to summarise these, especially as this contributes to communication difficulties between parents and team members.

One of the main issues is to determine what the overall benefit or best interests of treatment are to the patient. This is difficult as a parent will have their own view on their child's best interest based on their emotional and psychological status, personal health and belief system. It is very important that staff remain as objective and unbiased as possible. There have been numerous studies that have shown that intensive care doctors tend to underscore their patients' quality of life in determining intensive care decisions[11]. Although all may perceive that they have an infant's best interests at heart it can be difficult to decide precisely and objectively what these interests are. One of the key issues in determining best interests is to picture what life would be like for the baby and what burdens would need to be shouldered throughout their life. In adult practice, there is now a best interests checklist and external independent advocates can be appointed to determine these when a patient lacks capacity under the terms of the Mental Capacity Act[12]. When discussing these best interests, it is important to consider all views and if there is uncertainty among clinicians, it is even more important to take the views of the parents into overriding consideration. The notion that best interest may be death over continued survival is a very difficult concept – for both staff and parents.

Step 4: Arrange a formal second opinion

When there are a number of consultants involved, it is often assumed that a second opinion is not needed. However, a complex case or differences of opinion may warrant opinion from a consultant outside the specialty (eg a paediatric surgeon in Amy's case or a respiratory paediatrician for Thomas). It may be appropriate to ask the parents if they would prefer to see a particular doctor or one from a specific unit. The parents may also independently arrange for a second opinion, although they will have to inform the Trust to allow the clinical records to be inspected.

Step 5: Refer to the clinical ethics committee (CEC)

The main aims of a referral to a CEC are to:

- Clarify the facts of the case to ensure that all choices, goals and outcomes are understood
- Analyse the ethical dimensions and uncertainty
- Mediate conflicts of opinion
- Review opinions on best interests and overall benefit from a patient's perspective
- Re-establish relationships between the family and clinical team
- Help the healthcare team to decide on the right course of action.

There are over 80 CECs currently within the major acute healthcare Trusts in the UK[13]. Although some CECs are in specialist paediatric centres, many are hosted by mixed adult and paediatric Trusts; the lack of neonatal experience on the committee is no bar to referral. In general, neonatal or paediatric cases tend to be more acute and the patients are often sicker. They are also more likely to involve ethical issues relating to limitation of life-sustaining treatment and be emotionally more demanding. One of the key benefits of referral to a CEC is to focus specifically on the moral dimensions and also to help recognise the difficulty in resolving the matter. If a referral is made, it is helpful to inform the parents – some CECs have an open policy allowing family members to attend. Any discussion and conclusion from an ethical referral is advisory, not statutory, although most Trusts would consider the implications to be important from a clinical governance perspective.

Step 6: Arrange for an external review

As a final resort, before referral to the Trust legal department, it may be appropriate to ask for a formal second external opinion. Although such reviews are not very common, they can be upsetting for all staff involved. It may be that trust between family and staff has broken down and unless addressed, this may make the situation more difficult. The reviewer must have access to all notes and investigations and should also speak to staff and family members. There is no formal legal guidance on how this external review should be arranged and, in general, the NHS Litigation Authority supports this approach prior to organising either formal dispute mediation or legal action. It would be advisable to inform the Trust's senior management team and legal department if this course of action is necessary.

Conclusion

Dealing with complex cases can be challenging for all members of the team. It may help to have a structured approach, to use an ethical framework or to refer to an ethics committee if the problem cannot be solved by standard approaches. It is crucial to identify the 'what, who and how' of best interests. Referring to the legal system is very much a last resort and hopefully will not be necessary when there is shared decision-making and good communication.

References

1. **Nuffield Council on Bioethics.** *Critical Care Decisions in Fetal and Neonatal Medicine: Ethical Issues.* [Online]; 2006. Available from: www.nuffieldbioethics.org/publications [Accessed: 4 Feb 2013].
2. **General Medical Council.** *Treatment and Care Towards the End Of Life: Good Practice in Decision Making.* [Online]; 2010. Available from: www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp [Accessed: 4 Feb 2013].
3. **British Association of Perinatal Medicine.** *Palliative Care (Supportive and End of Life Care): A Framework for Clinical Practice in Perinatal Medicine.* [Online]; 2010. Available from: www.bapm.org/publications/documents/guidelines/Palliative_Care_Report_final_%20Aug10.pdf [Accessed: 4 Feb 2013].
4. **AAP Committee on Fetus and Newborn.** Non-initiation or withdrawal of intensive care for high-risk newborns. *Pediatrics* 2007;119;401.
5. **Peerzada J.M., Richardson D.K., Burns J.P.** Delivery room decision-making at the threshold of viability. *J Pediatr* 2004;145:492-98.
6. **Garel M., Caeymaex L., Goffinet F. et al.** Ethically complex decisions in the neonatal intensive care unit: impact of the new French legislation on attitudes and practices of physicians and nurses. *J Med Ethics* 2011;37:240-43.
7. **Carter B.S., Brown J.B., Brown S., Meyer E.C.** Four wishes for Aubrey. *J Perinatol* 2012;32:10-14.
8. **Sokol D.** Ethical dilemmas in the acute setting: a framework for clinicians. *BMJ* 2011;343:d5528.
9. **Baumann-Holze R., Maffezzoni M., Bucher H.U.** A framework for ethical decision making in neonatal intensive care. *Acta Paediatr* 2005;94:1777-83.
10. **De Boer J., van Blijderveen G., van Dijk G. et al.** Implementing structured, multiprofessional medical ethical decision-making in a neonatal intensive care unit. *J Med Ethics* 2012;38:596-601.
11. **Quartin A.A., Calonge R.O., Schein R.M., Crandall L.A.** Influence of critical illness on physicians' prognosis for underlying disease: a randomized study using simulated cases. *Crit Care Med* 2008;36:462-70.
12. **HMSO.** *Mental Capacity Act.* [Online]; 2005. Available from: www.legislation.gov.uk/ukpga/2005/9/contents [Accessed: 4 Feb 2013].
13. **UK Clinical Ethics Network.** *Information About Clinical Ethics Committees.* [Online]. Available from: www.ukcen.net/index.php/committees [Accessed: 4 Feb 2013].