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Some ethical considerations in the neonatal intensive care area

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Introduction

Sick newborn infants are critically dependent on the success of the partnership of care which develops between their parents and the clinical team. Because both groups are duty-bound to promote the best interests of the infant and have a strong personal interest in doing so, effective relationships usually evolve. Ideally, both parents and clinicians need to feel that the best possible decisions have been made for the infant. When conflict arises, both groups experience considerable distress and intrusive media interest can develop as the issues are publicly dissected [18, 19, 21, 23]. Because most clinicians are poorly trained in ethics and moral reasoning and have an inadequate knowledge of the law [17], they are ill-equipped to deal with these situations. Difficulties can arise as a result of misunderstandings in a number of areas. This article will consider some of the ethical and legal issues in relation to consent to treatment, withholding or withdrawing life-prolonging treatment, euthanasia and the role of ethics committees.

Parental rights and duties in relation to consent

The moral and legal position in relation to consent for medical treatment is relatively clear. Ordinarily, medical treatment may only proceed in the presence of a valid consent. Since newborn infants cannot make their own

choices it is the assumed but not absolute right of their parents to give or refuse consent for them. It is morally correct that this right belongs first to the parents' because they will usually safeguard the interests of their child to a greater degree than will any other person [3] but it is a conditional right that is dependent on them fulfilling their duty of care to the child [7]. Infants have the same rights to life, liberty and autonomy as any other person. Benevolent paternalism is only justified because they cannot make their own choices. Anyone, including parents, making choices for them must represent their best interests. Some parents neglect their children. Even if they are acting in good faith and on the basis of strongly held religious beliefs, parents are not free to place their children at risk by their decisions. Under these circumstances parental rights may be forfeited.

Clinicians rights and duties

Clinicians have a duty of care which compels them to protect their patient's life and health. If a patient is injured as a result of a failure of the doctor to fulfil this duty then the doctor is guilty of negligence. The minimum legal standard of competence expected of a doctor (the Bolam test) is that he act in accordance with the practice accepted by a responsible body of medical men skilled in his branch of medicine [5]. Treatment decisions must be consistent with the basic ethical principles of beneficence and non-maleficence.

There is no duty to prolong life at all costs. In the UK, doctors alone have the right to decide whether a treatment is medically appropriate. Parents have no right to demand treatments that the doctor does not deem to be in their child's interests unless the doctor's competence is in question. The courts cannot oblige doctors to any specific medical treatment [22] though they can prohibit or authorise interventions. Doctors have no moral or legal authority to institute routine treatments in the absence of consent. In an emergency situation however, their duty of care compels them to administer treatment deemed to be in the infant's best interests [6]. Even if there is some doubt as to the infant's best interests they should, in an emergency, act on the presumption that the infant would want to be saved. Under these circumstances, if the action satisfied the Bolam test it is likely that the courts would support it. Other than in an emergency, doctors have no moral or legal authority to proceed without consent. Doctors must do their best to provide parents with sufficient information to allow them to make informed decisions although it is debatable whether informed consent in its fullest sense is ever achieved whatever the standard of communication [10, 26].

Sources of conflict

There are many reasons why the best course of action may seem different to doctors and parents. Neonatologists are self-selected enthusiasts for innovation and technology, excited by the year on year improvements in neonatal outcomes that have been observed. The great personal investment that they make in their patients can give rise to a reluctance to accept failure and a drive to try out new treatments that a less involved clinician may not recommend. The converse is also true. Experienced clinicians may be more pessimistic than parents about what the future might hold for their child [14]. What is seen as the balance of best interests in a given clinical situation will vary between clinicians and within individual doctors over time. Both changing experience and new knowledge can alter an individual clinician's views [15, 16]. Given the same clinical problem some would recommend treatment when others would believe it was futile [12]. Clinicians have their own values and their decisions are significantly related to age, religious affiliation, religious activity, gender and specialisation [27]. Parents' values show similar variation and will be influenced by their past reproductive and personal life history. This may be the first major life event that they have had to face. The strength of their desire to be a parent can be overwhelming. There may be little chance of a future successful pregnancy. The concept of futile treatment can be difficult for them to accept [4]. Some will find even a small possibility of a lifetime caring for a dependent person too difficult to contemplate and may refuse medical intervention. Their

religious beliefs may limit the number of options that they see as open to them.

Minimising conflict

Good medical communication is the most important factor in avoiding conflicts in decision making. Parents and Carers have common interests and this should be reinforced. Parental trust and confidence will usually grow in line with the amount of time spent talking with them. It is essential to spend time listening as well as speaking so that you can better appreciate the parental views and their understanding of the situation. The whole medical team should be involved from the beginning. When difficult moral issues are shared amongst the caregivers, the fallibility of individual decision-makers is more easily avoided, individual sensitivities are protected and the team is strengthened. The parents must feel free to consult whoever they wish but will often prefer a small number of experienced team members to act as the key information sharers. Communication should be open, honest and intimate. It is always challenging. Even a normal birth is an emotionally demanding experience. When problems arise, elation is replaced by fear and uncertainty. The mother may be exhausted from the labour and delivery, or may still be affected by sedative drugs. Cultural and language barriers may add to the problem. Conflicts with the wider family can arise. When different clinicians give what is essentially the same information to parents there are inevitably differences in what information is received. This is a difficult time for parents to take in and process complex information and events may be unfolding too rapidly for them to keep up. Clinicians and parents differ in the degrees of importance that they attach to individual components of the information communicated [20] so feedback should be sought repeatedly to ensure that the parental information needs are being met.

Few parents wish to be offered facts and statistics and be left to decide for themselves. The doctor is generally viewed as a trusted adviser and if the medical situation is clear, a recommendation should be made. Uncertainty should be acknowledged to the parents. Good factual information is essential. It should be clearly established what is known, what may still be discovered in the infant concerned and what is currently unknowable [11]. Discussion with trusted friends and advisers may allow the parents helpful support outside the hospital. The greater the openness of the process the easier it is for all to feel there has been full and careful consideration of all relevant options and that the balance of moral judgements is appropriate. When conflict arises its origins must be analysed. If the parents lack confidence in the validity of the medical information it may be appropriate to offer them the option of a second opinion. The family's General Practitioner may be able to organise someone independent of the hospital team directly concerned. Interpreters can help with language barriers. Speaking to

the family's religious adviser may clarify the origins of specific moral viewpoints. The need for communication does not end once a decision has been made. Clinicians must do their best to maintain effective mutually respecting relationships with the parents in the aftermath of a contested decision if the best interests of the infant are to be maintained.

Decision making

If a decision is more a value judgement than a matter of clear medical facts and no single path is obvious then it is reasonable that the parents' values should carry more weight than those of the doctor because the quality of future life for the child will be determined to a large extent by their parents' input [8]. If an urgent decision must be made because the situation is one of life and death then the approach is relatively straightforward. Whether the key issue is one of clinician refusal of treatment or parental refusal of consent there will be no time to consult widely on the appropriate action. There are only two options. If the medical facts are certain (for instance if the parents wished active treatment of an anencephalic child or refused consent to treat a morphologically normal 28 week gestation infant born in good condition) then the appropriate medical action or inaction should be taken as soon as possible and before any additional harm arises from the delay. Once the urgency has passed all efforts at maintaining communication should continue. There may be great difficulty salvaging any ongoing relationship with the parents. When the degree of certainty is this high, there is little prospect that later judicial review will not be supportive. If the medical facts are uncertain then the clinician should act on a presumption in favour of preserving life until the situation can be clarified. Continuing positive action without alternative authorisation is only justified as long as the situation remains urgent.

In the non-urgent situation there are different scenarios to consider. Firstly there may be *physician refusal of treatment*. If the parents are pressing the clinician to administer a treatment that he believes is inappropriate then efforts should be made to resolve the disagreement through further communication. If these efforts do not succeed then the clinician should go to reasonable lengths to find an alternative clinician for the family, although if good decision making practices have been followed there may not be one identifiable easily. If these measures do not succeed and the clinician has the support of his colleagues then he should not treat – to treat with a therapy believed inappropriate or ineffective would be tantamount to assault [1]. The parents should be informed of their right to obtain judicial review if they wish. If the medical reasoning has been sound and the clinician's colleagues support him then the courts will probably do so too.

The alternative situation is where there is *parental refusal of consent*. In this situation where the treatment is

important but non-urgent, attempts should again be made to resolve the dispute through further communication. A second opinion particularly from an acknowledged expert may help. If these measures do not succeed and the clinician has the support of his colleagues in the view that the treatment is strongly in the best interests of the child then a judicial decision should be sought. Again the sharing of the information with colleagues and presence of their support will make it most likely that the court will support the doctor's viewpoint but if the decision making process has lacked balance then the court will rightly support the parental position.

Withdrawing or withholding life prolonging treatment

The term 'medical treatment' is often used synonymously with attempt to cure with 'nursing care' being regarded as palliation, but the medical team should be intimately involved as should the nurses with both aspects of care. Where treatment aimed at alleviation or cure of a condition has been withdrawn, the clinical team always has a duty to offer palliative care [9]. Palliative care should consider the child's physical needs including the relief of pain and other symptoms and also address the emotional and social and spiritual aspects of care. The child should be nursed in a pleasant, child-centred environment with staff they trust. The child's dignity should be respected. They should be kept clean, and food and fluid should be offered (but not forced) on a regular basis. The role of assisted feeding for infant or child (by nasogastric tube or gastrostomy) should be considered very carefully and discussed fully with the family. It may be entirely appropriate, for example, in a child with a swallowing disorder due to progressive neurodegenerative disease, but would rarely be introduced for an anorexic child with rapidly progressive, disseminated malignant disease.

It is important that decisions are made calmly and without rush and with all evidence available. In emergency situations it is often doctors in training who are called to resuscitate collapsed or dying patients. Rigid rules, even for conditions which seem hopeless, should be avoided and life-sustaining treatment should be administered and continued until a senior and more experienced doctor arrives. The document published by the Royal College of Paediatrics and Child Health outlines five situations where it might be reasonable to consider the withdrawal [24] or withholding of life-saving treatment, three of which are applicable in the neonatal period:

1. The 'No Chance' Situation. Here the child has such severe disease that life-sustaining treatment simply delays death without significant alleviation of suffering. Medical treatment is inappropriate and if given knowingly (futile treatment) may constitute an assault.

2. The 'No Purpose' Situation is the most difficult and contentious category. The patient may be able to survive with treatment, but in this situation we believe that the degree of physical or mental impairment will be massive and it is unreasonable to expect them or the family to bear it. The child in this situation will never be capable of taking part in decisions regarding treatment or its withdrawal. For instance this would apply to the newborn infant with profound neurological damage following severe asphyxia where microcephaly, profound developmental delay, blindness and quadriplegia are believed to be inevitable.
3. Finally the 'Unbearable' Situation. Here the family feel that in the face of progressive and irreversible illness *further* treatment is more than can be borne. They wish to have a particular treatment withdrawn or to refuse further treatment irrespective of the medical opinion on its potential benefit. An infant with progressive and deteriorating respiratory failure from bronchopulmonary dysplasia might be considered in this category.

In situations that do not fit with these categories, or where there is dissent or uncertainty about the degree of future impairment, the child's life should always be safeguarded by *all* in the Health Care Team in the best way possible.

Euthanasia

Giving a medicine with the primary intent to hasten death is unlawful but giving a medicine to relieve suffering which may, as a side-effect, hasten death is lawful and can be appropriate. Increasing doses of analgesia may be necessary to control pain or distress and it is recognised in English and Scottish law that this may shorten life. Medication in this situation is being prescribed for the benefit of the patient during life not in order to cause or hasten death.

The use of muscle paralysing agents often causes considerable anxiety. Withdrawal of ventilatory support while paralysing agents are effective inevitably leads to death within minutes. Such agents are used in infants with severe cardiopulmonary problems to facilitate artificial ventilation. When the decision is made to withdraw treatment, it is not necessary to withdraw the paralysing agent before the respiratory support is withdrawn. However it would be euthanasia, deliberately to induce muscle paralysis in order to avoid the terminal gasping which sometimes occurs when ventilation is withdrawn. Instead specific treatment to reduce this distress may be necessary if it occurs.

In some instances withdrawal of ventilatory support will not lead to death. In this situation it must be made clear that euthanasia is not appropriate and that palliative care for discomfort is all that is appropriate: the child must receive, and the family and the medical team

must provide, appropriate nursing care. The lives of unexpected survivors, even when badly disabled, should be respected and they should be cared for appropriately.

Role of ethics committees

In the United States the development of multidisciplinary institutional ethics committees has been encouraged by professional bodies [2]. They are widely recognised to be an important resource helping with the education of both doctors and patients, and also for trouble shooting and case consultation when there are communication difficulties [25]. In UK law, ethics committees have no statutory position. Any medical decision made remains the legal and professional responsibility of the doctor (consultant) concerned. The Royal College of Paediatrics and Child Health believes that the clinical team as a group has a moral responsibility to carry out the task of decision making and that it should in general not be given to an independent ethics committee [24]. In the UK, doctors and nurses do not express widespread support for such a decision making committee [17] and neither do parents [14]. Nevertheless, a clear need for education of health care staff in the ethical and legal background to these situations has been identified and education committees to inform and discuss difficult issues in retrospect may have a useful role [13].

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